

Palliative care is holistic, including biopsychosocial and spiritual dimensions of care. All members of the team must address spiritual needs; much of what patients and significant others want to discuss is spiritual in nature, and spirituality is an important way of coping. Most social workers address spirituality with patients and significant others, but they may not identify the issues they are addressing as spiritual. This underscores the importance of training in this area. This chapter will define spirituality and describe relevant theoretical frameworks, assessment and intervention approaches, and guidelines for referral to a spiritual caregiver.

Keywords: biopsychosocial-spiritual, relational model, spiritual assessment, spiritual intervention, spirituality, transpersonal social work

Chapter 4

Spirituality and Social Work Practice in Palliative Care

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Why would God do this to me?

Key Concepts

- Spirituality is the most important way of coping for many patients, families, and their support network.
- Confrontation with a serious illness can spur spiritual growth in patients, families, their support network, and the staff who work with them.
- Spirituality can be defined in two dimensions: (1) philosophy of life, which is an intellectual dimension that includes philosophical, religious, nonreligious, and existential perspectives; and (2) unity consciousness, which is an experiential dimension that includes direct spiritual experience.

- Palliative social workers have an important role in assessing spirituality with patients and their support network. It can be explicitly addressed where the conversation is welcomed.
- Spiritually sensitive social work is culturally responsive in that it honors all religious and nonreligious spiritual paths as well as the values of those who consider themselves secular humanists or existentialists.
- The relational model provides a framework for spiritually sensitive application of traditional approaches to social work intervention as informed by the strengths perspective, ecological-systems theory, and biopsychosocial-spiritual model.

Introduction

From the beginning of the hospice and palliative care movement in the United States, its leaders have advocated for a holistic approach that addresses biopsychosocial as well as spiritual needs. Medicare regulations for hospice certification require an interdisciplinary team that includes a spiritual caregiver. The National Consensus Project (NCP) for Quality Palliative Care¹ has espoused eight domains of palliative care, one of which is spiritual, religious, and existential aspects of care. It recommends that all members of the palliative care team be trained in spiritual care and that a board-certified chaplain be included on the team. It also calls for evidence-based practice addressing spirituality, including assessment using standardized instruments; intervention that honors patient and family cultural and religious values; involvement of religious leaders and communities as desired by patient and their support network; documentation of the impact of spiritual interventions; services provided by professionals trained to address the common spiritual issues that arise in serious illness; and referrals to professionals with specialized knowledge when appropriate. In order to further these goals and foster education across disciplines, an influential interprofessional

conference was organized in 2009: *Improving the Quality of Spiritual Care as a Dimension of Palliative Care*, which aimed to build a consensus-derived definition which focused on universal constructs of meaning and purpose and collect evidence-informed interventions. Recommendations and the publications from this conference influenced the integration of spiritual care into subsequent guidelines, spurred further conferences, and increased interprofessional attention to this domain of care.²

This requirement to address spirituality is justified by its importance as a way of coping for patients, families, friends, or intimate networks and professional staff when a patient is facing serious illness.³ It may be seen as a source of hope, for example, when death is seen as a transition, hence the descriptors “traveling” or “crossing over” rather than the end of life. In addition to spiritual coping, spirituality and religion represent dimensions of diversity that are expressed through cultural norms and practices as well as moral and ethical values. There is evidence that patients and their support networks want to discuss spirituality as part of healthcare provision with social workers in the position to respond to this need.⁴ In addition, the end of life may be seen as an opportunity for great spiritual growth, including for staff who work with patients and their support network.⁵

Clients’ religious and cultural values and beliefs may influence decisions about medical care, for example, medically provided hydration and nutrition, forgoing or withdrawing a ventilator, or use of blood products. Engaging these values early in the work of palliative care includes exploring the beliefs and raising the voice of religious and community leaders who may influence decisions and sustain and support patients and family long beyond their connection with palliative care or hospice teams. For example, clinicians who appreciate the place and importance of religious teachings from the Talmud, Koran, or New Testament can engage a shared exploration as to how specific beliefs and guidance apply to the unique circumstances that serious illness creates. The palliative care, and the

social work, perspective is to honor beliefs and share the important work of understanding how beliefs, teachings, and preferences apply to such aspects of palliative care as decision-making and prognostication. In a 2017 national survey, 74% of psychosocial assessments in hospice included content on religiosity and/or spirituality.⁶ Training in spirituality is increasing in social work education, although it is not included in all social work programs. This chapter will help to address that need.

What Is Spirituality?

