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Assessing and Managing Spiritual Distress in Cancer Survivorship

Evidence-based recommendations for addressing patients' spiritual needs.

ABSTRACT: More than 67% of people diagnosed with cancer in the United States are alive five years after receiving the diagnosis; but even if they are cancer free, the effects of the disease and its treatment will remain with them for the rest of their lives. Distress, which can be of a psychological, social, physical, or spiritual nature, is common among cancer survivors. Spiritual distress is a broad concept that is not necessarily associated with any specific religious beliefs, practices, or affiliations. Both religious and nonreligious people may have a strong sense of spirituality and may experience spiritual distress at various points throughout cancer survivorship. But clinicians often neglect to explore the spiritual components of distress, and despite the well-established association between spiritual well-being and quality of life, few of the instruments designed to assess the care needs of cancer survivors address spiritual needs. Through a composite clinical case, this article illustrates how nurses can incorporate into practice evidence-based recommendations for assessing and managing spiritual distress in cancer survivors.

Keywords: cancer survivorship, distress management, holistic care, spiritual distress, spirituality

Sandra Henderson, a 32-year-old African American woman, presents to a survivorship clinic five months after completing treatment for cancer of the left breast. (This case is a composite based on our experience.) Ms. Henderson's course of treatment included chemotherapy, mastectomy, and radiation. Ms. Henderson works full time and has medical benefits through her job.

During her intake interview with a nurse at the survivorship clinic, Ms. Henderson expresses several concerns suggestive of distress. She tells the nurse that while she continues to worry about the same issues that troubled her when she was initially diagnosed with cancer—paying off her medical bills, keeping up with her work, and advancing her career—she feels cancer has changed almost everything else about her life. She often naps after work and no longer joins friends for dinner. Although her friends and family members tell her she looks great and encourage her to start dating again now that she's "beaten cancer," she confides that she's nervous about starting to date because she'll need to disclose her cancer history and manage intimacy as a "woman with one breast." She tells the nurse she feels frustrated because she sees herself as different from the person she was before the cancer diagnosis and isn't sure she can ever be that person again.

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She says that having had cancer has changed even her spiritual practices: she no longer attends church services, feels she's losing hope, and finds it difficult to think about the future. She recalls that when her work supervisor asked her, "Where do you see yourself in three to five years?" she answered, "I have no idea; I can't think that far ahead." She tells the nurse that no one understands her—that her worries are not typical of her peers. "God is testing me," she says. "I lost a critical year of my life, and now I can't move forward. I feel stuck. My life is passing me by, and I don't know what I'm supposed to do anymore."

The feelings Ms. Henderson describes illustrate "distress in cancer," which the National Comprehensive Cancer Network (NCCN) defines as unpleasant psychological, social, physical, or spiritual experiences that may interfere with the ability to cope effectively with life after cancer diagnosis.[1] Of the 15.5 million cancer survivors in the United States,[2] more than 67% have passed the five-year survival point.[3] But even among survivors who remain cancer free, the distress brought on by the effects of cancer and its treatment are often lifelong.

Distress among cancer survivors may stem from the cancer diagnosis, its residual impact on the survivors' sense of control or self-efficacy, and unmet informational needs, all of which can reduce quality of life.[4] Distress may present as fear, sadness, anger, concerns about the future, financial worries, and spiritual or existential concerns.[1] Severity of distress can range from normal fears and sadness to debilitating depression, anxiety, social isolation, or spiritual crisis.[1]

The NCCN, National Cancer Institute (NCI), and National Consensus Project for Quality Palliative Care (NCP) endorse the routine assessment and documentation of distress among cancer survivors across the care continuum in all health care settings, followed, if necessary, by appropriate intervention.[1, 5, 6] However, while the clinical literature is replete with guidance concerning psychological, social, and physical aspects of distress among cancer survivors, the spiritual components of distress have received less attention. Clinicians often neglect to explore survivors' spiritual well-being, though it has been identified as an important factor in health-related quality of life and is significantly associated with cancer survivors' enjoyment of life despite high levels of pain or fatigue.[5, 7] This article describes the concept of spiritual distress, explaining how and why it may manifest, even in the absence of religious belief.

It further provides evidence-based recommendations for assessing and managing spiritual distress in cancer survivors and illustrates how nurses can incorporate such guidance into practice.

