Interventions to Enhance the Spiritual Aspects of Dying

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ABSTRACT

In recent years, medical and allied health publications have begun to address various topics on spirituality. Scholars have posited numerous definitions of spirituality and wrestled with the notion of spiritual pain and suffering. Researchers have examined the relationship between spirituality and health and explored, among other topics, patients' perceptions of their spiritual needs, particularly at the end of life. This paper summarizes salient evidence pertaining to spirituality, dying patients, their health care providers, and family or informal caregivers. We examine the challenging issue of how to define spirituality, and provide a brief overview of the state of evidence addressing interventions that may enhance or bolster spiritual aspects of dying. There are many pressing questions that need to be addressed within the context of spiritual issues and end-of-life care. Efforts to understand more fully the constructs of spiritual well-being, transcendence, hope, meaning, and dignity, and to correlate them with variables and outcomes such as quality of life, pain control, coping with loss, and acceptance are warranted. Researchers should also frame these issues from both faith-based and secular perspectives, differing professional viewpoints, and in diverse cultural settings. In addition, longitudinal studies will enable patients' changing experiences and needs to be assessed over time. Research addressing spiritual dimensions of personhood offers an opportunity to expand the horizons of contemporary palliative care, thereby decreasing suffering and enhancing the quality of time remaining to those who are nearing death.

INTRODUCTION

In recent years, medical and allied health publications have begun to address various topics on spirituality. Scholars have posited numerous definitions of spirituality and wrestled with the notion of spiritual pain and suffering. Researchers have examined the relationship between spirituality and health and explored, among other topics, patients' perceptions of their spiritual needs, particularly at the end of life.

This paper summarizes salient evidence pertaining to spirituality, dying patients, their health care providers, and family or informal caregivers. We examine the challenging issue of how to define spirituality, and provide a brief overview of the state of evidence addressing interventions that may enhance or bolster spiritual aspects of dying. Finally, we suggest several avenues for future spiritually-focused research in end-of-life care.

SPIRITUALITY IN PALLIATIVE CARE

Among Western health practitioners, interest in attending to the spiritual concerns of dying pa-

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patients is a relatively recent phenomenon. Although religion and medicine were linked in ancient times, the Renaissance witnessed the separation of science and religion. Cartesian dualism, the separation of body and mind, established a paradigm in which science dealt with the physical world, whereas the noncorporeal, spiritual realm was left to the clergy.2 Certain consequences naturally followed; for instance, “suffering” in modern medicine became understood mostly in terms of its physical dimensions.3 Indeed, some argue that the ensuing scientific tradition hampered our ability to empathize truly with our patients.4 This thinking continues to dominate contemporary medicine, although its edges have been blunted by ideas such as Engel’s biopsychosocial model, which asserts that psychological and social factors, in addition to biological factors, are responsible for disease processes.2

Despite this dualistic paradigm, the importance of spirituality in care of the dying is increasingly acknowledged by clinicians, researchers, and educators in end-of-life care. The Institute of Medicine5 lists spiritual well-being as one of six domains of quality supportive care of the dying. Some investigators suggest, therefore, that there be routine inquiry by physicians about the relevance of spirituality to the patient within the context of taking a medical history.6 Guidance for discussing religious and spiritual issues with dying patients has been published.7,8 By 1999 nearly one half of 126 medical schools in the United States taught courses on spirituality and medicine,9 and it was anticipated that by the turn of the century most medical schools would have similar courses.10 Several standard palliative care textbooks now include chapters on spirituality.11,12 In a survey of empirical studies published in leading palliative care journals between 1994 and 1998, 6.3% of studies included spiritual or religious variables, compared to 1% reported in a similar study of the Journal of the American Medical Association, The Lancet, and New England Journal of Medicine.13