Scholars in the field of spirituality and social work have developed definitions of spirituality that generally refer to one or both of the aspects of (1) transcendence in terms of meaning and purpose in life, which is intellectual, and (2) direct spiritual experience of transcendence and oneness/unity, which is experiential. Transcendence refers here to going beyond one's self—in a purpose in life that is focused on the well-being of all, and in direct spiritual experience in which one feels a sense of unity rather than a separate identity. Spirituality is a different concept from religion, which refers to affiliation with a religious tradition.

For example, Edward Canda, the founder of the field of spirituality in social work, along with coauthors Furman and Canda (2020), reviews definitions of spirituality and summarizes them as “an aspect of the person that is distinctively human; namely, the search for a sense of meaning, purpose, connectedness, and morality with special reference to what is considered sacred, transcendent, or ultimate.”^{7(pp.95-96)} Canda, Furman, and Canda's own definition is as follows:

A process of human life and development

—Focusing on the search for a sense of meaning, purpose, morality, and well-being;

- In relationship with oneself, other people, other beings, the universe, and ultimate reality however understood (e.g., in animistic, atheistic, nontheistic, polytheistic, theistic, or other ways);
- Orienting around centrally significant priorities; and
- Engaging a sense of transcendence (i.e., experience of what is deeply profound, sacred, or transpersonal).^{7(p.96)}

Similarly, Reese⁸ defines spirituality as a two-dimensional construct, including transcendence in terms of *philosophy of life* and transcendence in terms of *unity consciousness*. Building on this collective work, Callahan⁹ defines spirituality as the experience of enhanced life meaning and purpose through relationships. Given the significance of relationships in hospice and palliative care, it follows that relationships have the potential to spiritually support patients.

Relational Spirituality

Relational spirituality has been described as the experience of a meaningful connection with the self, others, and/or beyond.¹⁰ Spiritually significant relationships can be any relationship or connection that inspires an authentic appreciation for that with which one relates. In the process of interacting, spiritually significant relationships enhance life meaning, inform life purpose, and/or facilitate a sense of connection. Although relational spirituality may lead to the experience of self-transcendence, it may also allow for a deeper awareness of an individual's humanity or facilitate a spiritual experience for another person. It could be, in fact, the appreciation for one's shared humanity through which self-transcendence occurs. Even if an individual does not recognize the opportunity for spiritually significant relationships, this does not diminish the spiritual significance of these relationships in the lives of those with whom (or what) that person relates. For example, the presence of a loved one can be deeply meaningful even when a patient is minimally conscious. Time together

allows for reflection on the significance of their relationship and the opportunity to say “thank you” as spirituality operates in close alignment with the psychosocial dimensions of being.

Why Is This Important?

Two patient narratives drawn from the first author’s experience as a hospice social worker illustrate how different the experience of serious illness can be for different people. In the first example, a 70-year-old Black woman, Joan, felt at peace, her little dog resting on the bed with her, her church choir singing softly around her bed. Joan often mentioned God, and when asked, “Do you feel the presence of God?” Joan answered, “Oh, yes, all the time!” In the second example, a young White state policeman, Ed, who was extremely fearful of dying, asked his doctor to continue treatments to extend his life, but the doctor told him that he had already received all available life-extending treatments and sent him to hospice, promising to call him if a new experimental treatment was developed. Ed became combative, punching the hospice staff if they came near, and died yelling, “Code 13! Code 13!,” which meant “officer in distress!”

Why was one person so peaceful and one so anxious? What makes the difference and how can we help them? These two examples are quite distinct. Joan expressed “a sense of the presence of God,” which implies a sense of spirituality in the unity consciousness dimension. Ed, however, appeared to be in distress. This experience could relate to spiritual concerns, such as unfinished business and questions about the meaning and lack of justice exemplified by his terminal illness. While these narratives may represent two extremes, there is a continuum of how much anxiety a client may have about their illness and death. And spirituality does not necessarily imply a belief in a deity as expressed by Joan. Research does indicate that addressing spiritual concerns may reduce anxiety about death and serious illness.⁸ To further delineate factors that may have influenced Joan and Ed’s end-of-life

experience, the remaining chapter will discuss what informs relational spirituality in palliative social work practice, including personal preparation, philosophy of practice, spiritual assessment, intervention with spirituality in palliative care, and cultural diversity considerations.

