

# Dying, Dignity, and New Horizons in Palliative End-of-Life Care<sup>1</sup>

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**ABSTRACT** Palliative care practitioners are now better able than ever before to ameliorate end-of-life symptom distress. What remains less developed, however, is the knowledgebase and skill set necessary to recognize, assess, and compassionately address the psychosocial, existential, and spiritual aspects of the patient's dying experience. This review provides an overview of these areas, focusing primarily on empirical data that has examined these issues. A brief overview of psychiatric challenges in end-of-life care is complemented with a list of resources for readers wishing to explore this area more extensively. The experience of spiritual or existential suffering toward the end of life is explored, with an examination of the conceptual correlates of suffering. These correlates include: hopelessness, burden to others, loss of sense of dignity, and desire for death or loss of will to live. An

empirically-derived model of dignity is described in some detail, with practical examples of diagnostic questions and therapeutic interventions to preserve dignity. Other interventions to reduce existential or spiritual suffering are described and evidence of their efficacy is presented. The author concludes that palliative care must continue to develop compassionate, individually tailored, and effective responses to the mounting vulnerability and increasingly difficult physical, psychosocial, and spiritual challenges facing persons nearing the end of life. (*CA Cancer J Clin* 2006;56:84–103.) © American Cancer Society, Inc., 2006.

Gerasim was the only one who understood him. It was a comfort when Gerasim sat with him sometimes the whole night through. . . Gerasim was the only one who did not lie; everything he did showed that he alone understood what was happening, and saw no need to conceal it. . . and so the relationship was a comfort to him.

—From “*The Death of Ivan Ilyich*,” *Leo Tolstoy*

## INTRODUCTION

Palliative care has matured over recent years, with little doubt that end-of-life care providers are better positioned to address various sources of symptom distress than ever before. It is also clear that the distinction between somatic distress and psychological or spiritual disquietude becomes less clear and increasingly entangled as death draws near.<sup>1</sup> Yet, there is an inclination for care providers to parse these out, focusing on those things that seem within our grasp to attenuate, while neglecting those we sense are beyond reach. There is, however, growing awareness in palliative care that patients must not only be made to feel more comfortable, but more broadly, provided with comfort. Although the distinction may appear subtle or merely semantic, it is in fact the difference between technically competent symptom management versus a holistic approach to end-of-life care—an approach that encompasses the psychosocial, existential, and spiritual aspects of the patient's experience.

Providing comfort to dying patients, however, can prove difficult. There are dimensions of suffering or personal anguish that are not readily accessible or even necessarily malleable.<sup>2</sup> As Ilyich's pantry boy intuitively understood, in these instances, comfort is often conveyed by a committed presence, various forms of affirmation, compassion and innumerable acts of kindnesses. Within the palliative care literature, these aspects of care are recently being described in terms of concepts such as *meaning, purpose, dignity, and spiritual or existential well-being*. Care that includes these components of attending to patients, combined with the best of modern medicine and symptom management techniques, provides an opportunity to

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achieve dignity-conserving end-of-life care.<sup>3</sup> This review article invites readers to explore these particular horizons of palliative care, to help them fulfill their role as competent and compassionate providers of care for patients with life-threatening illness.

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#### DEFINING PALLIATIVE CARE

The modern hospice movement began with Dame Cicely Saunders, whose philosophy of palliation included holistic care, along with a progressive and modern approach to the medical management of end-of-life symptoms. Dame Saunders opened St. Christopher's Hospice, the first residential hospice, in 1967.<sup>4</sup> As fate would have it, she died in St. Christopher's Hospice at age 87 years, on July 14, 2005.

Palliative care offers specialized treatment to people whose illness is no longer considered curable. Its primary goals are to provide comfort and care for those with life-limiting illnesses and their families, so that patients are able to die peacefully in the setting of their choice—often their own home—while receiving all necessary nursing, medical, psychosocial, and spiritual care.<sup>5</sup> The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”<sup>6</sup> Embedded within the WHO definition is a commitment to relieving pain and other distressing symptoms, the affirmation of life while regarding dying as a normal process, an intent to neither hasten nor postpone death, an integration of psychological and spiritual aspects of patient care, the provision of support to help patients live as actively as possible until their death, with support being provided to help families cope during their loved ones' illnesses and into their own bereavement. Whenever possible, palliative care endeavors to enhance the quality of life of patients as they move toward death. Palliative care can be applied at all stages of life-threatening disease and

should intensify once cure is no longer deemed possible.

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#### DEFINING A “GOOD DEATH”

Although dying is part of the human condition, dying poorly ought not to be. Investigators have begun to look at various domains of what constitutes a “good death.” A meaningful dying process is one during which the patient is physically, psychologically, spiritually, and emotionally supported by his or her family, friends, and caregivers. According to the Institute of Medicine, a good death is one that is “free from avoidable distress and suffering for patient, family and caregivers, in general accord with patient's and family's wishes, and reasonably consistent with clinical, cultural, and ethical standards.”<sup>7</sup> Weisman described four criteria for what he referred to as “an appropriate death”: internal conflicts, such as fears about loss of control, should be reduced as much as possible; the individual's personal sense of identity should be sustained; critical relationships should be enhanced or at least maintained, and if possible, conflicts resolved; and the person should be encouraged to set and attempt to reach meaningful, albeit limited, goals such as attending a graduation, a wedding, or the birth of a child, as a way to provide a sense of continuity into the future.<sup>8</sup>

On the basis of qualitative studies, Singer, et al. determined the primary concerns of patients regarding their impending deaths.<sup>9</sup> These included receiving adequate pain and symptom management, avoiding inappropriate prolongation of dying, achieving a sense of control, relieving burden, and strengthening relationships with loved ones. Creating every opportunity to bolster or enhance these relationships is in keeping both with patient wishes and fundamental principles of palliative care. In a recent Institute of Medicine report entitled “Approaching Death: Improving Care at the End of Life,” several domains of quality end-of-life care were identified: overall quality of life, physical well-being and functioning,

achieving a sense of spiritual peace and well-being, patient perception of care, and family well-being and functioning.<sup>7</sup>

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PSYCHIATRIC CHALLENGES

These definitions of palliative care and descriptions of a good death would suggest great sensitivity to the psychosocial, existential, and spiritual aspects of patient well-being. Yet, in spite of this, there are aspects of end-of-life distress that are not routinely assessed, let alone effectively treated or managed. Recent evidence suggests that as patients with cancer or acquired immunodeficiency syndrome (AIDS) enter the advanced stages of illness, the burden of both physical and psychological symptoms becomes staggering. Physical concerns such as pain, dyspnea, and constipation have been reported to be less prevalent in patients with advanced cancer or AIDS than symptoms such as worrying, nervousness, lack of energy, insomnia, and sadness.<sup>10</sup>

Over the last decade, much work has been done to establish the incidence and prevalence of psychiatric issues among patients nearing death.<sup>11</sup> For example, anxiety disorders in terminally ill cancer and AIDS patients ranges from 15% to 28%,<sup>12</sup> with some studies indicating a higher prevalence of mixed anxiety and depressive symptoms in cancer patients rather than anxiety alone.<sup>13</sup> The prevalence of anxiety appears to increase with advancing disease and mounting deterioration in the patient's physical status.<sup>14</sup> As patients become sicker, their anxiety may include fears about the disease process, the clinical course, possible treatment outcomes, and death. In addition, particularly in patients with AIDS, anxiety may result from fear of increasing social stigma as their medical illness deteriorates and becomes more evident.<sup>12</sup>

Among patients who are terminally ill, anxiety can occur within the context of an adjustment disorder (characterized by a response that is considered excessive and impairs social or occupational functioning), with anxious mood alone or in combination with depressed mood; it can be a disease-related or treatment-related condition or an exacerbation of a pre-existing anxiety disorder.