**Spirituality and patient perspectives**

There is evidence that some dying patients, and those with life-threatening illnesses, would like health practitioners to be attuned to their spiritual needs. Post and colleagues6 cite four American surveys of inpatient and ambulatory patient samples in which patient acceptance of physician inquiry into their spiritual needs and other spiritual matters were studied. Of the patients, 40–94% were interested in having their physicians consider their spiritual needs. Variations in regional religiosity may have accounted for the variability in findings. A 1997 Gallup survey of a representative sample of 1200 American adults found that just over half of respondents anticipated a need for companionship and spiritual support in their dying days. Although most would look to their family (81%) or close friends (61%) for these sources of comfort, 36% would choose the clergy, and 30% would choose doctors for such support. Nearly 40% of respondents indicated that, if they were dying, having a doctor who was spiritually attuned to them would be very important.14

Existential questions may be particularly relevant to individuals facing life-threatening illness or death. In one study, 16 hospice patients were interviewed about their attitudes toward discussing spiritual issues with their physicians. They had favorable attitudes toward religious or spiritual discussions with doctors, but they did not want to be “preached” to. Moreover, patients indicated that they wanted to be treated as whole persons and with sensitivity.15 In Norway, 20 patients with advanced cancer were asked to respond to the inclusion of faith as a topic in conversation with a medical oncologist. Of the 20 subjects, 18 expressed positive interest in an open question about religious faith.16

Moadel and colleagues17 identified the nature, prevalence, and correlates of spiritual and existential needs in 248 ethnically diverse, urban cancer outpatients in the U.S. They found that “unmet spiritual or existential needs” ranged from 25% to 51%. In order of prevalence, patients wanted help in overcoming fears (51%), finding hope (42%) and meaning in life (40%), finding spiritual resources (39%), and having someone to talk with about the meaning of life and death (25%). Patients reporting five or more needs were more likely to be Hispanic or African American, more recently diagnosed, and unmarried. Although the authors discussed the implications for developing interventions in this setting, the study did not identify who patients would like to address their spiritual needs.

Ehman and colleagues18 studied a group of 177 ambulatory pulmonary outpatients regarding their acceptance of a question introducing spiri-
tuality as part of the medical history. In all, 45% reported that religious beliefs would influence their medical decisions if they became gravely ill; of those, 94% agreed or strongly agreed that doctors should ask them whether they have such beliefs if they became gravely ill. Almost half of respondents who did not have religious or spiritual beliefs still agreed that doctors should ask about them. Nearly one quarter of patients found the idea of their physicians discussing religion or spirituality with them objectionable, with just less than 10% reporting strong reservations. The investigators did not pursue the rationale of the 13 respondents who expressed these reservations, nor did the researchers report demographic characteristics of this small group. They speculated that respondents may have misunderstood the question or were offended by even an intermediate question about spirituality.

Some studies regarding patient’s attitudes towards spiritual dimensions of care are more equivocal. Murray and colleagues19 compared the spiritual needs of two groups of dying patients, namely, those with lung cancer and those with end-stage heart failure. The authors noted that the extent to which patients and their caregivers wished to have spiritual care incorporated into their health care was unclear, with people often expressing reluctance to raise spiritual issues with “busy” health professionals.

Spirituality and health care provider perspectives

One study, a survey of family physicians and adult outpatients in Vermont, reported significant discrepancies between physicians and patients pertaining to beliefs in God, engaging in regular prayer, and feeling close to God. Doctors endorsed these beliefs or practices significantly less often than patients \((P = 0.01)\). Nonetheless, the majority of physician respondents made inquiries about their patients’ religious beliefs either occasionally \((77\%)\) or frequently \((10\%)\).20 A recent survey of American physicians, conducted by the National Opinion Research Center at the University of Chicago, found that 81% of respondents agreed that a patient’s spirituality could directly affect clinical outcomes and 91% agreed with the importance of doctors understanding the religious and spiritual beliefs of their patients.21 Similarly, a survey of members of the American Academy of Family Physicians found that 74% of respondents attended religious services on a weekly or monthly basis, and 79% reported a strong religious or spiritual orientation. Only a small percentage \((4.5\%)\) reported that they did not believe in God.22 A survey of 231 family physicians in Missouri indicated that 96% of respondents considered spiritual well-being an important health component, 86% would refer hospitalized patients with spiritual questions to chaplains, and 58% agreed that physicians should address patients’ spiritual concerns.23 In addition, in one recent U.S. survey of 299 hospital-based bedside nurses, between 92% and 100% of respondents believed that spirituality could give their patients inner peace, give them strength to cope, bring about physical relaxation and self-awareness, and give them a sense of connection with others.24 Of hospice social workers, 83% reported that religion and spirituality were very to extremely, important to their clients.25

One argument for health care providers attending to the spiritual needs of patients is the possible connection between religion and health, a relationship that has been investigated extensively. Research has examined the relationship between religion or spiritual beliefs and a variety of issues, including patients’ reliance on health professionals to meet their psychosocial needs (depending on the patients’ degree of religious faith),26 coping behaviors,27 bereavement,28 and morbidity and mortality.

