Symposium Article

Spirituality in the cancer trajectory

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Spirituality is an essential element of person-centered care and a critical factor in the way patients with cancer cope with their illness from diagnosis through treatment, survival, recurrence and dying. Studies have indicated a significant relationship between spirituality and quality of life. Spirituality, in its broadest sense speaks to the meaning patients find in their lives especially during times of stress, illness and dying. Illness can trigger deep existential issues that could trigger profound suffering and distress. A model is presented that describes the role of each member of the healthcare team in addressing patients’ spirituality. Spiritual distress, as a diagnosis, requires attention and treatment just as any other clinical symptom. Spiritual resources of strength need to be identified and recognized as positive factors in patients’ coping. Finally a treatment plan needs to include the spiritual as well as the physical and psychosocial issues of patients. Chaplains and other spiritual care professionals need to be recognized as the experts in spiritual care and should be integral members of the healthcare team. Integrating spirituality as an essential domain of care will result in better health outcomes, particularly quality of life for patients across the trajectory of cancer care.

Key words: spirituality, religion, cancer, health, spirituality and health, spiritual issues, spiritual stress

Introduction

Spirituality is an integral dimension of human beings and has been recognized as a critical factor in the health and well-being of patients. Numerous studies have demonstrated a relationship between spirituality and a variety of patient outcomes including quality of life, and coping with illness. Spiritual practices such as meditation have also demonstrated some health benefits. Spirituality is also part of patients’ experiences with illness, such as cancer [1–3]. From initial diagnosis, through treatment, survivorship, recurrence, and dying, cancer patients’ understanding of their illness and their lives with their illness range from the physical, social, emotional, and spiritual. A diagnosis raises spirituality-related questions and concerns, both existential and religious [4–8]. Diagnosis of cancer changes the lives of patients forever, the diagnosis often triggering deep questions of meaning and purpose, and with the journey through treatment, deep issues of hope and fulfillment. The uncertainties and myriad decisions may raise spirituality-related issues more often in persons diagnosed with cancer than with other long-term illnesses [9]. Spirituality is also an important component of quality of life of patients with cancer. Quality of life for patients with cancer includes spiritual well-being as well as physical and psycho-social well-being [10–12], with spiritual well-being in one study found to be as significant as physical well-being [13]. A literature review found half of the identified quality of life instruments include items on spirituality, with most focusing on the existential aspects of spirituality related to meaning or purpose in life [14].

For many years, a diagnosis of cancer signaled a short life span, or what many called a death sentence. But, scientific advances have resulted in longer life for patients with cancer, many of whom are now considered survivors. With more than 10 million cancer survivors in the United States today [15], a cancer diagnosis now means many will live with the disease or with the sequelae of treatment for a long time. Thus, in the clinics today patients’ issues are not just about planning for an imminent death, but rather about living well with the disease through the trajectory of their cancer. With an estimate that 41% of people born today will be diagnosed with cancer during their lifetime [16], the National Cancer Institute and cancer organizations are shifting their focus to longevity and quality of life across the continuum of cancer care. Therefore, it is critical that health systems find ways to integrate spirituality more fully in patient care.

Spirituality

Spirituality is defined as the way people find meaning and purpose, and how they experience their connectedness to self, others, the significant, or sacred [17]. Spirituality is seen as a universal human characteristic [18]. Spirituality can be understood as one’s relationship with the transcendent, expressed through one’s attitudes, habits, and practices [19]. Religion, one type of expression of spirituality, is a set of organized beliefs about God that is shared within a community of people. Spirituality also embraces the arts and humanism, as well as cultural beliefs and practices. Spirituality can be understood as the inner life of a person.