<sup>12,15,16</sup> Adjustment disorder with anxiety is often related to the existential crisis surrounding the uncertainties that accompany a life-limiting prognosis.<sup>17</sup> Patients confronting a terminal illness who have pre-existing anxiety disorders are at risk for reactivation of their symptoms. Symptoms such as pain or dyspnea may reactivate a generalized anxiety or panic disorder, whereas patients with a history of phobias—especially fear of death—may manifest anxiety symptoms requiring both medication and emotional support. Posttraumatic stress disorder may be reactivated in dying patients if their illness experience resonates with prior near-death encounters or other significant trauma.<sup>18</sup>

All dying patients will experience times of sadness as a normal part of coming to terms with life drawing to a close. Approximately 25% of all cancer patients, however, will experience severe depressive symptoms, with the prevalence increasing with higher levels of disability, advanced illness, and pain.<sup>19–22</sup> Although concern is often raised about the nonspecificity of somatic symptoms in reaching a diagnosis of depression, clinical wisdom and experience suggest that greater diagnostic emphasis should be placed on psychological symptoms, such as depressed mood, loss of interest, helplessness, hopelessness, excessive guilt, feelings of worthlessness, and desire for death, as opposed to physical criteria.<sup>21,22</sup> Although screening strategies as simple as asking the patient if they are depressed “most of the time” have shown good diagnostic sensitivity and specificity, depression continues to be overlooked among patients who are terminally ill. This further adds to their burden of suffering and undermines their quality of life.<sup>23</sup>

Although a complete overview of psychiatric disorders in end-of-life care is beyond the scope of this review, several monographs and key references are readily available (Table 1). Psychiatric diagnoses, however, provide too narrow a framework to contain the broad spectrum of end-of-life distress.<sup>24</sup> More ubiquitous aspects of suffering—including psychological, existential, or spiritual distress—are not necessarily well understood or researched, nor do they necessarily engender a well-considered response. Distress of

TABLE 1 Additional Palliative Care/Psychiatry References

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this kind may express itself as an overwhelming sense of hopelessness, existential or spiritual angst; loss of sense of dignity; sensing oneself a burden to others; or a waning of one's will to live and a growing desire for death or wish to no longer carry on living. What follows is an overview of the empirical work that has explored these facets of the dying experience.

#### THE EXPERIENTIAL LANDSCAPE OF APPROACHING DEATH

Good palliative care practice obliges us to acknowledge the innate existential nature of distress that accompanies the experience of dying people. Rooted as we are in a contemporary biomedical model of disease, it is tempting to direct most, perhaps all, of our attention to the diagnosis and alleviation of physical symptom distress. Yet within one-to-one interactions with dying patients, few care providers remain unaware that there are aspects of distress that defy even the most sophisticated of medicinal or technological modalities. Something else is at play and we know it, because it evokes empathy toward our

patient's illness experience and resonates with a sense of our common humanity.

Holistic care acknowledges that each individual is an integrated whole, more than the simple sum of physical and psychological "parts," a unity or total person who is situated in a social world that includes the ill person and caregivers.<sup>25</sup> The ineffable in our relationships with patients and their families derives from our personal and professional response to the confluence of existential, spiritual, physical, and psychosocial concerns that arise toward the time of death. To be sure, these sources of distress are intricately interconnected, although the independent effect of spiritual concerns on quality of life has been empirically demonstrated. Using the spirituality subscale of the Functional Assessment of Chronic Illness Therapy (FACIT-Sp) Scale, Brady and colleagues found a unique positive association between spirituality and quality of life that equaled the association between physical well-being and quality of life in an ethnically-diverse sample of 1,610 cancer patients.<sup>26</sup> Despite the artificiality of parsing spiritual or existential distress from physical and psychosocial concerns, doing so provides an opportunity to more fully explore the meaning of spiritual or existential "suffering."

### Spirituality and Existentialism

Spirituality is variably understood, with one comprehensive review of the health literature counting 92 separate definitions.<sup>27</sup> These definitions were divided between seven major thematic categories, including: a relationship to God, a spiritual being, a higher power, or a reality greater than the self; not of the self; transcendence or connectedness unrelated to a belief in a higher being; existential, not of the material world; meaning and purpose in life; life force of the person, integrating aspect of the person; and summative definitions that combined multiple themes. Spirituality embodies a sense of connectedness to a personal god or higher force or power, and is considered a broader construct than religion.<sup>28,29</sup>

Some initial contemporary efforts have been made to define spirituality from the perspective of dying patients. Chao and colleagues asked six Buddhist and Christian terminally ill cancer patients in Taiwan what the essence of spirituality was to them. Ten themes in four broad categories emerged: communion with self (self-identity, wholeness, inner peace); communion with others (love, reconciliation); communion with nature (inspiration, creativity); and communion with a higher being (faithfulness, hope, gratitude).<sup>30</sup> Hermann noted that as in-depth interviews with 19 hospice patients progressed, many whose initial definitions of spirituality related to God or other religious terms later identified terms associated with meaning and purpose or nature and acknowledged that spirituality was part of their total existence.<sup>31</sup>

McGrath interviewed 14 people living at home in Australia with a prognosis of less than 6 months. She found that most did not seek explicitly religious comfort in response to their illness and that there was a degree of eclecticism in the religiospiritual concepts expressed by participants.<sup>32</sup> In a comparative study of cancer survivors and hospice patients, McGrath concluded that maintaining an intimate connection with life through family, friends, leisure, home, and work was just as important to individuals as transcendent meaning-making, religious or otherwise.<sup>33</sup>

Palliative care researchers have increasingly recognized the importance of examining spir-

itual dimensions of end-of-life experience. Between 1994 and 1998, 6.3% of empirical studies in palliative care journals included spiritual and religious variables, versus 1% of empirical studies published in leading medical journals. Of 1,117 empirical studies published in five palliative medicine/hospice journals, researchers measured spirituality using variables such as spiritual well-being, meaning, or transcendence (32%), followed by religious affiliation (29%) and spiritual/religious services provided (19%).<sup>34</sup>

In our secular society, explicit or implicit religious connotations associated with the term *spirituality* have been moderated such that many definitions make no mention of God or a higher power. Instead, the term evokes a sense of searching or yearning for significance or meaning in life. Existentialism is a body of thought originally enunciated by philosophers such as Arthur Schopenhauer, Soren Kierkegaard, Friedrich Nietzsche, and Martin Heidegger. Existentialists appreciate the individual's experience of living and acknowledge meaning, purpose, and value in everyday life. A psychotherapeutic orientation has grown out of existential philosophy. It views serious illness—especially life-threatening illness—as an opportunity for growth. Confronted with the prospect of annihilation, patients' lifetime assumptions about meaning and value may be shattered by their daily illness experience. This affords an opportunity, a moment of insight, to re-evaluate life activities and to choose those that add greatest meaning, purpose, and value in the time left.<sup>35</sup> Distinguishing between the terms *spirituality* and *existentialism*—particularly in the context of palliative care—is perhaps less important than recognizing the common ground between the two terms: the human urge to imbue life with purpose, meaning, and hope.