THE CONCEPT OF SPIRITUAL DISTRESS

Spiritual distress is a broad concept that is not necessarily associated with any specific religious beliefs, practices, or affiliations. Spirituality encompasses a wide variety of relationships that impart a sense of meaning or purpose, such as felt connections to a higher power, nature, the world, humanity, or a religion. Both religious and nonreligious people may have a strong sense of spirituality.[5] And spiritual well-being has been shown to correspond with the following aspects of health-related quality of life among cancer survivors[7]:

- lower levels of anxiety
- good health habits
- hope
- greater satisfaction with life
- better psychological adjustment

Nevertheless, a 2017 review of instruments used to assess supportive care needs among breast cancer survivors found that, of the 82 tools evaluated, only four (4.8%) addressed survivors' spiritual concerns.[8] Building awareness among clinicians working in oncology and primary care of the importance of assessing survivors' spiritual well-being is essential to the provision of holistic care.

ASSESSING SPIRITUAL WELL-BEING

In order to assess spiritual well-being, clinicians generally need to identify the following patient factors[6]:

- spiritual or religious affiliations
- related beliefs, practices, and struggles
- sources of strength and support
- concerns about meaning and suffering
- cultural norms and preferences
- hopes, values, and fears

Given the established relationship between spiritual well-being and health-related quality of life, it is important to assess cancer survivors for spiritual distress. The NCCN recommends screening all survivors before clinical visits using the Distress Thermometer and the Problem List, which can help clinicians to, respectively, assess the level of distress and identify potential causes, including those of a spiritual nature.[1] (See Table 1.[1,5,6]) This assessment usually occurs within the context of a sociocultural assessment of health beliefs and behaviors that is intended to promote the provision of culturally informed, interdisciplinary care.[6] Interdisciplinary teams may include physicians, nurses, psychologists, and social workers, who operate either directly, through referral, or in collaboration with a professional chaplain.[1,6]

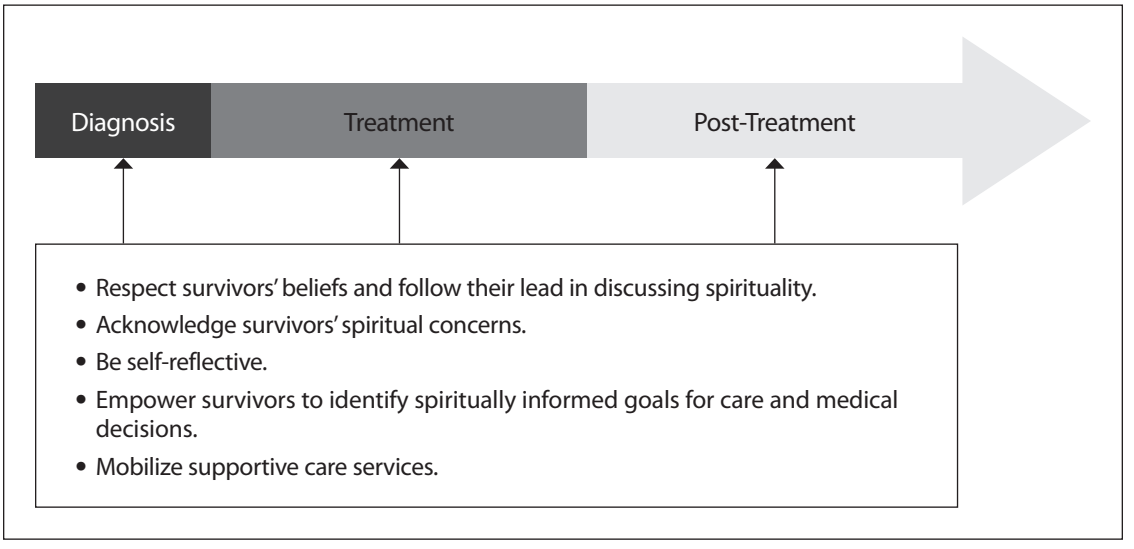
Survivors may be uncomfortable talking about spiritual concerns with clinicians, but a 2007 survey of 369 outpatients at Saint Vincent's Comprehensive Cancer Center in New York City showed that, although more than half of cancer survivors felt it was appropriate for their clinician to inquire about their religious beliefs (52%) or spiritual needs (58%), only 9% reported that staff had asked about either.[9] Clinicians are often reluctant to raise the issue of spiritual well-being and thus wait for survivors to voice any spiritual concerns. While this approach is effective in some cases, if the conversation never occurs, the survivor's spiritual needs may be unmet. To prevent this, the NCI suggests that clinicians ask survivors to complete a brief self-assessment on