Preparing to Address Spirituality in Palliative Care

Spiritual sensitivity adds value to social workers' unique contribution as members of palliative care teams. The focus of spiritually sensitive social work is to convey respect for spiritual diversity and, in doing so, facilitate quality of life. This entails an awareness of how one's own relationships inform life meaning; empathic understanding of how relationships inform life meaning for patients; and ability to facilitate evidence-based interventions that support a patient's experience of meaningful relationships.¹⁰ Personal preparation is important to appropriately address spirituality in palliative care. This begins with spiritual self-awareness and attunement to institutional standards surrounding the expression of spirituality in order to avoid unconsciously imposing either on clients. See the spiritual self-reflection exercise under Learning Exercises, for an approach to increasing self-awareness. Continuing education as well as consultation with colleagues and/or supervision with self-reflection and self-care¹¹ can help social workers further determine how to best convey spiritual sensitivity.

Philosophy of Practice

Spiritual interventions require a philosophy of practice that views the patient and support network as having unconditional worth and unlimited possibilities for growth, a perspective that creates an environment of attention and intention, no matter what the focus of intervention. This is a concept very similar to the social work value of dignity and worth of the person,¹² the strengths-based perspective of social work practice, and the foundation for a spiritually sensitive relationship. Crises are seen as opportunities for growth; problems are

understood within an awareness of and support for the possibility of spiritual development. Transformative palliative care emanates from the quality of the relationship, the spiritual self-awareness of the clinician, and the ability to learn the practice of “compassionate presence” with patients.¹³

Spiritually Sensitive Social Work

The seminal work of Canda and Furman¹⁴ initially informed the definition of spiritual sensitivity advanced by Callahan¹⁵ as the ability to convey respect for the inherent value and dignity of patients. This is referred to as Buber’s “I-thou” rather than “I-it” communication, which risks the objectification of patients. Callahan⁹ subsequently conducted a qualitative study with 16 hospice workers to clarify what defined spiritual sensitivity. Results indicated that hospice workers recognized personhood, used therapeutic touch, conveyed presence, listened, sang, reframed, affirmed, used self-disclosure, normalized, and advocated for patients. As described in Callahan’s¹⁰ relational model later in this chapter, spiritually sensitive social workers attend to what makes patients, family, and context unique. It creates the conditions for a patient’s experience of enhanced life meaning through significant relationships, starting with the therapeutic relationship. A patient’s need for enhanced life meaning may not be recognized as a “spiritual” need by the patient, but spiritually sensitive social workers recognize the restorative power of significant relationships and when ruptures in relationships evoke spiritual suffering.

Respect for Diversity

Social workers also need to value cultural diversity, which includes spiritual diversity, to be spiritually sensitive. As part of culturally responsive care, spiritually sensitive social workers respect differing worldviews, understanding that the social worker’s own perspective is only one of many in a diverse world, and operate with the purpose of helping the patient and family to clarify their own views rather than imposing a belief system.⁷ In addition to

spiritual diversity, demographic diversity such as age, gender, education/income, race/ethnicity/culture, belief system, physical and mental ability, health condition, and sexual orientation can have spiritual implications for palliative care.

Social workers must be aware of intersecting identities and when it is necessary to advocate for clients to offset systemic barriers and mitigate disparities.¹⁶ For example, social workers risk perpetuating common myths and misperceptions that undermine LGBTQ-inclusive palliative care. Based on the third author's experience, sexual minorities have experienced condemnation by religious leaders that may be considered tantamount to spiritual abuse with potential for long-term consequences. LGBTQ individuals may feel on guard around others who identify as religious. They may turn away from a religious affiliation for want of a safe spiritual space. A blind eye to heterosexism has potential to reinforce decades of oppression against sexual minorities, including internalized homophobia. Social workers can ensure palliative care providers employ inclusive policies, paperwork, and procedures. As described by Acquaviva (2017), social workers must evaluate their propensity to facilitate LGBTQ-inclusive care and create a mitigation plan, rooted in self-awareness, to remain client-centered. Social workers can employ LGBTQ-inclusive language, affirm a patient's gender identity, and recognize diverse family forms starting with the assessment. All patients need to feel safe to express their needs, including their spiritual needs, rather than to sink into despair.¹⁶