### Spiritual and Existential Suffering

Spiritual suffering or pain may manifest itself within various domains of the patient's experience, be it physical (eg, intractable pain), psychological (eg, anxiety, depression, hopelessness), religious (eg, crisis of faith), or social (eg, disintegration of human relationships). However, it is not possible to recognize spiritual pain on the

basis of symptoms alone. Rather, spiritual pain is the combination of these aforementioned symptoms and characteristic behaviors, including: patients who are desperate to escape their situation; patients with expectations of caregivers that are impossible to meet; patients who continue to try new therapies in the absence of any benefit; and patients who require escalating doses of analgesics and sedatives despite no apparent benefit, or even when these measures are clearly counterproductive. These behaviors often evoke descriptions such as “suffering” or “anguish,” which can help identify this form of pain.<sup>29</sup>

In a study of caregivers, hospital chaplains, palliative care physicians, and pain specialists, definitions of existential pain ranged from those that stressed issues of guilt and religion (chaplains) to those that related to annihilation and impending separation (palliative care physicians). Although some pain specialists emphasized that living is painful, they concluded that existential pain is most often used as a metaphor for suffering.<sup>36</sup>

According to McGrath,<sup>29</sup> who developed a paradigm of spiritual pain from a qualitative study of 12 survivors of hematological malignancies, the notion of spiritual pain or suffering includes: “. . . a sense of diffuse emotional/existential/intellectual pain directly related to the meaninglessness created as a result of a break with the expected/normal network of relationships that function to connect one to life. A key ingredient in that pain is the sense that the . . . experience *with* life is failing to meet the individual’s needs, and thus the expected satisfaction and *meaning-making* from life are not forth-coming.”

Few researchers have studied the effect of spiritual or existential well-being on dying patients’ senses of suffering, but those who have report a protective effect against end-of-life despair. Nelson, et al. studied the impact of spirituality and religiosity on depressive symptoms in 162 patients dying of cancer or AIDS.<sup>37</sup> Using the Functional Assessment of Chronic Illness Therapy Spiritual Well-Being (FACIT-Sp) Scale and the Hamilton Depression Rating Scale (HDRS), they demonstrated a statistically significant negative association between HDRS scores and FACIT-Sp total

scores ( $\beta = -0.30$ ,  $P < 0.001$ ), indicating that individuals scoring higher on the spiritual measure were less depressed. In a sample of 160 hospitalized cancer patients admitted for terminal care, McClain, et al.<sup>38</sup> assessed the relationship between spiritual well-being, depression, and end-of-life despair. The study demonstrated significant negative correlations between spiritual well-being and desire for hastened death ( $r = -0.51$ ,  $P < 0.001$ ), hopelessness ( $r = -0.68$ ,  $P < 0.001$ ), and suicidal ideation ( $r = -0.41$ ,  $P < 0.001$ ). They concluded that spiritual well-being offered some protection against end-of-life despair, based on the additional findings that depression was significantly correlated with desire for hastened death in patients low in spiritual well-being ( $r = 0.40$ ,  $P < 0.001$ ), but not in those high in spiritual well-being.

Similarly, McClain-Jacobson, et al.<sup>39</sup> studied the effect of afterlife beliefs on psychological distress and end-of-life despair in 276 palliative care cancer inpatients. Belief in an afterlife was associated with lower levels of hopelessness (4.6 versus 7.9,  $P = 0.001$ ), desire for death (3.5 versus 5.4,  $P = 0.027$ ), and suicidal ideation (12.0% versus 27.7%,  $P = 0.029$ ), which are factors considered important in end-of-life despair. Belief in an afterlife was not significantly associated with depression or anxiety. When spirituality levels were controlled for, the effect of afterlife beliefs disappeared, suggesting that spirituality has a more powerful effect on psychological functioning than beliefs regarding an afterlife.

If spiritual or existential well-being imbues life with a sense of purpose or meaning, then it follows that a lack of purpose or meaning may lead to a disinvestment in life itself. Over the last decade, researchers—recognizing the importance of existential or spiritual issues for dying patients—have begun to conceptually parse out and examine the effect of hopelessness, burden to others, loss of sense of dignity, and loss of will to live on patients approaching death. Greater understanding of the influence of these issues on distress and despair will afford opportunities to improved comfort and care toward the end of life.

### Hopelessness

Intuitively, one might suspect that patients whose medical prognosis is “hopeless” would uniformly endorse a sense of hopelessness. Yet, this is not supported by the empirical data. For instance, in reporting existential distress among 162 terminally-ill Japanese hospice inpatients, Morita, et al.<sup>40</sup> found that only 37% expressed a sense of hopelessness. Other sources of distress included feeling a sense of dependency (39%), meaninglessness in present life (37%), feeling a burden to others (34%), loss of social role functioning (29%), and feeling emotionally irrelevant (28%).<sup>40</sup> Given that this was a group of dying patients, it is clear that hope is based on something other than prognosis, or, as stated by Hockley,<sup>41</sup> it is a “concept that suggests a greater emotional component than mere expectation, and is seen as an active process of conscious and unconscious meaning.”

Several studies have shown that, among patients with advanced disease, severe or pervasive hopelessness tends to be confined to those who are depressed or have expressed a genuine desire for early death.<sup>42,43</sup> Breitbart, et al.<sup>42</sup> reported that, in a group of 92 patients in a palliative care inpatient facility, 17% were classified as having a high desire for hastened death and 16% met criteria for a current major depressive episode. Desire for hastened death was significantly associated with clinical depression ( $P = 0.001$ ) and hopelessness ( $P < 0.001$ ), with both providing independent, unique contributions to the prediction of desire for hastened death. Chochinov, et al.<sup>43</sup> found that hopelessness was more highly correlated with suicidal ideation than was depression, thus providing an important clinical marker for patients harboring thoughts of early death.

This connection between hopelessness and suicidal thinking begins to reveal the experiential landscape of people approaching death. Besides its connection with depression, loss of hope—however that might be experienced by someone facing a life-limiting illness—seems closely aligned with a wish to die. This conclusion is supported by Wilson, et al.<sup>44</sup> They reported that terminally ill patients who would elect death-hastening measures, if legally avail-

able, were more likely than other participants to express hopelessness, a loss of interest or pleasure in activities, and a desire to die; they were also more likely to have depressive disorders. Similarly, Virik and Glare<sup>45</sup> reported that among terminally ill patients requesting euthanasia, half endorsed a sense of hopelessness.