Table 1. Guidelines and Recommendations for Assessing and Managing Spiritual Distress[1,5,6]

National Comprehensive Cancer Network	National Cancer Institute	National Consensus Project for Quality Palliative Care

• Use the Distress Thermometer to assess the survivor's distress.
  ◦ Score < 4 = supportive services
  ◦ Score ≥ 4 = mental health evaluation
• Identify specific spiritual or religious concerns using the 39-item Problem List.
• Consider a referral to a certified chaplain to evaluate spiritual needs and provide guidance.
• Integrate a certified chaplain into the interdisciplinary team that conducts routine clinical practice.
	• Ask the survivor to complete a spiritual assessment tool, using paper and pencil.
	• Express openness to a discussion of spiritual needs or distress to encourage the survivor to participate in a spiritual inquiry.
		• Screen for survivor spirituality needs using validated symptom and functional assessment instruments.
		• Create a palliative plan based on the survivor's needs and goals of care.
		• Provide resources based on the survivor's needs, including spiritual care services, counseling, or clergy relationships.
		• Incorporate spiritually trained professionals into patient's palliative or hospice plan of care.
		• Develop partnerships with community clergy to deliver education and counseling for end-of-life care.

Figure 1. The Cornerstones of Managing Spiritual Concerns and Needs Throughout Survivorship



paper or simply ask survivors if they have experienced any spiritual or religious distress, thereby providing an opening for further discussion.[5]

The NCCN's Distress Thermometer and Problem List are commonly used together in health care facilities to quantify and identify the sources of a patient's distress. The Distress Thermometer prompts survivors to rate the level of their distress on a scale from 0 ("no distress") to 10 ("extreme distress"), while the Problem List asks them to indicate any practical, family, emotional, physical, or spiritual problems they've experienced within the past week.[1]

The spiritual inquiry, which takes the form of a semistructured interview, is another approach to spiritual assessment. The SPIRITual History[5, 10] and the Faith, Importance/Influence, Community, and Address (FICA) Spiritual History[5, 11] are two such commonly used qualitative tools. Spiritual inquiry may include open-ended or directed questions, such as the following:

- Do you have spiritual or religious beliefs?
- Is there anything you'd like to share with me about your beliefs?
- Have your beliefs been affected by your cancer diagnosis and, if so, how?
- Have your spiritual beliefs influenced your health care decisions and, if so, how?
- Do you wish to learn more about spiritual resources?

Both quantitative and qualitative screening tools can provide clinicians with valuable information about the state of survivors' spiritual well-being, helping them identify survivor concerns and needs, or even potential factors that promote resilience (for a list of such tools, see Table 2[12-23]). When selecting a tool to assess a survivors' spiritual well-being, consider whether the survivor

- believes in a god or gods.
- participates in any religious or nonreligious spiritual practice.
- is interested in measuring spiritual well-being or identifying spiritual needs.

MANAGING SPIRITUAL DISTRESS

The NCCN's recommendations for managing distress are focused on psychosocial components of distress, but they take into account spiritual and existential concerns, which may be significantly associated with distress in cancer survivors.[24] While both the NCCN and NCP guidelines advocate interdisciplinary management of spiritual distress, including referral for chaplaincy care with a certified professional,[1, 6] neither discourages assessment and management of spiritual distress by clinicians—and surveys cited by the NCI indicate that patients want clinicians to consider their spiritual needs and report lower satisfaction with care when spiritual needs are not met and improved quality of life when spiritual support is provided.[5] Nurses in particular are trained to provide culturally congruent holistic care. Nurses can help patients surmount spiritual distress throughout cancer survivorship. Their approach should be informed by spiritual inquiry and by the cornerstones of managing spiritual concerns and needs, which have been identified in the literature[1, 5, 6, 25-29] and are described as follows (see Figure 1).