Another challenge is a patient's belief that a miracle has occurred, and their health problem will be healed. For example, based on the first author's experience, a traditional Christian Black family believed that God had performed a miracle, and their loved one, a hospice patient with terminal cancer, would be healed. They were not just praying for God to perform a miracle in the future; they firmly believed it already had happened and was represented by her continued life. The patient's acceptance of death and affiliation with

hospice philosophy was seen as a lack of faith. In some narratives, the patient and family may insist on aggressive treatment that is considered medically inappropriate, in order to extend the patient's life while waiting for the miracle to happen.¹⁷ A social work response would be to honor this perspective and perhaps recognize that there have been instances of spontaneous remission, sometimes referred to in the language of miracles. The social worker could communicate that the doctors do not have additional treatments toward controlling disease and it is now up to God. In this narrative, the social worker helped the family, as they awaited God's will, to accept the patient's preference for hospice services. At her funeral, the family was able to adapt their perspective, which mitigated any threat to their faith, saying, "We loved you, but God loved you more." Similarly, it is also important to ensure palliative care providers respect the end-of-life care preferences of patient and families historically marginalized.¹⁸ (For additional information see Chapter 89, "Ethical Considerations in Palliative Care," this volume.)

Spiritual Assessment

Along the continuum of serious illness and toward the end of life, spiritual awareness may increase as patients consider what they still want to accomplish. Any spiritual or life meaning tasks they want to complete to uphold their quality of life in the dying experience may surface at this time, even among those who previously may not have lived according to any spiritual framework. For a few patients, these spiritual tasks could also pose life meaning or existential/humanistic questions. Sharing these questions is often of value, even if the answers are unavailable. Palliative care may be a time for spiritual growth and transformation, or a time of spiritual pain that sinks to a soul or existential level, for what has been left unresolved.

Spiritual screening and assessment are important for a number of reasons. Ethically, conducting a spiritual assessment ensures that individual preferences are respected. If a

patient holds religious values as important, this may enable that person to integrate these values into care and decision-making and engage in religious rituals that hold meaning. Such assessment is also important if some aspect of spiritual or religious practice is to be addressed through a care plan to maintain well-being. Further, while not all patients hold specifically spiritual or religious values, many do want healthcare professionals to ask them about their views and values.¹⁹ A spiritual assessment helps differentiate spiritual needs, if any, and helps craft a response sensitive to the need.²⁰ The spiritual assessment should be conducted periodically since spiritual needs evolve with time and events. This includes ensuring sensitivity and alignment with cultural customs and worldviews, particularly related to world religions. One example of this would be ensuring availability of Halal foods for Muslim patients. Research tends to support the relationship of spirituality to positive health outcomes,²¹ and spirituality may play an important role when individuals face the stress of terminal illness. Finally, many organizations such as the Joint Commission have policies that make accreditation dependent on inclusion of spiritual assessment in some form.²²

Spiritual assessment is an important area of expertise for social workers, many of whom have both training and an intuitive understanding of spiritual need reinforced by expertise in assessment and intervention, as well as experience working with families, cultural differences, complex end-of-life ethical conflicts, transdisciplinary teams, and self-reflection. However, training in work with spiritual, religious, and existential/meaning issues is still not consistent across social work schools. Moffat and colleagues (2019) conducted a survey of United States schools of social work, with 40% responding to the survey. Nearly 37% of those responding reported some form of integration of spiritual and/or religious content in the curriculum.²³

Spiritual Assessment Approaches

The National Consensus Project for Quality Palliative Care (2018) suggests that the exploration of a person's spirituality ideally consists of a standardized three-part process including a spiritual screening, a spiritual history, and a spiritual assessment. A spiritual screening includes a brief question or two to determine whether this is an area in which the patient has concerns and/or wants to engage. The screening instrument may be administered by any member of the team, while a spiritual history or assessment is best conducted by clinicians with increasingly specialized expertise. A spiritual history allows the exploration of the person's spiritual background to gather further details, such as faith or belief affiliation and information about the importance of faith and religious community and possible need for a spiritual referral. The spiritual assessment is considered more comprehensive and is typically completed by a chaplain or other team member with spiritual expertise. On any given team, it is understood that certain team members may have a stronger proclivity for one area of practice than another, including determining whether spiritual needs are present. On some teams, a social worker with background and training in spiritual care might be positioned to perform this role. A spiritual assessment approached with sensitivity, creates an equal opportunity for the patient to decline to engage in this assessment as to participate, with equal respect provided for each decision.^{1,24}

Whatever model is followed, the assessment may be done flexibly, so patients have the freedom to identify the diverse ways spirituality and existential meaning is expressed in their life, if important to any extent. Spiritual assessment may also be accomplished through spiritual history trajectories, life maps, genograms, and eco-maps.²⁴ The National Coalition for Hospice and Palliative Care recommends use of a validated instrument for comparability. There are many instruments with differing emphases. A few of the most common or most related to social work are presented in the section on "Spiritual Assessment Scales and Narrative Frameworks."