In one study seeking to gain conceptual clarity of the notion of hopelessness from dying patients, Chochinov, et al.<sup>46</sup> reported that within this patient population, hope was related to concepts of meaning and purpose. For patients nearing death, maintaining hope was intimately connected with a sense that life continued to serve some purpose or held meaning enough to sustain their continued existence. Similarly, Duggleby<sup>47</sup> reported that maintaining hope was a way for terminally ill patients to endure and cope with their suffering. For these patients, hope was defined in terms of hope for no more suffering, living each day, a peaceful death, and hope for their families.<sup>48</sup> To “live with hope,” palliative care patients had to transform hope, which involved acknowledging life the way it is, searching for meaning and positive reappraisal.<sup>49</sup> This conceptual clarification is critical, in that it offers insight into the potency of hopelessness as an experience that can undermine a sense that life has ongoing value or intrinsic worth. This clarity also has implications regarding therapeutic options that might engender a sense of meaning and purpose for patients expressing overwhelming hopelessness (see Opportunities for Interventions to Reduce Suffering).

Other investigators have begun to make a connection between hope, meaning, and purpose. For example, in their study of Japanese hospice patients, Morita, et al.<sup>40</sup> identified three factors—loss of autonomy, lowered self-esteem, and hopelessness—in connection with existential distress. Of note, “meaninglessness in one’s present life” appeared within all three factors, suggesting a conceptual conflation between hopelessness and meaning. Kissane and colleagues<sup>50</sup> have introduced the concept of demoralization syndrome, in which the core features consist of hopelessness, loss of meaning, and existential distress. They suggest this syndrome can be associated with chronic med-

ical illness, disability, bodily disfigurement, fear of loss of dignity, social isolation, and feelings of greater dependency on others or the perception of being a burden to others, especially where there is a subjective sense of incompetence. They further suggest that a sense of impotence or helplessness will almost invariably lead to a desire to die or suicidal ideation.

Finally, Lin and Bauer-Wu<sup>51</sup> conducted an integrative literature review, examining the psychospiritual well-being of terminally ill people with advanced cancer. They identified 43 primary research studies, within which six major themes emerged: self-awareness, coping and adjusting effectively with stress, relationships and connectedness with others, sense of faith, sense of empowerment and confidence, and living with meaning and hope. The conflation of these latter terms—meaning and hope—again speaks to their conceptual overlap. Patients with an enhanced sense of psychospiritual well-being were reportedly better able to cope effectively with the process of terminal illness and to find meaning in the experience. Along with family and social support, prognostic awareness, and autonomy, “hope and meaning in life” contributed to positive psychospiritual well-being, whereas emotional distress, anxiety, helplessness, hopelessness, and fear of death detracted from it. This review, along with the other studies cited, suggests that enhancing psychospiritual well-being, in part, rests on understanding the nature of hope and the extent to which loss of meaning and purpose can undermine a patient’s sense of life’s value or worth. Interventional strategies sensitive to this existential landscape must target hopelessness to effectively contribute to positive patient outcomes.

#### **Burden to Others**

Self-perceived burden has been described as “a multidimensional construct arising from the care-recipient’s feelings of dependence and the resulting frustration and worry, which then lead to negative feelings of guilt at being responsible for the caregiver’s hardship.”<sup>52</sup> Among patients with life-threatening illness, sensing oneself as a burden to others seems to

be an important theme related to quality of life, optimal palliative care, and maintenance of dignity at the end of life.<sup>9,52,53</sup> Personal or individual autonomy—especially in Western society—is often conflated with the notion of being a whole person, so that dependency can be seen or experienced as threatening the integrity of personhood itself. Therefore, a bad death is frequently characterized by “feeling a burden to others” and is often invoked in matters pertaining to suicide or requests for hastened death among patients with advanced disease.

According to reports from family members of patients who had died after having previously expressed a wish for hastened death, 58% to 94% were distressed about being a burden to others.<sup>54,55</sup> Physicians who had been asked to assist with death-hastening measures indicated that patients’ concerns about being a burden to others was a motivating factor in 41% to 75% of requests.<sup>56–58</sup> Among dying patients who actually killed themselves, feeling a sense of burden to others was almost universal.<sup>59,60</sup> Data from Oregon indicates that 63% of patients who received a hastened death under that state’s Death with Dignity Act had expressed a strong sense of having become a significant burden to their family, friends, or caregivers.<sup>61</sup> The authors further report that this motivation for death-hastening practices is becoming more prominent over time.

Wilson, et al.<sup>62</sup> conducted one of the few studies to directly examine the notion of burden to others among a group of 69 patients with advanced cancer. A sense of burden to others was common in this group of patients: 39% reported a minimal to moderate concern and 38% reported moderate to severe levels of distress around being a burden to others, whereas only 23% reported that they experienced no sense of burden. Burden to others had very little correlation with physical symptoms, somewhat higher correlations with psychological symptoms, and the highest correlations with existential issues, including loss of dignity ( $r = 0.49, P \leq 0.01$ ), hopelessness ( $r = 0.46, P < 0.01$ ), and loss of control ( $r = 0.45, P \leq 0.01$ ). They also reported modest, significant correlations between burden to oth-



ers and desire for death and suicidal ideation. Multiple regression modeling confirmed the association between burden to others and dignity, with dignity entering as the first predictor variable of burden to others.

If dignity can be understood as deserving honor, respect, or esteem,<sup>63</sup> its conceptual overlap with burden to others suggests a self-perception wherein patients no longer consider themselves worthy of these attributes. Sensing they no longer have value, meaning, or purpose—and therefore are unworthy of honor, respect, or esteem—patients with advanced illness may perceive their neediness or dependency as unfolding in a context shaped by an inability to give anything in return. This perception of needing to take, while feeling they have little to give back, further clarifies the psychological landscape of “sense of burden to others.”

#### Loss of Sense of Dignity

Palliative care has been characterized as care that “honors and protects those who are dying, and conveys by word and action that dignity resides in people.”<sup>7</sup> Most palliative care providers would claim that dignity is an overarching value or goal, which shapes the delivery of service to dying patients and their families. For some patients, a sense of dignity is indivisible from their core being or essence. The notion of “basic dignity” has been described as a universal moral quality that is internally held and inalienable from life itself.<sup>64,65</sup> “Personal dignity,” on the other hand, is frequently invoked in reference to the potential indignities of death and dying.<sup>3,65,66</sup> Personal dignity is individualistic, transient, and often tied to personal goals and social circumstances. When individual autonomy is conflated with the notion of dignity, the inability to maintain independence while dying may be experienced as a fundamental loss of dignity, undermining the value of life itself.<sup>3</sup>

The term *dignity* has become highly politicized and is frequently invoked as justification for various end-of-life care practices and policies. In many circles, the term “death with dignity” is synonymous with the right to assisted suicide and euthanasia.<sup>62,67–70</sup> Several

studies have reported that loss of dignity is very closely linked to why patients have either sought or, in some instances, received death-hastening assistance.<sup>62,69–71</sup> According to a US survey of physician-assisted suicide and euthanasia, loss of dignity was the reason cited by physicians in 53% of cases where prescriptions had been written for the purpose of hastening death (second only to discomfort other than pain in 79% of cases).<sup>71</sup>

Historically, the topic of dignity has not been extensively researched and has tended to enter palliative care discourse in the context of social policy, philosophical, or religious considerations. Thus, although many palliative caregivers purport to deliver care that preserves dignity, little empirical data has been available to guide them on how to achieve this particular goal. Over the last decade, several studies have examined some of the factors that might support, or undermine, a dying patient’s sense of dignity.<sup>3,46,72–75</sup> A qualitative study of dying patients produced an empirically based model of dignity in the terminally ill.<sup>3,46</sup> This model provides insight into what influences a patient’s wish to go on living in the face of their impending death and establishes the foundation for a model of palliative care, coined *dignity-conserving care*.<sup>3</sup> This model provides therapeutic direction for health professionals, advising they pay heed to a broad range of physical, psychological, social, and spiritual/ existential issues that may affect individual patient perceptions of dignity.