Respect survivors' beliefs and follow their lead in discussing spirituality. Spirituality and religion are often related to culture, as described in the HealthCare Chaplaincy Network handbook

Table 2. Spiritual Assessment Tools

Tool	No. of Items[a]	Domains (subscales)	Strengths	Limitations
Spiritual Well-Being Scales				
Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp).[12] Accessible as FACIT-Sp-12 at www.facit.org/facitorg/questionnaires.	12	Meaning/peace, faith	Widely used in randomized clinical trials. Available in 32 languages, validated in multiethnic populations and early-to-late-stage cancer diagnoses. Does not assume a belief in a god or higher power.	Does not capture behavioral aspects of spirituality.
Spiritual Well-Being Scale (SWBS).[13]	20	Existential well-being, religious well-being	Available and validated in multiple languages and countries.	Does not capture behavioral aspects of spirituality. Validated in cancer patients only in Taiwan. Assumes a belief in a god or higher power.
Spirituality Index of Well-Being (SIWB).[14, 15] Accessible at www.annfammed.org/content/suppl/2004/10/04/2.5.499.DC1/Daaleman_Appendix.pdf.	12	Self-efficacy, life scheme (which encompasses life purpose, direction, and meaning)	Unique that it incorporates self-efficacy. Does not assume a belief in a god.	Does not capture behavioral aspects of spirituality.
JAREL Spiritual Well-Being Scale.[16]	21	Faith/belief, life/self-responsibility, life satisfaction/self-actualization	Covers cognitive, behavioral, and affective expressions of spirituality.	Validated in older adults, healthy to terminally ill, but not cancer patients. Assumes a belief in a god or higher power.
Spiritual Needs Assessment Scales				
Spiritual Needs Questionnaire (SpNQ-20).[17] The English version is accessible at www.spiritualneeds.net (click on the Translations tab).	20	Religious needs, existential needs, peace needs, giving needs	Available in 12 languages. Covers cognitive, behavioral, and affective expressions of spirituality. Validated in cancer patients, chronic disease patients, and healthy individuals.	Main validation studies are in the German population. Assumes a belief in a god or higher power.
Spiritual Needs Assessment for Patients (SNAP).[18]	23	Spiritual needs, religious needs, psychosocial needs	Covers behavioral and affective expressions of spirituality. Identifies spiritual needs with which patients say they would like help. Validated in a racially diverse sample of cancer patients in which 68% self-identified as spiritual but not religious.	Does not cover cognitive expression toward spirituality. Assumes a belief in a god or higher power.

Table 2. Continued

Tool	No. of Items[a]	Domains (subscales)	Strengths	Limitations
Spiritual Needs Inventory (SNI).[19]	17	Outlook, inspiration, spiritual activities, religion, community	Covers cognitive, behavioral, and affective expressions of spirituality. Does not assume a belief in a god.	Validated only in end-of-life cancer patients.
Spiritual Needs Scale.[20]	26	Love and connection, hope and peace, meaning and purpose, relationship with God (the divine or sacred), acceptance of dying	Covers cognitive, behavioral, and affective expressions of spirituality.	Validated only in Korean cancer patients. Assumes a belief in a god or higher power.
Spiritual Distress Assessment Tool (SDAT).[21-23] Accessible at www.ncbi.nlm.nih.gov/pmc/articles/PMC3017043/bin/1471-2318-10-88-S1.DOC.	5, open-ended answers	Meaning, transcendence, values, identity	Scoring based on open-ended questions allows for more patient-centered care.	Does not capture behavioral aspects of spirituality. Validated in older hospitalized patients, not cancer patients. Scoring method requires more time. Assumes a belief in a god or higher power.

[a]All items are measured using a Likert scale, unless otherwise noted. Measures of cognitive expression, behavioral expression, and affective expression of spirituality are intended to gauge attitudes toward spirituality, practices of spirituality, and feelings associated with spirituality, respectively.

Patients' Spiritual and Cultural Values for Health Care Professionals.[25] It's therefore important for clinicians to familiarize themselves with survivors' cultural background, beliefs, and practices.

Acknowledge survivors' spiritual concerns. Spiritual concerns are as real as physical, psychological, and social concerns and should be managed as such. When a survivor communicates spiritual concerns, clinicians should reiterate an understanding of those concerns and of the impact they have on the survivor's life. Survivors grappling with questions about their life's purpose or with feelings of hopelessness or uncertainty should be referred to a mental health professional, social worker, or spiritual counselor.[1]

Be self-reflective. To effectively assess survivors' spiritual well-being, clinicians must assess their own feelings about spirituality, acknowledging any personal biases they may have and any preparation they may require to help them mitigate self-identified biases in advance of spiritual conversations.[26] In this, as in many other aspects of care, failure to do so may contribute to patient discontent, inadequate adherence, poor health outcomes, and disparate health care.[27] If unable to overcome bias in order to provide necessary care, the clinician should refer the survivor to appropriate supportive care services.