The Ironson-Woods Spirituality/Religiousness Index identified four factors associated with longer survival in people living with HIV/AIDS: sense of peace, faith in God, religious behavior, and compassionate view of others. Long-term survivors of AIDS, that is, individuals who lived beyond twice the median expected survival time, scored significantly higher on these factors than did the HIV-positive comparison group.29 In 1998, Larson and colleagues published a systematic analysis of 329 peer-reviewed studies and 35 review articles on religion or spirituality and health.30–34 A major conclusion drawn from the review was that there is a positive association between religiosity or spirituality and health. However, the generalizability of the findings to populations other than Caucasian, American, Christian subjects is questioned.35 Mortality research over the last three decades demonstrates significant associations between frequent attendance at religious services and reduced risk of early mortality.36 A meta-analysis of data from 42 independent studies of the association of reli-
igious involvement and all causes of mortality found that religious involvement was significantly associated with lower mortality (odds ratio = 1.29). On the other hand, religious distress may put seriously ill patients at increased risk for earlier death by as much as 28%, and persons who refuse medical treatment for religious reasons may incur higher mortality. The robustness and implications of these findings have been vigorously debated.

Cohen and colleagues establish the ethical grounds for physician inquiry into patients’ religious and spiritual beliefs asserting that “the question of whether religious and spiritual beliefs improve [patient] outcomes is misplaced . . . The real issue is not whether religious and spiritual commitments improve patients’ health, but rather whether physician inquiries into such commitments honor patients as . . . whole and integrated persons” (p. 32). Similarly, even in the face of scientific evidence for the salutary effects of spirituality, respect for patients as persons prohibits proselytizing by physicians. As medicine continues to move away from paternalism and toward a partnership model with its attendant respect and support for patient autonomy, respect for patients’ values and beliefs is essential.

WHAT IS SPIRITUALITY?

Palliative care endeavors to attend to the whole person. Inroads have been made in the areas of physical and psychological symptom control associated with advanced disease in the final phase of life, but there are aspects of suffering and distress toward the end of life that too often remain beyond the abilities of contemporary palliative care. To understand this more fully requires a careful examination of the spiritual and existential domains of patients’ experiences. Although these are always embedded within the complexities of conventional symptom distress, discussing them separately, artificial though that may be, offers an opportunity to explicate these aspects of patients’ suffering.

Acknowledging a spiritual dimension to one’s personhood may be relatively easy; defining what that means, and examining it through a scientific lens, is more challenging. Definitions of spirituality abound. One comprehensive review of the health literature documented 92 definitions of spirituality. The authors identified seven definitional themes: 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.

Kearney and Mount distinguish “the spiritual” from “religion.” “The spirit is a dimension of personhood . . . a part of our being. Religion, on the other hand, is a construct of human making that . . . enables conceptualization and expression of spirituality” (p. 359). According to Rousseau, “Religion encompasses structured belief systems that address spiritual issues, often with a code of ethical behavior and a philosophy” (p. 2000). As a construct, it would appear that spirituality is broader than religion. Although some authors have cautioned for the separation of psychosocial from spiritual domains of care, Brady and colleagues used the spirituality subscale of the Functional Assessment of Chronic Illness Therapy (FACIT) Scale to show a unique association with quality of life (QOL) within an ethnically diverse sample of 1610 cancer patients, which was equal in its association with physical well-being. Clearly, although parsing out these domains provides an opportunity to discuss them separately, they are overlapping, interconnected constructs experienced by whole persons.