The Dignity Model consists of three major categories including: 1) illness-related issues pertaining to bodily concerns or problems; 2) dignity-conserving repertoire pertaining to the patient’s psychological makeup and spiritual beliefs; and 3) the social dignity inventory, referring to external influences affecting dignity (Figure 1).<sup>46</sup> These categories refer to broad issues that determine how individuals experience a sense of dignity as death approaches. Each category contains several carefully defined themes and sub-themes, enhancing our understanding of dignity considerations among the dying.

*Illness-related concerns* are issues that result from the illness itself and threaten to, or actually do, impinge on the patient’s sense of dig-

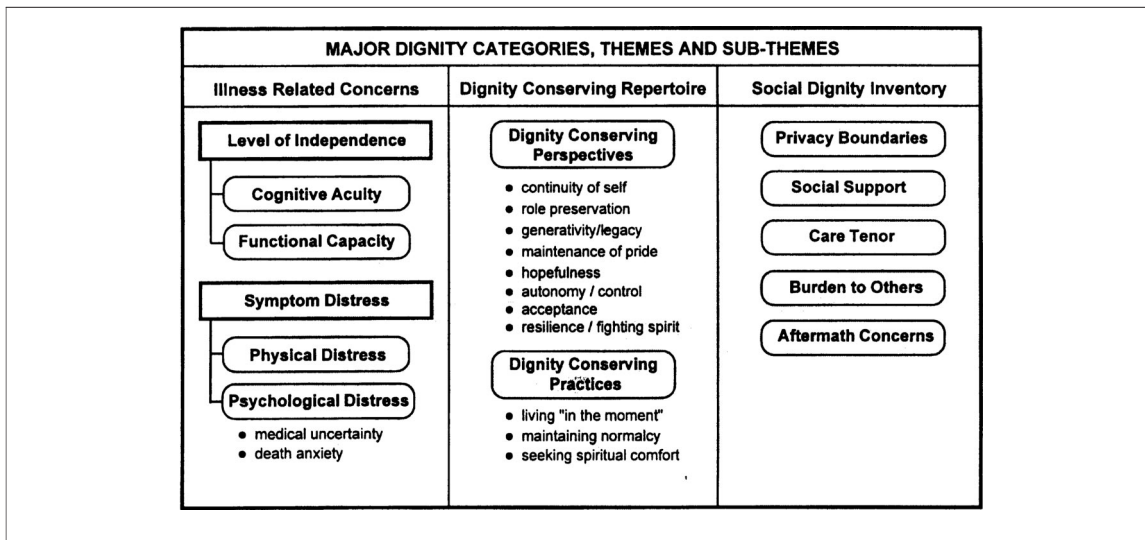


FIGURE 1 The Dignity Model. Reprinted from Chochinov et al,<sup>46</sup> with permission from Elsevier.

nity. Their defining characteristic is that they are mediated via the illness and are very specific to the patient's illness experience. The two broad themes within this category consist of "level of independence," (which is determined by an ability to maintain cognitive acuity, as well as "functional capacity," referring to the ability to perform daily living tasks) and "symptom distress." Symptom distress is divided into physical distress and psychological distress, with the latter including uncertainty (the distress associated with the uncertainties of one's health status) and death anxiety (worry or fear specifically associated with the process or anticipation of death and dying).

The *dignity-conserving repertoire* is comprised of two major themes: dignity-conserving perspectives and dignity-conserving practices. The former are internally held qualities or views of one's place in the world, and include the sub-themes:

- Continuity of self: the sense that the essence of who one is continues to remain intact.
- Role preservation: an ability to continue functioning in usual roles as a way of maintaining congruence with prior views of oneself.
- Generativity/legacy: the sense that one will leave behind something lasting and transcendent of death.
- Maintaining pride: the ability to maintain positive self-regard in the face of diminish-

ing independence.

- Maintaining hope: an ability to see life as enduring, with sustained meaning or purpose.
- Autonomy/control: the sense that one can influence or direct one's life circumstances.
- Acceptance: the internal process of resigning oneself to changing life circumstances, in the attempt to maintain one's sense of dignity.
- Resilience/fighting spirit: the mental determination some patients exercise to overcome their illness-related concerns or optimize their quality of life.

Dignity-conserving practices consist of "living in the moment," focusing on immediate issues in the service of not worrying about the future; "maintaining normalcy," or carrying on usual routines and schedules while coping with the physical and emotional challenges of being ill; and "seeking spiritual comfort," which is turning toward or finding solace within one's religious or spiritual belief system.

The *social dignity inventory* refers to the quality of interactions with others that enhance or detract from a sense of dignity. The defining characteristic of this inventory is that it refers to external sources or issues that might impinge on a patient's sense of dignity. Five primary inventory themes were identified:

- Privacy boundaries: the extent to which dignity can be influenced by encroachments

one's personal environment during the course of receiving care or support.

- Social support: the presence of an available and helpful community of friends, family, or health care providers.
- Care tenor: the attitude others demonstrate when interacting with the patient.
- Burden to others: the distress engendered by having to rely on others for various aspects of personal care or management.
- Aftermath concerns: the worry or fears associated with anticipating the future burden or challenges that dying will impose on others.

The model highlights how dying patients may experience a waning of their dignity and, in turn, provides direction for how to construct dignity-enhancing interventions for patients nearing death (Table 2).

The Dignity Model can be thought of as a therapeutic map, guiding clinicians to find interventional strategies or insights based on each of the themes and subthemes subsumed within the model (Table 2). Although this has been extensively described elsewhere, a few illustrative examples may highlight its clinical utility.<sup>3,46,72,73</sup> Within the broad theme of illness-related concerns, medical uncertainty and death anxiety are listed as sources of distress that would precipitate enquiry such as “is there anything further about your illness that you would like to know” or “if you are getting all the information you feel you need.” For some patients, knowing the details of their condition and how death will arrive is part of a dignity-conserving strategy. Case in point: the most frequently downloaded article at the Canadian Virtual Hospice, a national web-based network of information and support for dying patients, their families, care providers, and volunteers, is one entitled “When Death is Near.”<sup>76</sup> This article describes the physical changes associated with dying and the progression of changes as death approaches. Clearly, for many patients and families, being able to access such information and knowing the contingencies invoked in response to any crises are critical aspects of a dignity-conserving strategy.

Under the heading “dignity-conserving repertoire,” various subthemes point to a variety of therapeutic insights and strategies (eg, see

Dignity Therapy). For example, under the subthemes of “continuity of self,” “maintaining pride,” and “role preservation,” the therapeutic correlate is listed as “see[ing] the patient as worthy of honor, respect, and esteem” by way of asking them things that are personally defining. Many would see these as the “niceties” of care, which may or may not occur depending on the competing interests of providing palliation. Yet, acknowledging patients as whole persons is one of the most ardent predictors of maintaining dignity.<sup>3,72,73</sup> In other words, finding out who the patient is as a person, what is important to them, and what they value are as central to dignity-conserving care as any other aspect of quality end-of-life care.