Having a strong sense of spirituality helps patients adjust to and cope with illness [20]. Spirituality may affect how a patient
copes with the cancer experience, finds meaning and peace, and defines wellness during cancer treatment and survivorship despite fatigue or pain, and may assist patients in finding a sense of health in the midst of disease [13, 21–23]. Brady et al. [13] found that patients with cancer who had high levels of spiritual well-being reported more enjoyment in life, and higher levels of meaning and peace, even in the midst of cancer-related symptoms such as fatigue or pain. Other studies have shown that spiritual well-being in cancer patients has been associated with lower levels of depression, better quality of life near death, and protection against end-of-life despair and desire for hastened death [24, 25]. Cancer patients report their spirituality helps them find hope, gratitude, and positivity in their cancer experience [26–28], and that their spirituality is a source of strength that helps them cope, find meaning in their lives, and make sense of the cancer experience as they recover from treatment [29]. Spiritual well-being has been associated with lower levels of distress and greater quality of life across life expectancy prognoses [30]. Spirituality can therefore be a resource of strength for patients.

Spirituality may impact patient quality of life and adjustment by providing a context in which to derive hope and meaning. A cancer diagnosis, as with any serious illness, triggers deep existential questions: Why me? Why now? Why would God allow me to suffer this way? What will happen to me after I die? [31]. Answers to these questions are not immediate, nor are they obvious. But with support, patients can reframe a negative experience into one with a potentially positive meaning. Patients talk of an illness as a blessing or an opportunity to see life in a different, perhaps more meaningful way. It is not uncommon for people with cancer to make major changes in their lives—changing jobs, recommitting to a relationship or making a decision to leave a relationship, making life-style changes—as they begin to prioritize what is important in the face of what might be a terminal illness.

Religions help people with spiritual suffering by offering them historical understandings of suffering and ways to reframe their distress. For example, Christians may relate to the suffering of Jesus Christ, which might give them solace or a path to acceptance of their own suffering. Rituals and spiritual practices are taught as a way to help people cope with suffering and eventual dying. Practitioners of Buddhism practice meditation as a way to achieve detachment from suffering and eventual enlightenment [32]. Muslims believe in life after death and see death not as an end, but as a transition from this life to the next [31]. Religious teachings also may help people find hope in the midst of despair. In Judaism, people are not taught that there is no hope, but what they can reasonably hope for [32]. Non-religious patients may find their meaning through philosophical ideologies, or through their relationships with others or nature. Numerous studies have reported that spirituality and/or religion may be important to cancer patients and may influence medical decision-making. One study found 88% of cancer patients considered spirituality to be at least somewhat important in their treatment decisions and frequently of extreme importance [33]. In a study of patients with advanced lung cancer, patients reported that after the recommendation of their oncologist, belief in God was the second most important factor in their decision-making, more so than the efficacy of treatment [4, 34].

Religious and/or spiritual beliefs can impact many healthcare decisions and are particularly important in end-of-life decisions. Personal philosophies may also impact decision-making. For example, a naturalist may decline medications in favor of dietary and other interventions. Patients may also delay treatment choices in order to participate in spiritual rituals such as celebration of the solstice in the woods or participation in a religious ceremony [35].

**spiritual distress: a clinical diagnosis?**

Spirituality, as discussed, impacts coping, decision-making, and quality of life. But, spirituality may also be a source or contributor to distress. Examples of spiritual distress are listed in Table 1. Spiritual suffering also may influence how a person experiences and expresses pain, with a spiritual intervention as effective as a medical intervention in pain management [36, 37]. Untreated spiritual suffering may worsen the pain experience [38, 39]. For some cancer patients spiritual suffering/distress may be of greater concern than physical symptoms [40, 41]. Cancer patients report feelings of anger and diminished self-esteem, which may be spirituality-related [42]. One study found that 73% of cancer patients expressed at least one spiritual need [4] and that up to 40% of individuals with newly diagnosed and recurrent cancer showed a significant level of spiritual distress [43]. Cancer patients with low levels of spiritual well-being were more likely to express hopelessness and a desire for hastened death [44] and may have more frequent follow-up visits [45]. Studies show individuals may have elevated levels of spiritual distress and clinical depression after a cancer diagnosis, and that spiritual distress also increases at the end of active treatment when predictable routines end [46]. Thus identifying spiritual distress can have important implications for health outcomes, including improved quality of life for patients.