There is little empirical evidence available of how dying patients define spirituality. However, Chao and colleagues studied six Buddhist and Christian terminally ill patients in Taiwan, asking them what the essence of spirituality meant 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). Hermann interviewed 19 hospice patients who, after initially defining spirituality as relating to God or religion, later acknowledged that spirituality was part of their total existence.

Increased secularism has witnessed diminution of the explicit and implicit religious connotation associated with the term “spirituality.” In the context of palliative care, spirituality “. . . has come to describe the depth of human life, with individuals seeking significance in their experiences and in the relationships they share with
family and friends, with others who experience illness, and with those engaged in their treatment and support\(^p\).\(^9\) Within the religious realm of this broad framework, spirituality aligns itself with a sense of connectedness to a personal God, whereas within the secular realm, it invokes a search for significance and meaning. Although the source or inspiration for such significance will vary from person to person, what they hold in common is their ability to imbue life with an overarching sense of purpose and meaning, including a sustained investment in life itself.

Puchalski and Romer\(^50\) emphasize the relationship between spirituality and experiencing transcendent meaning in life. Karasu\(^51\) views spirituality as a construct that involves concepts of faith and meaning. The faith component of spirituality is most often associated with religion and religious belief, whereas the meaning component of spirituality appears to be a more universal concept that can exist in religious or nonreligious individuals. According to Frankl,\(^52\) meaning, or having a sense that one’s life has meaning, involves the conviction that one is fulfilling a unique role and purpose in a life that is a gift: a life that comes with a responsibility to live to one’s full potential as a human being, thereby achieving a sense of peace, contentment, or even transcendence through connectedness with something greater than oneself.

Bergman sounds a cautionary note. Documenting the shift in meaning of the spirituality concept over the last 20 years, she calls spirituality a “glow-word,” occupying a niche once occupied by the term “faith” or what sociologists once called personal or invisible religion. She argues that the term is variably applied as a vaguer synonym for religion, personal side of religion as distinguished from organized religion, and that it has taken over the existential core human dimension, once the domain of humanistic psychology. She suggests that spirituality becomes a “handy” term shifting its meaning with various historical nuances and, consequently, may become virtually meaningless.\(^53\)

McGrath suggests the need for a new language to articulate spirituality and affirms the recent move away from conflating religion with spirituality. She examined the concepts of spirituality and spiritual pain among hospice patients, their formal and informal caregivers, as well as cancer survivors in Australia. Of 14 people living at home with a prognosis of less than 6 months to live, most did not seek religious comfort in response to the challenge of their illness; a minority held conventional religious beliefs. McGrath reports that maintaining an intimate connection with life through family, home, friends, leisure, and work is just as vital spiritually to individuals as transcendent meaning making (religious or otherwise). She believes that her findings highlight the importance of maintaining a clear distinction between religion and a more generalized notion of spirituality, that is, finding meaning.\(^54,55\) Palliative care researchers may make this distinction more frequently than other researchers who typically have measured spirituality and religiosity in terms of religious affiliation. Of 1117 empirical studies published in five palliative medicine/hospice journals, researchers assessed spirituality using variables such as spiritual well-being, meaning or transcendence (32%), followed by religious affiliation (29%), and spiritual/religious services provided (19%).\(^13\)

Chochinov and colleagues have examined notions of meaning and purpose, using the paradigm of dignity. They have shown that patients are readily able to access discussions pertaining to dignity, which can include matters of spiritual investment, meaning, purpose, and various other social, physical, and existential considerations relevant to dying with dignity.\(^56–58\) Their work has also demonstrated the connections between existential considerations—such as hopelessness, being a burden to others, and dignity—and a loss of will to live.\(^59\) If the essence of spirituality is connectedness to something that imbues life with a sense of purpose or meaning, a paucity of either would logically correlate with a disinvestment in life itself.\(^60,61\) It is therefore consistent that spiritual well-being may be a buffer against depression, hopelessness, and desire for death in patients with advanced cancer.\(^52–64\)

**WHAT IS SPIRITUAL OR EXISTENTIAL SUFFERING?**

Just as the term spirituality needs definition, so too do the terms “spiritual suffering” and “existential pain.” Spiritual pain may manifest itself as symptoms in any area of a person’s experience—physical (e.g., intractable pain), psychological (e.g., anxiety, depression, hopelessness), religious (e.g., crisis of faith), or social (e.g., disintegration of human relationships). However, it is not pos-
S-108

CHOCHINOV AND CANN

sible to recognize spiritual pain on the basis of symptoms alone; it is the combination of the symptoms with characteristic descriptions and behaviors that help identify this form of suffering. As Cassell describes it, “Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it.” (p. 639).