The social dignity inventory contains various subthemes that are externally mediated, with dignity-related implications. The subtheme “care tenor” refers to the tone of care that might influence perceptions of dignity, with each patient encounter being an opportunity to support, or undermine, their sense of dignity. At some level, patients are looking for affirmation regarding their sense of worth, in spite of their dyspnea, incontinence, or disfigurement. The therapeutic correlates of care tenor would include a range of subtleties that would convey such affirmation. Do you stand at the doorway of their room or do you enter and take a seat? Do you meet their gaze or do you avert it? Do you include them in decision-making conversations or so you automatically exclude them or defer to others? In other words, are you able to see and acknowledge the person beyond even the most overwhelming of symptoms? Again, although this is often pejoratively consigned to the realm of the “touchy-feely,” evidence would suggest that it lies at the heart of being able to truly accomplish dignity-conserving care.<sup>3,72,73</sup>

Quantitative approaches, while asking dying patients to rate their sense of dignity, have also examined the correlates of dignity. Within a cohort of 213 terminally ill cancer patients, nearly half indicated they experienced some, or occasional, dignity-related concerns. Compared with patients whose dignity was intact, patients with significant dignity-related concerns reported that they had increased pain, decreased quality of life, difficulty with bowel

TABLE 2 Diagnostic Questions and Examples of Therapeutic Interventions to Conserve Dignity<sup>3</sup>

	Diagnostic Questions	Therapeutic Interventions
<b>Illness-related concerns</b>		
<i>Symptom distress</i>		
Physical distress	"How comfortable are you? Is there anything we can do to make you feel more comfortable?"	Vigilance to symptom management; frequent assessment, and application of comfort care.
Psychological distress	"How are you coping with what is happening to you?"	Assume a supportive stance; empathic 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?"	
<i>Level of independence</i>		
Cognitive acuity	"Are you having any difficulty with your thinking?"	Have patients participate in decision-making, regarding both medical and personal issues. Treat delirium; when possible, avoiding sedating medication(s).
Functional capacity	"How much are you able to do for yourself?"	Use orthotics, physiotherapy, and occupational therapy.
<b>Dignity-conserving repertoire</b>		
<i>Dignity-conserving perspectives</i>		
Continuity of self	"Are there any things about you that this disease does not affect?"	See the patient as worthy of honor, respect and esteem. Soliciting stories, life review or narrative; sharing of photographs or crafts.
Maintenance of pride	"What about yourself or your life are you most proud of?"	
Role preservation	"What things did you do before you were sick that were most important to you?"	
Hopefulness	"What is still possible?"	Encouraging and enabling the patient to participate in meaningful or purposeful activities.
Generativity/legacy	"How do you want to be remembered?"	Life project (eg, making audio/video, writing letters or journal), dignity psychotherapy.
Autonomy/control	"How in control do you feel?"	Involve in treatment and care decisions.
Acceptance	"How at peace are you with what is happening to you?"	Support the patient in their outlook; encourage doing things that enhance their sense of well being (eg, meditation, light exercise, listening to music, prayer).
<i>Resilience or fighting spirit</i>		
<i>Dignity-conserving practices</i>		
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, listening to music, daily outings).
Maintaining normalcy	"Are there things you still enjoy doing on a regular basis?"	
Finding spiritual comfort	"Is there a spiritual or religious community that you are connected with, or would like to be connected with?"	Make referrals to chaplain or spiritual leader; enable the patient to participate in their particular spiritual and/or culturally based practices.
<b>Social dignity inventory</b>		
Privacy boundaries	"What about your privacy or your body is important to you?"	Ask permission to examine patient; proper draping to safeguard and respect modesty.
Social support	"Who are the people that are most important to you? Who is your closest confidante?"	Liberal policies about visitation, rooming in; enlisting 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.

functioning, and were dependent on others (bathing, dressing, and incontinence issues). These patients also reported a loss of will to live, increased desire for death, depression, hopelessness, and anxiety.<sup>72</sup> These studies have established the importance of self perception,

and the way in which patients experience themselves to be seen or appreciated, as powerful mediators of preservation of one's sense of dignity.<sup>72,73</sup> The data suggest that listening to patients, validating their concerns, and ascribing meaning to their experience may engender

hope and ultimately bolster dignity toward the end of life. Each encounter with a patient thus provides an opportunity to affirm their sense of worth: “The reflection that patients see of themselves in the eye of the provider must ultimately affirm their sense of dignity. At least in part, it would appear, dignity resides in the eye of the beholder.”<sup>73</sup>

#### **Desire for Death/Loss of Will to Live**

To some degree, the loss of will to live or a mounting desire to die may be a litmus test for quality end-of-life care. Although in some instances it may represent a growing acceptance or readiness to die, most empirical data has connected loss of will to live and desire for death—along with interest in euthanasia or assisted suicide—with various forms of end-of-life distress. One study of 200 terminally ill patients in a palliative care facility reported that 44.5% acknowledged at least a fleeting desire to die.<sup>77</sup> In most instances, these episodes were brief and did not reflect a sustained or committed desire to die. Seventeen patients (8.5%), however, reported an unequivocal and consistently held desire for death to come soon. Within this group, 59% received a diagnosis of depression, compared with 8% in patients who did not endorse a genuine, consistent desire for death. Patients with depression were approximately six to seven times more likely to have a desire for hastened death than patients without depression. Patients with a desire for death were also significantly more likely to experience pain and less social support than those patients without a desire for death. Logistic modeling of the data revealed that depression was the only significant predictor of desire for death in this patient population. This underscores the importance of psychological variables in understanding the notion of desire for death in the face of a life-limiting illness.

A more recent study of 92 terminally ill cancer patients reported similar findings.<sup>42</sup> Within this cohort, 16 patients (17%) were classified as having a high desire for death, with 16% meeting criteria for a major depressive episode. Among the depressed patients, seven (47%) were classified as having a high desire for

hastened death, whereas only 12% without a desire for death met criteria for depression. Patients with major depression were four times more likely to have a high desire for hastened death, whereas no significant association with present pain intensity was found. Again, the psychological influence on desire for death was reported to be paramount.

Few studies have directly examined the construct of “will to live” among patients nearing the end of life. A study of 168 terminally ill cancer patients—seen within a tertiary care palliative care unit—found that will to live, measured twice daily using visual analog scales, tended to fluctuate rapidly, even over very brief time intervals.<sup>78</sup> During the transition between community living and inpatient palliative care, anxiety accounted for most of the fluctuation or variance in will to live; once patients had been hospitalized for several days, depression accounted for most variance in will to live. Finally, as death drew nearer, physical symptom distress—particularly dyspnea—accounted for most of the variance in will to live. Further studies reveal that the majority of patients (ie, 58%) maintain a high will to live even as they are approaching death. Some maintain a moderate level of will to live (11%), some patients lose their will to live as death draws nearer (18%), whereas a minority actually gain their will to live (10%), likely as a result of reduced symptom distress.<sup>79</sup> Finally, a small but interesting minority (3%) demonstrate a consistent, low will to live; these patients were significantly more likely to report anxiety, nausea, dyspnea, and least likely to be married or living with a partner. Again, this evidence suggests that for many—although certainly not all—loss of will to live is a reflection of underlying psychological, physical, and socially mediated distress.