The National Comprehensive Cancer Network (NCCN) identifies spiritual distress that may extend along the continuum of care from ‘common, normal feelings of vulnerability, sadness, and fear, to problems that become disabling such as depression, anxiety, panic, social isolation, and existential spiritual crises’ [47]. Studies show that spirituality is an integral component of cancer care, with an intrinsic significance to caring for and respecting patients as whole persons [48–50]. The Joint Commission requires spiritual assessments [4]. The National Quality Forum (NQF) identifies spiritual, religious, and existential aspects of care as one of eight domains of quality palliative and hospice care [51].

Individuals diagnosed with cancer understand the significance of their spirituality in helping them plan for treatment, experience survivorship, and prepare for eventual death. The majority of cancer patients want their oncologists and healthcare professionals to inquire about their spirituality and to integrate their spiritual strengths and needs in the treatment plan [4, 31, 52–55]. These findings are reported in the Spirituality in Cancer Care (PDQ®): Relation of Religion and Spirituality to Adjustment, QOL, and Health Indices on the NCI website [56].
Attending to cancer patients’ spiritual issues

The need to attend to the psychosocial-spiritual needs as well as physical needs of cancer patients across the continuum of care is well documented, both from the perspective of patient desire and the benefits to patients’ quality of life of [57, 58]. Clinician inquiry into patients’ spirituality is also important in terms of building trust with the patient as well as ensuring treatment plans are congruent with patients’ beliefs and values [59]. Not addressing spirituality could result in poorer outcomes, increased non-compliance with the treatment plan, and failure to help patients find effective coping mechanisms [17, 35]. In one study, failure to attend to spiritual needs resulted in lower quality-of-care ratings and less satisfaction with care [4].

Attending to an individual’s spiritual distress and/or spiritual resources of strength correlates with quality of life across the trajectory of the cancer experience [10, 20–21, 27, 60–63]. Inquiring about a cancer patient’s spirituality also correlates with a whole-person healthcare model that shifts care from a focus on disease cure to one that addresses how an individual cancer patient defines wellness in the context of the disease experience [64, 65]. Wellness, defined by the World Health Organization (WHO), is the ‘dynamic state of complete physical, mental, spiritual, and social well-being and not merely the absence of disease or infirmity’ [66]. Thus, spiritual well-being is a determinant of whole health and, by extension, quality of life.

Currently, attention to spiritual needs is most prevalent at end of life. A study of physicians found 85% acknowledged they should be aware of their patients’ religious or spiritual beliefs, but only 31% said they should ask about these beliefs during a routine office visit, though the percentage increased to 74% when the person was dying [51]. Evidence shows, however, that addressing spiritual distress and spiritual resources of strength are integral to care across the trajectory of illness. In 2001 the National Cancer Policy Board adopted the WHO definition of palliative care in cancer ‘as active total care of patients whose disease is not responsive to curative treatment’ [67]. In its follow-up report, Improving Palliative Care for Cancer, the Board focused ‘on the importance of palliative care beginning at the time of a cancer diagnosis and increasing in amount and intensity throughout the course of a patient’s illness, until death’. The report also states, ‘Palliative care focuses on addressing the control of pain and other symptoms, as well as psychological, social, and spiritual distress’ [67, 68]. Framing cancer care within palliative care seeks to attain the highest level of quality of life for cancer patients regardless of disease stage or treatment, and refocuses supportive care to include interventions that address spiritual well-being [24, 44]. Attention to a patient’s spiritual well-being can help the individual find meaning and live life to the fullest from diagnosis through treatment, survivorship, and dying [69].
barriers in care

Despite evidence that spirituality plays an integral role in helping oncology professionals understand how a person defines quality of life in the context of his or her cancer experience, cancer patients report their psychosocial spiritual needs are not understood—and that healthcare professionals do not recognize, treat, or offer appropriate referrals to address their spiritual needs [70–72]. In a study of oncologists, one third said they did not routinely screen patients for spiritual distress and those that did often used non-validated methods [73]. Another study found 38% of oncologists said they were responsible for addressing patients’ spiritual distress but still gave this issue low priority compared with competing concerns [74].