One study asked hospital chaplains, palliative care physicians, and pain specialists to define existential pain. In their definitions, chaplains more often stressed issues of guilt and religious questions, whereas palliative care physicians related existential pain to annihilation and impending separation. Although some pain specialists emphasize that living is painful, they concluded that existential pain is most often used as a metaphor for suffering. In a qualitative study of 12 survivors of hematological malignancies, McGrath found that a key ingredient in the subjects’ spiritual pain was “the sense that the normal network of relationships and experience with life is failing to meet the individual’s needs, and thus the expected satisfaction and meaning-making from life are not forthcoming.” (p. 639).

Spiritual crisis towards the end of life sometimes takes the form of losing one’s will to live, or expressing a heightened desire for death. A great deal of work has been done in this area, showing these are often, although not always, associated with a high prevalence of syndromal depression, pain and a paucity of social support. McClain and colleagues demonstrated significant correlations between spiritual well-being and desire for hastened death ($r = -0.51$), hopelessness ($r = -0.68$), and suicidal ideation ($r = -0.41$). 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 ($r = 0.40$) but not in those high in spiritual well-being ($r = 0.20$). Loss of dignity is also frequently cited as the reason patients make (and in the Dutch experience, receive) death hastening measures such as euthanasia or assisted suicide. Wilson and colleagues asked seventy dying patients about whether they would choose physician hastened death now, if it were available. Of the patients, 58% could imagine using it under particular circumstances at some future point in time, should they experience uncontrolled pain, severe physical symptoms, a diminished quality of life, or find themselves a burden to others. In addition, 12% would have requested a hastened death at the time of the interview, if it were legally available, for reasons of drowsiness, weakness, a sense of loss of control and loss of interest, hopelessness, and a desire to die. Reports on the Death with Dignity Act in Oregon indicate that patients who sought out a hastened death did so largely because of suffering based on a perception of lost autonomy and loss of control. In fact, every study reporting on the experiences of patients who chose, or expressed an interest in death-hastening measures, indicates that the most salient issues refer to suffering and its various dimensions (loss of autonomy, loss of control, fear of being a burden to others, hopelessness, and general despair). Clearly, loss of control, feeling burdensome to others, hopelessness, and a desire to die begin to cross over from the domain of conventional symptom distress and into the realm of spiritual and existential suffering.

**SPIRITUAL CARE: INTERVENTIONS FOR ALLEVIATING SUFFERING**

A systematic search of the major medical, allied health, social science, and humanities research data bases yielded few rigorous evaluations of spiritual interventions using randomized controlled trial standards. Similar to Cohen and colleagues’ analysis published in 1997, we found largely descriptive studies and scholarly discussions. Highlights of our review are summarized below.

*Data bases included: Medline, CINAHL, Humanities, and PsycINFO. Search terms included: religion, spirituality, faith, existentialism, hospice, palliative, or terminal care, end of life, dying, death. We focused on intervention studies, clinical trials or randomized clinical trials, and literature reviews in English language publications.*

Spiritual care and who should provide it

Lunn defines spiritual care in terms of “meeting people where they are and assisting them in connecting or reconnecting to things, practices, ideas, and principles that are at their core of their being—the breath of their life, making a connection between yourself and that person” (p. 154).
A Swedish national survey of hospital chaplains identified categories of questions posed to them by patients with terminal illness. Five main categories were identified, in order of frequency including: meaning; death and dying; pain and illness; relationships; and religious issues. Religious issues accounted for only 8% of the questions posed to chaplains. The authors conclude that physicians and other professionals should be able to address many of the questions posed to chaplains. A study of nurses’ spiritual interventions found that the majority used the following five “therapies”: holding a patient’s hand, listening, laughter, prayer, and being present with a patient. More than 90% of 299 respondents indicated that they would offer, suggest, or provide spiritual help in the following situations: when a patient explicitly request spiritual support, is about to die, is grieving, or receives bad news.