A more recent study examined a broader range of concurrent influences on the will to live in 189 patients with end-stage cancer.<sup>80</sup> The authors reported significant correlations between will to live and existential, psychological, social, and (to a lesser degree) physical sources of distress. Existential variables proved to have the most influence, including hopelessness, burden to others, and sense of dignity.

Although it may be difficult to disentangle various sources of suffering such as depression, hopelessness, despair, pain, or even the effects of social isolation in the context of end-of-life care, these findings speak to the importance of existential issues within the experiential landscape of patients nearing death.

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#### OPPORTUNITIES FOR INTERVENTIONS TO REDUCE SUFFERING

Palliative care aims to improve quality of life, enhance spiritual or existential well-being, and reduce suffering. It embodies an approach to the care of the dying, rather than simply a prescribed set of treatment modalities. Moreover, this approach is holistic, in that it includes and extends beyond the attenuation of physical symptoms, encompassing psychosocial, existential, and spiritual aspects of each person's unique illness experience. Recent research has begun to demonstrate the value of various interventional approaches in addressing these facets of end-of-life care.

#### General Approaches to Care

Palliative care, in and of itself, has been shown to have salutary effects that extend well beyond the purview of physical symptom control. Cohen, et al.<sup>81</sup> studied quality of life in 88 patients admitted to palliative care units in two distinct regions of Canada. The McGill Quality-of-Life Questionnaire and semistructured interviews were administered to patients when they were admitted to a palliative care unit and again 7 to 8 days later. Significant improvements in quality-of-life scores (including subscore improvements on physical, psychological, and existential well-being) were demonstrated. These findings suggest that palliative care is an effective, holistic intervention that mitigates suffering across a broad spectrum of end-of-life concerns.

A Swedish survey<sup>82</sup> of hospital chaplains concluded that physicians and other professionals should be able to address many of the questions posed to chaplains. Chaplains identified five main categories of questions they encoun-

tered from terminally ill patients: meaning, death and dying, pain and illness, relationships, and religious issues. Religious issues accounted for only 8% of these questions. Grant<sup>83</sup> identified five "spiritual interventions" used by nurses: holding a patient's hand, listening, laughter, prayer, and being present with a patient. Over 90% of 299 nurse respondents indicated that they would offer, suggest, or provide spiritual help in the following situations: when a patient explicitly requests spiritual support, is about to die, is grieving, or receives bad news.

The very act of acknowledging spiritual or existential distress appears to be interventional. Such acknowledgment, however, requires being able to find appropriate language that patients and physicians find comfortable and accessible. Some authors emphasize the importance of having a framework to guide the assessment of spiritual well being. Puchalski and Romer<sup>84</sup> recommend the mnemonic device *FICA* as a way of structuring spiritual inquiry. *FICA* stands for: **F**aith or beliefs, **I**mportance and influence, **C**ommunity, and **A**ddress. Some of the specific questions in each category include: What is your faith or belief? What role do your beliefs play in regaining your health? Are you part of a spiritual or religious community? How should these issues be addressed by your health care provider?

Rousseau<sup>85</sup> offers practical guidance for treating spiritual or existential suffering among dying patients. He describes a framework that includes: controlling physical symptoms; providing a supportive presence; encouraging life review to help the patient recognize purpose, value, and meaning; exploring guilt, remorse, forgiveness, and reconciliation; facilitating religious expression; and focusing on meditative practices that promote healing rather than cure. Whether using formatted approaches or more open-ended questioning, the goal is to demonstrate openness to ongoing dialogue regarding spiritual or existential concerns, however patients happen to frame or define them.

Chochinov and colleagues<sup>86</sup> reviewed various psychotherapeutic approaches in the context of end-of-life care. The mainstay of therapy for terminally ill patients is supportive therapy, which aims to bolster adaptive coping

mechanisms, minimize maladaptive ones, and when possible, attenuate anxiety and fear. Other interventions, such as insight-oriented therapy or interpersonal therapy, are limited in their application with dying patients because of a longer time frame often embedded within these approaches.

In a review of psychotherapeutic interventions for cancer patients, Breitbart concludes that, in populations of early-stage cancer patients and in patients with advanced disease, group psychotherapy is an effective means of improving quality of life and reducing psychological distress, anxiety and depression, and physical symptoms.<sup>87</sup> These group therapy approaches primarily fall within the categories of patient education, supportive-expressive interventions that encourage the expression of feelings toward illness and changing life circumstances, and cognitive-behavioral interventions. As Breitbart notes, however, few cancer group psychotherapy intervention trials have focused specifically on existential or spiritual themes.

Kearney and Mount<sup>28</sup> describe “surface-work” and “depth-work” as psychotherapeutic responses to spiritual or existential pain. Surface-work refers to interventions aimed at alleviating distress at the conscious or concrete level of the individual’s experience. Depth-work is an approach that moves a person toward deeper levels of the psyche, helping the individual reconnect with simple and ordinary aspects of life that they once found significant. Examples of depth-work interventions include art and music therapy, image work, dream work, and certain types of meditation.

Clark and Kissane<sup>88</sup> advocate the adoption of demoralization syndrome as a relevant palliative care diagnosis, defined as “a psychiatric state in which hopelessness, helplessness, meaninglessness, and existential distress are the core phenomena.”<sup>89</sup> Treatment consists of the following elements: providing continuity of care and active symptom management; exploring attitudes toward hope and meaning in life; balancing support for grief with promotion of hope; fostering the search for renewed purpose and role in life; using cognitive therapy to reframe negative beliefs; involving pastoral

counseling for spiritual support; promoting supportive relationships and use of volunteers; conducting family meetings to enhance family functioning; and reviewing goals of care in multidisciplinary team meetings. Future studies of this interventional approach will determine its feasibility and efficacy in this patient population.

### Specific Approaches to Care

Thus far, we have described therapeutic approaches that are general in nature. Few specific interventions addressing spiritual or existential suffering at the end of life have been developed and tested. Some, at various stages within the process of being tested, are described briefly below.

One pilot psychotherapy program integrates spiritual issues and resources for people diagnosed with cancer.<sup>90</sup> It aims to address four concerns: control, identity, relationships, and meaning. In psychotherapeutic groups, participants are asked to reflect on the four thematic spiritual issues and draw on internal spiritual resources that support adaptive coping. The language used in the therapy sessions is overtly religious. For example, therapists encourage participants to visualize God’s presence and to view God as a partner in their group therapy work. A study is currently underway to assess the efficacy of this program. An important limitation of this approach may be its inaccessibility to patients who do not believe in God, or whose religion is not of the Judeo-Christian tradition. It is also not clear whether the therapy would be appropriate for people in the late stages of their illness.