Empower survivors to identify spiritually informed goals for care and medical decisions. Information gleaned from the spiritual assessment should be used to facilitate conversations about goals for care and medical decisions. Among certain survivors, such practices may foster hope and be essential to their recovery from distress.[28] For example, survivors might be encouraged to pray, meditate, or consult with a spiritual advisor before making decisions. Psychospiritual integrative therapy, an intervention that combines cognitive behavioral therapy, mindfulness, and meditation, may also be a viable option to assist cancer survivors with psychological and spiritual needs.[29]

Mobilize supportive care services. These may take many forms across health care systems and within communities. The clinician can suggest goals and options for care that honor the survivor's spiri-

tual or religious views, such as speaking with religious or spiritual leaders with experience managing existential concerns.[5,6] As additional support, the clinician might refer survivors to either a clinical chaplain or a local support group that can help with spiritual issues.[1] Survivors may prefer to seek spiritual guidance from a member of their community, especially if receiving treatment away from home. Palliative care teams may be consulted to identify programs with a specific care focus.

Spiritual well-being is a well-known component of quality of life and is associated with better coping strategies.

MS. HENDERSON'S SPIRITUAL ASSESSMENT

In accordance with clinic protocol, the nurse asks Ms. Henderson to complete the NCCN's Distress Thermometer and Problem List before meeting with the NP. Ms. Henderson rates her distress as a 3 on the 10-point scale, indicating on the Problem List that the sources of her distress are emotional and spiritual or religious problems. Based on these sources of distress, the nurse asks Ms. Henderson to complete a Patient Health Questionnaire-2 (PHQ2) form[30] and a Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being Scale (FACIT-Sp).[12] Her score of 2 out of 6 on the PHQ2 indicates no clinical depression, but her score of 32 out of 48 on the FACIT-Sp indicates spiritual distress. The nurse documents the results of these assessment instruments and notes in Ms. Henderson's medical record that, in conjunction with having symptoms of spiritual distress, Ms. Henderson was questioning the direction of her life, expressing loss of hope, and had mentioned that she no longer attends church services. Ms. Henderson then meets with the NP, who conducts an in-depth spiritual assessment.

The NP takes the time to try to understand and validate Ms. Henderson's concerns, telling her that "addressing spiritual concerns can be difficult, because it requires self-reflection about personal beliefs, your present life, and what the future may hold." When the NP asks about Ms. Henderson's spiritual beliefs and practices, Ms. Henderson explains that she's Catholic and once attended mass every Sunday. Since she acknowledges previous involvement in religious activities, the NP encourages her to attend a church-based support group for cancer survivors and puts her in touch with a peer breast cancer survivor who assists other survivors in navigating available supportive care services. At the close of the survivorship visit, the NP reviews the prescribed spiritual distress management plan with Ms. Henderson, makes the referrals they had discussed, and recommends that Ms. Henderson return for a follow-up survivorship appointment within one month. The NP reminds Ms. Henderson to call the office if she has any questions or concerns, or if she decides she'd like a referral to a chaplain.

In the support group, Ms. Henderson finds several cancer survivors who let her know she is not alone in her concerns. They share stories about how they have fostered their faith and have begun to feel hopeful again. The group encourages Ms. Henderson to find time to enjoy nature and to meditate.

PROMOTING SPIRITUAL CARE

Distress among cancer survivors can be complex and multifactorial. Spiritual well-being is a well-known component of quality of life and is associated with better coping strategies. Clinicians must be willing to acknowledge patients' spiritual concerns during routine survivorship and primary care visits.[5] Clinicians must also be equipped with evidence-based strategies to ensure that survivors' spiritual needs are met. In addition to making referrals to a chaplaincy or mobilizing supportive care resources, clinicians can play an active role in assessing survivors' spiritual needs and empowering them to identify spiritually informed goals for care and medical decisions.

Given the broad scope of spiritual concerns and the dearth of literature addressing spiritual support as a component of care, more research is needed to guide clinical care and educate clinicians on how to integrate the assessment and management of spiritual concerns and needs into care. ▼

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