Walter argues that spiritual care in palliative settings may not be so much an opportunity as it may be a burden for some caregivers. He suggests that we drop the assumption that any health care provider can provide spiritual care to any patient and find ways instead of acknowledging the differing spiritual or religious needs of individual patients as well as what spiritual care each team member can or cannot offer. On the other hand, Derrickson believes that, at the very least, each member of the hospice team should be able to recognize spiritual work when it is being done and to listen respectfully to a patients’ individual expressions of their spirituality.

General spiritual care approaches to end-of-life care

Palliative care is an interventional approach aimed at improving quality of life, enhancing spiritual well-being, and reducing suffering. In a study of 88 patients admitted to five palliative care units across two distinct regions of Canada, Cohen and colleagues used the McGill Quality of Life (QOL) Questionnaire to document self-rated QOL of patients on admission to the palliative care unit and again 7–8 days later. The questionnaire was supplemented with semistructured interviews. Significant improvements in quality-of-life scores, including subscore improvements in physical, psychological, and existential well-being, were demonstrated. This is one of the few studies showing that palliative care can improve existential well-being, in addition to psychological and physical symptoms, among dying patients. Similarly, Nelson and colleagues used the Functional Assessment of Chronic Illness Therapy Spiritual Well-Being Scales (FACIT-Sp) to examine the impact of spirituality and religiosity on depressive symptoms in a sample of terminally ill cancer and AIDS patients. They observed a negative association between meaning and peace and depression scores, but no such association for religiosity.

In summarizing the literature, Breitbart concluded that there is clear evidence that traditional group psychotherapy interventions for cancer patients are effective in improving quality of life and reducing psychological distress, anxiety, and depression, and in reducing physical symptoms, both in populations of early-stage cancer patients and in patients with advanced disease. These therapeutic approaches largely fall within the categories of patient education or psycho-education interventions; supportive–expressive interventions; and cognitive–behavioral interventions. He further notes that few cancer group psychotherapy intervention trials have focused specifically on existential or spiritual themes.

Chochinov and colleagues reviewed various psychotherapeutic approaches that have been considered within the context of end-of-life care. They note that supportive therapy has been the mainstay of therapy for patients who are terminally ill. The goal of supportive therapy is 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 may have limited application for patients nearing death, because of the longer time frames associated with these therapeutic approaches. Several investigators have begun to explore intervention strategies, largely targeting constructs such as meaning and purpose or their antithesis—hopelessness, burden to others, loss of will to live, and suffering.

Kearney and Mount describe “surface-work” and “depth-work” as psychotherapeutic responses to spiritual 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 to reconnect with simple and ordinary aspects of life that, in the past, brought that person a sense of significance. Examples of
depth-work interventions include art and music therapy, image work, dream work, and certain types of meditation. Rousseau offers practical guidance for treating spiritual suffering among dying patients. He describes a framework that includes the following: control of 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.

Another treatment approach is based on the construct of demoralization. Clarke and Kissane advocate the adoption of demoralization syndrome as a relevant diagnostic entity in palliative care. Demoralization syndrome is defined as “a psychiatric state in which hopelessness, helplessness, meaninglessness, and existential distress are the core phenomena” (p.13). Their treatment approach for Demoralization Syndrome consists of the following elements: provide continuity of care and active symptom management; explore attitudes toward hope and meaning in life; balance support for grief with promotion of hope; foster search for renewed purpose and role in life; use cognitive therapy to reframe negative beliefs; involve pastoral counseling for spiritual support; promote supportive relationships and use of volunteers; conduct family meetings to enhance family functioning; and review goals of care in multidisciplinary team meetings. Future studies using this approach will answer the questions of feasibility and efficacy in this patient population.