This reluctance of physicians to discuss a person’s spirituality is evident in numerous studies: 81% of cancer patients reported that no member of the healthcare team inquired about their spiritual or religious beliefs [4]; 72% reported their spiritual needs were supported minimally or not at all by the medical system [49]; 68% said their physician had never discussed religious beliefs with them [53]; fewer than 10% of patients with significant levels of spiritual distress were identified and referred for psychosocial help [43]. The lack of understanding of a person’s spiritual well-being is underscored by a study that found oncology clinicians did not accurately associate cancer patients’ quality of life with spiritual well-being [60].

Studies show cancer patients’ spiritual needs are under-addressed due to time constraints, lack of confidence in effectiveness, and role uncertainty [75]. Other limiting factors include healthcare professional education and training, design of clinical practices, shortages of healthcare providers, and payment and policy constraints [76].

Educational barriers identified in the Institute of Medicine’s Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs include a communication gap between healthcare professionals who have a medically focused education and pastoral counselors and chaplains who have a spiritually focused education, creating a potential barrier to the understanding and coordination of cancer patient care [73]. Adding to the challenge are limited information systems to document and share findings. Ethical and confidential issues arise over who should see what portion of a cancer patient’s medical records, which, without training, can further complicate communications about the individual’s spiritual needs [77, 78].

Training in the identification of spiritual needs is only one component of an effective model for the delivery of spiritual care. Screening for spiritual needs or spiritual distress is not effective if there is no capability to address these issues, including supportive resources (referral to chaplains and other resources) for coordinating spiritual care with physical care across the continuum of care [48, 76]. A survey of 20 of the world’s top-rated cancer centers found only eight screened for psychosocial distress in at least some patients and only three routinely screen all patients [76]. One problem is that there are no standardized clinical instruments for screening, history and assessment other than the FICA tool [79] and the spiritual needs scale for Korean patients with cancer [80].

the biopsychosocialspiritual assessment and treatment plan

To address some of these barriers, a National Consensus Conference (NCC) was convened to develop standards and guidelines for integrating spirituality into palliative care [17]. As the definition of palliative care spans the time from diagnosis to eventual death, the care of patients with cancer across the trajectory of care is essentially a palliative care model. An innovative process model was developed at the NCC that is based on the principle that all members of the healthcare team are responsible for attending to a patient’s spiritual issues, recognizing that the board-certified chaplain is the spiritual expert on the team. A key component of this model is the notion of the biopsychosocialspiritual assessment and treatment plan. In this model, the approach to patient care is inquiry about all dimensions of that patients care, including the spiritual. In fact, the model recognize that spirituality underlies all the dimensions of care (see Figure 1). In this model, spirituality is the essence of humanity as described by Viktor Frankl [81]. The inner core of the person is not possible to understand, diagnose or treat. However, where spirituality interacts with the other domains is the area that is relevant for clinical care. So, physical pain may in fact be an expression or complication of spiritual distress. Social support may come from a spiritual support group. Depression may be a dual diagnosis with meaninglessness, hopelessness or despair.

The biopsychosocialspiritual model recognizes the distinct dimensions—biological, psychological, social, and spiritual—of a person and the fact that no dimension can be left out when caring for the whole person [82–86]. For the same reason current practice includes psychosocial inquiries, spiritual inquiry also is needed in recognition that each person’s history and illness is unique and will affect all dimensions of that person in unique ways [39]. Spiritual screening tools include a two-question model developed by Fitchett and Risk [87], where a patient can be asked if spirituality or religion is important to them and if so, are their spiritual resources working for them. A yes/no combination would signal a referral to a board certified chaplain. There are also examples of one-sentence questions such as ‘Do you have any spiritual beliefs or practices that might affect your care here?’ [88]. There are three spiritual history tools: FICA, which is a
Table 2. Biopsychosocialspiritual assessment and treatment plan. A 59-year-old female with newly diagnosed colon cancer, stage 4 with minimal symptoms, not interested in aggressive surgical techniques but desiring to integrate natural and spiritual ways of dealing with her cancer. Is willing to see an oncologist for options. Has insomnia since surgery. Is open to short-term med use. Has some pain at incision site that is 3/10 at its worse, some anxiety about her new diagnosis, good family support and strong spiritual beliefs. Is very sad with some hopelessness about outcome and dealing with uncertainty. Wonders why she has cancer and how could God do this to her.