Miller and colleagues<sup>91</sup> describe a supportive-affective program focusing on spirit, emotions, and relationships. The program targets adults experiencing heart or lung disorders, HIV/AIDS, cancer, or geriatric frailty, with a life expectancy of at least 6 months but likely not more than 24 months. Special attention is devoted to the needs of African American patients and their caregivers. Participants meet for monthly group discussions and are encouraged to raise issues related to spirituality, emotions, and relationships. The program is designed to accommodate participants

from diverse religious backgrounds and also patients who do not participate in organized religion. A randomized controlled trial demonstrated significant improvement on depression and measures of religious well-being, but not existential well-being. Patients in the intervention groups were more likely to raise spiritual issues with their primary physician. Depression symptoms were reduced in the intervention group compared with controls, but this did not reach statistical significance. State anxiety remained unchanged. Positive changes in religious and existential spiritual well-being also did not reach statistical significance. Death meaningfulness, however, was significantly lower at posttest in the intervention group. When noncompliant patients were withdrawn from the analysis, the effects for depression and spiritual well-being were statistically significant and the effect for death meaningfulness remained positive. Despite several limitations associated with this study, the authors believe it offers qualified support for the intervention's ability to reduce depressive symptoms and death-related feelings of meaningfulness while increasing spiritual well-being.

Spira and Breitbart<sup>35,92,93</sup> address spiritual suffering in ambulatory advanced cancer patients with meaning-centered group psychotherapy. This therapeutic approach is based on the work of existential psychotherapist Viktor Frankl.<sup>94</sup> According to Frankl, meaning (or sensing that life has meaning) requires the conviction that one is fulfilling a unique role and purpose. With this comes the responsibility to live to one's full potential as a human being, thus achieving a sense of peace, contentment, or even transcendence through connectedness with something greater than oneself. The primary tenet of Frankl's logotherapy is that people always have control over their attitude or outlook, no matter how enormous the adversity. Logotherapy aims to decrease patients' suffering and have them live life to its fullest, by engaging in activities that engender the greatest amount of meaning and purpose.

Meaning-centered group psychotherapy aims to help participants sustain or enhance a sense of meaning, peace, and purpose in their lives, and to make the most of each group member's remaining time.<sup>93,95</sup> A combination of instruction, discussion, and experiential ex-

ercises are used in eight group sessions. Each session is organized around a specific meaning-centered theme. Because the therapists view the search for meaning as a creative, individual, and active process, patients are encouraged to be active participants in the group process. Preliminary evaluation points to favorable results. Before the intervention, approximately 40% of study participants did not report a sense of meaning or purpose in their lives. Postintervention, none of the participants perceived life as meaningless; at 2-month follow up, beneficial treatment effects continued to mount. A version of this intervention for individual use is currently being developed.<sup>95</sup>

Based on the previously described Dignity Model, Chochinov and colleagues<sup>75</sup> developed a therapeutic intervention called "Dignity Therapy," targeting depression and suffering in palliative care patients. Briefly, Dignity Therapy poses questions that offer an opportunity for patients to address aspects of life that they feel were most important or were most meaningful; the personal history they most want remembered; or things that need to be said (Table 3). Within a Phase I trial of Dignity Therapy, this intervention was carried out by psychiatrists, psychologists, and experienced palliative care nurses. Dignity therapy allows the patient to address grief-related issues, offer comfort to the soon-to-be bereft loved ones, or provide instructions to friends and family. The sessions (usually not more than two, each less than 1-hour duration) are tape recorded, transcribed and edited, and then returned to the patient. This creates a tangible product—a legacy or generativity document—that, in effect, allows the patient to leave behind something that is permanent or lasting; in most instances this is bequeathed to a family member. In contrast to other psychotherapies, Dignity Therapy is brief, can be done at the bedside, and aims to affect both patients and their loved ones.

Chochinov and colleagues<sup>75</sup> found that of 100 terminally ill patients who took part in Dignity Therapy, 91% reported being satisfied. Additionally, a heightened sense of dignity was found in 76% of patients, an increased sense of purpose in



TABLE 3 Dignity Psychotherapy Question Protocol

<p>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?</p> <p>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?</p> <p>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?</p> <p>What are your most important accomplishments, and what do you feel most proud of?</p> <p>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?</p> <p>What are your hopes and dreams for your loved ones?</p> <p>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)]?</p> <p>Are there words or perhaps even instructions you would like to offer your family, to help prepare them for the future?</p> <p>In creating this permanent record, are there other things that you would like included?</p>
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68%, a heightened sense of meaning in 67%, an increased will to live in 47%, and 81% reported that it had been (or would be) of help to their family. Postintervention measures of suffering showed significant improvement ( $P = 0.023$ ) and reduced depressive symptoms ( $P = 0.05$ ). Patients who felt Dignity Therapy helped their family reported feeling life was more meaningful ( $r = 0.480$ ;  $P < 0.0001$ ), accompanied by a heightened sense of purpose ( $r = 0.562$ ;  $P < 0.0001$ ), will to live ( $r = 0.387$ ;  $P < 0.0001$ ), and a lessened sense of suffering ( $r = 0.327$ ;  $P = 0.001$ ). The salutary effects of enabling dying patients to attend to the well-being of loved ones may help explain the ability of Dignity Therapy to reduce suffering and distress at the end of life.

Dignity Therapy and meaning-centered group psychotherapy have shown initial promise, and are currently undergoing more rigorous testing using a randomized controlled trial design. Although these interventions aim to bolster dignity, hope, and meaning, their ability to reduce existential or spiritual distress is independent of any explicit religious or faith-based focus. Whether religious or secular in nature, approaches that guide or shape spiritual or existential care need to be evaluated to answer the question of their feasibility and efficacy. How we broach these aspects of care—including the language we use to frame these issues—also needs to be evaluated, to assure that patients are approached in a way that is comfortable and accessible, regardless of individual religious or secular orientation. Ultimately, however, as Marrone notes, “in the midst of dealing with profound loss in our lives, the ability to reinscribe meaning to a changed

world through spiritual transformation, religious conversion, or existential change may be more significant than the specific content by which that need is filled.”<sup>96</sup>

#### CONCLUSION

In his extensive writings on despair at the end of life, Eric Cassel<sup>97</sup> suggests that suffering is proportionate to the extent that an individual’s sense of self or personhood undergoes, or is threatened by, disintegration. Yet, for patients approaching death, these assaults on personhood are often unavoidable. The process of dying sees mounting vulnerability punctuated by increasingly difficult physical, psychosocial, and spiritual/existential challenges. Patients may struggle to locate a sense of self that is unencumbered by illness. In many instances, they will undergo a gradual redefining of self and personal expectations shaped by the daily realities of accommodating to deteriorating health. In turn, health care providers committed to dignity-conserving care must find ways of responding to patients—or rather to whole persons—that are not solely defined by the exigencies of the underlying illness. Within the field of palliative care, developing compassionate and effective responses, which are individually tailored and sensitive to a patient’s fluctuating deteriorating health status, is a critical challenge.

Significant advances have been made in the area of palliative symptom management. Yet, a mechanistic or technological paradigm is too narrow to encompass the full potential of palliative

care, which aims to deliver holistic, compassionate, and medically savvy end-of-life care. These attributes are by no means mutually exclusive and, in fact, are highly interdependent within a dignity-conserving model of care. Nowhere is the adage “to cure sometimes, to heal often, to comfort always” more salient than in end-of-life care. Yet, knowing how to provide comfort requires insight into the complete landscape of a dying patient’s experience. Within the new horizons of palliative care, these insights will provide the foundation for novel and compassionate approaches, intended to bolster hope, enhance

meaning, and lessen suffering for patients nearing death. In this way, and in accordance with the vision of the late Dame Cicely Saunders, palliative care “will do all [it] can, not only to help you die peacefully, but also to live until you die.”

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