Specific spiritual care interventions for end-of-life care

Acknowledging spiritual distress, in and of itself, can be interventional. Providing such acknowledgement requires being able to find language that patients and physicians find comfortable and accessible, and the development of assessment approaches that evaluate spiritual well being. For example, Puchalski and Romer recommend the mnemonic “FICA” as a way of structuring spiritual inquiry. FICA stands for Faith or beliefs, Importance and influence, Community, and Address. 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 the health care provider? MacInnis and colleagues have developed a spiritual assessment tool to guide interdisciplinary palliative care team assessments of spiritual pain with strategies for alleviating suffering throughout the illness trajectory. Whether using formatted approaches or more open-ended questioning, the goal is to demonstrate openness to ongoing dialogue regarding spiritual concerns, however broadly patients frame or define them.

Some investigators suggest that music and art may contribute to spiritual healing, particularly for those who are dying. The alternative modalities used in the service of spiritual care of the dying include acupuncture, therapeutic touch, biofeedback, relaxation, guided imagery, and aromatherapy. Evaluation of the therapeutic efficacy of these modalities is largely descriptive and exploratory.

Cole and Pargament describe a pilot psychotherapy program that integrates spiritual issues and resources for people diagnosed with cancer. The program aims to address four concerns including control, identity, relationships, and meaning. In psychotherapeutic groups, participants are encouraged to reflect on the four thematic spiritual issues and to 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 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 persons in the late stages of their illness.

Miller and colleagues have developed a supportive–affective program that focuses on three main areas: 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 en-
encouraged to raise issues related to spirituality, emotions, and relationships. The program is also designed to accommodate participants from diverse religious backgrounds and also for patients who do not participate in an 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 physicians.88

Breitbart80 and Breitbart and Heller89 are applying the work of Viktor Frankl and his concepts of meaning-based psychotherapy, to address spiritual suffering amongst ambulatory patients with advanced cancer. Their application of a Meaning-Centered Group Psychotherapy aims to help participants to 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. This approach uses a combination of instruction, discussion, and experiential exercises in eight group sessions, with each session 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; after the intervention, none of the participants perceived life as meaningless, and at 2-month follow-up, beneficial treatment effects continued to mount. A version of this intervention for individual use is currently being developed.90

Chochinov and colleagues have developed an empirically derived model of dignity towards the end of life. This model is based on a qualitative study of 50 dying patients and their perceptions and concerns related to dignity.56 Three major categories emerged from the qualitative analysis: illness-related issues that threaten to or actually impinge on a patient’s sense of dignity; the repertoire of perspectives and practices that patients use to conserve dignity; and an inventory of social interactions that either detract from or enhance one’s sense of dignity. The Dignity Model provides caregivers a therapeutic framework incorporating a broad range of physical, psychological, social, and spiritual/existential issues that may affect a person’s perception of dignity. Based on their model of dignity, Chochinov and colleagues have developed a therapeutic intervention coined Dignity Therapy, targeting depression and suffering, along with enhancing a sense of meaning, purpose and will to live in palliative care patients.57, 91 Briefly, the Dignity Therapy protocol poses questions that offer an opportunity for patients to address aspects of life that they feel most proud of or that were most meaningful; the personal history that they most want remembered; or things that need to be said. This allows the patient to address grief-related issues, to offer comfort to soon-to-be bereft loved ones, or to provide instructions to friends and family. These sessions are tape recorded, transcribed and edited, and then returned to the patient. This creates a tangible product, a legacy, or generativity document, which in effect allows the patient to leave behind something that will transcend death. 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.

Within a cohort of 100 terminally ill patients, Chochinov and colleagues found that 91% reported being satisfied with Dignity Therapy; 76% reported a heightened sense of dignity; 68% an increased sense of purpose; 67% a heightened sense of meaning; 47% an increased will to live; in addition, 81% reported that it had been or would be of help to their family. Post-intervention measures of suffering showed significant improvement ($P = 0.023$), and reduced depressive symptoms ($P = 0.05$). Patients who felt that Dignity Therapy helped their family reported feeling that life was more meaningful ($r = 0.480; P = 0.000$), accompanied by a heightened sense of purpose ($r = 0.562; P = 0.000$), will to live ($r = 0.387; P = 0.000$), and a lessened sense of suffering ($r = 0.327; P = 0.001$).91 They concluded that Dignity Therapy showed promise as a novel therapeutic intervention for suffering and distress at the end of life. One feature of interventions that target the bolstering of dignity, hope, and meaning is that they may reduce existential or spiritual distress, without an explicitly religious or faith-based focus. Whether religiously framed, or more secular in nature, there may be various useful approaches to alleviating suffering. As Marrone stated, “In the midst of dealing with profound loss in our lives, the ability to re-ascibe 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” (p. 495).92