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<th>Dimension</th>
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| Physical  | 1) Post-op pain minimal, managed with occasional Tylenol #3 and natural herbal meds  
2) Insomnia—likely secondary to recent surgery, as well as anxiety about her diagnosis | 1) Continue current pain medication regimen.  
2) Referral to CAM center for treatment options  
3) Referral to oncologist for evaluation for possible chemotherapeutic options  
4) Ambien for one week to assist with insomnia |
| Emotional | Anxiety, stress secondary to recent diagnosis and large input of information about treatment options | Refer to counselor for anxiety management and exploration of issues related to new diagnosis |
| Social    | Strong family support. Patient willing to have family involved in decision-making although is hesitant to ‘bring them down’ | Encourage patient to include family in medical appointments to assist pt in decision-making |
| Spiritual | Existential distress, some hopeless and perhaps a sense of abandonment by God  
Insomnia and anxiety likely related to this  
Has strong faith community, and strong spiritual beliefs | Refer to chaplain for spiritual counseling. Continue presence and support. |

Table 3. Spiritual care treatment plan examples

1) Referral to board-certified chaplain or other spiritual health care professional  
2) Referral to specific therapies such as meaning oriented or dignity therapies  
3) Referral to art, dance, music therapists  
4) Participation in a faith or other spiritual community  
5) Twelve-Step program, group spiritual direction or other support groups  
6) Meditation  
7) Prayer or reading from a sacred text  
8) Gratitude practices  
9) Reflection practices and/or retreats  
10) Journaling or reflective writing  
11) Participation in the arts  
12) Appreciation of beauty in nature  
13) Embodied spiritual practices such as yoga, dance, walking meditation or exercise, hiking  
14) Hobbies, studies outside of work  
15) Continued presence and support from healthcare team

validated tool [59, 80], Hope [89], and Spirit [90]. A spiritual assessment, a more detailed inquiry and assessment is done by chaplains, and work is underway to develop validated assessment tools.

Treatment plans also need to be multidimensional as shown in Table 2. The assessment would be for each of the domains of care, and include diagnosis as well as resources of strength for each. The appropriate treatment plan would include elements for each domain. Ideally, spirituality-related treatments should be developed with a board-certified chaplain as a member of the team. For clinicians who practice apart from teams, referral to chaplains and other spiritual care professionals, such as spiritual directors, pastoral counselors, or religious-specific providers such as clergy, should be considered as part of the plan. Other treatment plans might include referral to art therapists, music therapists, or specific therapies such as dignity therapy [44] or meaning-centered therapy [24]. Patients may have their own resources that they find as helpful, and those can also be integrated. Examples include yoga, spiritual or religious practices or rituals, journaling, walking in nature, intentional appreciation of beauty, and retreats among others shown in Table 3. In all of this work, compassionate presence practiced by the healthcare team is an important intervention [91].

To standardize and institutionalize spirituality as a component of whole-patient care, the biopsychosocialspiritual model must be integrated across the continuum of care for cancer patients. Training oncology professionals and integrating quality improvement projects in clinical settings to standardize and institutionalize clinical practices that identify spiritual distress, spiritual needs, and spiritual strengths will help to make attending to spiritual issues a standard part of cancer patients’ care across the trajectory of their experience with cancer.

conclusion

From the moment of diagnosis of cancer through treatment, survivorship, recurrence, and dying, patients with cancer are faced with spiritual issues that may cause spiritual distress or may help them as they face their illness. Spirituality can be a powerful positive force in helping patients frame their illness, find greater meaning in life, and recognize what is ultimately important and of value to them. Unresolved spiritual distress, however, can lead to poorer quality of life and poorer health outcomes. It is therefore critical that clinicians address spiritual issues of the patient, diagnose and treat spiritual distress and integrate patients’ spiritual resources of strength into the
treatment plan. Working with board-certified chaplains as the expert spiritual care professionals is essential to attending to patients’ spiritual issues. But every member of the healthcare team must be responsible for attending to all dimensions of patients’ suffering—spiritual as well as psychosocial and physical. In this way, patients can receive the most compassionate and person-centered care with improved quality of life as well as patient health outcomes.

disclosure

The author has declared no conflict of interest.

references