RECOMMENDATIONS FOR FUTURE RESEARCH

The intangible nature of spiritual and existential issues related to dying raises the question of whether any amount of research will enable us to unravel fully this aspect of terminal care. Nevertheless, it is important to try to understand, as best we can, all facets of suffering toward the end of life, and to determine what actions may best provide necessary comfort. To that end, holistic clinicians should be mindful of these issues, and researchers will need to follow a deliberate and systematic path within the realm of spiritual and existential enquiry.

Who should be doing spiritually focused research?

Research addressing the topic of spirituality is being undertaken within various health disciplines, including medicine,10 nursing,24,47 social work,25 occupational therapy,43 and chaplaincy.84,93 For the most part, researchers tend to work within their disciplinary silos, publishing in their discipline-specific journals. Most of the English publications have been produced in the United States; hence, they tend to reflect American attitudes and practices. Research interest also exists in the United Kingdom,19 Canada,58–61,79,94 Australia,83 Sweden,66,76 Norway,16 and Taiwan.47 Future research needs to engage expertise across a broad spectrum of perspectives, integrating the insights and proficiencies that each of these vantage points has to offer. To the extent that religiosity and spirituality are culturally or ethnically bound, research of this nature needs to take place across a broad range of international constituencies.

What should spiritual research be addressing?

There are many pressing questions that need to be addressed within the context of spiritual issues and end-of-life care. Framing these issues from a secular perspective, constructs such as spiritual well-being, transcendence, hope, meaning, dignity, and demoralization have begun to appear in the literature.83 Efforts to measure and track these constructs, to understand more fully the spiritual needs of the dying, and to correlate them with variables and outcomes such as quality of life, pain control, coping with loss, and acceptance are warranted.15 Framing these issues from a religious or faith-based perspective, further research is needed to examine various dimensions of a person’s religious life and how these correlate with similar outcomes. Multicenter studies to ensure generalizability are necessary,74 with longitudinal studies needed to assess patients’ changing experiences and needs over time.58,74

What are the methodological issues in spirituality research?

Cohen and colleagues74 assert that a lack of appropriate or robust outcome measures, especially those tracking existential and spiritual issues, have proved a barrier to the scientific evaluation of palliative care interventions and programs. Qualitative research may provide an important methodological approach in that it enables the assessment of subjective experience of illness embedded within its historical, cultural, social, and spiritual contexts.58,94 Although quantitative approaches may suit particular protocols, qualitative methods may provide a greater understanding of spirituality and religiosity and enable the subjective reporting of experiences for which robust measures are only starting to emerge.63,74

What are the interventional challenges?

A number of interventional opportunities to enhance spiritual well being are now being investigated. Some, such as Dignity Therapy and Meaning-Centered Group Psychotherapy have shown initial promise, and are currently undergoing more rigorous testing using a randomized control trial design. Other conceptual approaches that provide frameworks or clinical guidelines for the provision of spiritual care need to be formally tested to answer the questions of feasibility and efficacy. The role of chaplains in spiritual care, and how they can best identify and meet the needs of their clientele, merits further investigation. Moreover, the way that we use language to broach spiritual aspects of care needs to be evaluated, to ensure that patients are approached in a fashion that is comfortable and accessible, no matter what their individual religious or secular orientation.
ENHANCING SPIRITUAL ASPECTS OF DYING

CONCLUSION

Palliative care is often described in terms of a holistic approach. This notion of holism or “total care” “turns on the insight that the physical, the psychological and the spiritual are but distinctive perspectives upon what is, in reality, a unity” (p. 952). Honoring this “unity,” or whole-person care, requires a heightened sensitivity to the spiritual aspects of end-of-life care. Research addressing these dimensions of personhood offers a unique opportunity to expand the horizons of contemporary palliative care, thereby decreasing suffering and enhancing the quality of time remaining to those who are nearing death.

REFERENCES


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