Spiritual Needs

The act of assessing spiritual needs calls awareness to areas for attention. Although these are often expressed in terms of what is absent or a source of suffering, these may include positive expressions of what addresses the patient's needs, such as spiritual strengths and what is deemed as a source of spiritual support. Examples might include virtual or in-person connection with members of their religious organization, writing a poem, or sharing a spiritual story with a grandchild. Commonly identified spiritual needs are the need to find meaning and purpose; the need for a spiritual connection outside oneself, such as to a higher power, sacred source of meaning, or nature; and the need to give and receive support.²⁵ Life completion tasks such as repairing relationships, letting go of and releasing material things or emotional blocks, or clearing negative energy have spiritual elements.²⁴ Some individuals hold fear or uneasiness about their mortality and want to be accompanied in their search to know what will happen to their bodies, spirit, and/or souls after death. Social workers may share their presence and quietly accompany patients on this quest, holding space for the uncertainties that these reflections may trigger.

Spiritual concerns especially draw attention in social work and may be referred to as spiritual distress or spiritual struggle. These struggles may be intrapersonal, interpersonal, or with the divine or transcendent force, and often result in emotional distress, one feature of which is felt isolation.²⁶ Relationships with family members and support networks are a key cause of patient worry.¹⁰ Social workers have sensitivity to cultural difference and also assess for misunderstandings and miscommunication in these critical areas, and many have skills needed to mediate complex family dynamics. Examples of spiritual needs and concerns are found in [Table 4.1](#).

[Insert Table 4.1 here]

Spiritual Assessment Scales and Narrative Frameworks

Social work, more than many professions, holds a holistic and integrative frame. In the combination of personal and environmental factors lies the key to well-being. A number of tools address spirituality within a larger social work frame, with some of these tools found in [Table 4.2](#). Some of these tools, which were developed by social workers, will be addressed in the following.

Reese and colleagues²⁷ developed the Social Work Assessment Tool (SWAT) to measure social work outcomes for patients and their support networks, in the major areas addressed by social workers in hospice and palliative care, including spirituality. Reese's 2013  includes transpersonal experiences as an important dimension of assessment. Interview questions related to experiences of spirituality and exploration of the anthropology of spirituality with other dimensions such as affect and behavior are suggested by Hodge.²⁸ Nelson-Becker, Nakashima, and Canda's (2007) assessment framework²⁵ suggests a narrative frame that includes questions related to existential issues, nature, the divine, and meaning or purpose in life that may influence medical care.

Several scales have also been developed in other disciplines to assess spiritual distress or spiritual pain. One study examined the comparative value of the Spiritual Well-Being 12-Item Scale (FACIT-Sp-12) and the Spiritual Injury Scale (SIS) among other measures, showing that the first two did well, but were far from perfect at determining level of spiritual distress, and lacked cultural sensitivity.²⁹

An example of cultural competence in spiritual assessment is with the Māori people from New Zealand. Social justice in social work suggests that a person's worldview matters. Spiritual pain increases when worldviews are ignored or, worse, dishonored. The term *Māori* refers to the indigenous people of Aotearoa, New Zealand, who as a minority, have been disadvantaged since the signing of the Treaty of Waitangi by representatives of the British crown. Following a terminal diagnosis, Māori *whānau* (family) surround the dying person

with compassion in a holistic system of care that may include saying goodbye to ancestral land. Care honors relationships through keeping sacred practices (*tapu*) and understanding that dying involves a felt spiritual energy as it leaves the body.³⁰ Both informal *whānau* caregivers and professional caregivers in hospice and palliative care are expected to support Māori beliefs and practices. When this is accomplished through careful assessment of both individual and cultural beliefs, healing can be experienced.

[Insert Table 4.2 here]

Other Spiritual Assessment Approaches for Social Workers

The foci of a spiritual assessment can take many different forms, including those that are symbolic or metaphorical, as well as those that are concrete and practical. Patients may discuss dreams about travel on a plane, boat, or by foot where they visualize themselves trying to leave the gate, sail across a dark cloudy sea, or move through a dense dark forest. A few may be comfortable discussing the symbols, but not the possible meaning of these symbols. A spiritually sensitive social worker could recognize this as an expression of spiritual issues and use a dreamwork approach if the patient expressed a desire to further their understanding of the dream.²⁴ This approach consists of asking questions to uncover the meaning of the dream to the patient rather than imposing meaning.

A practical way of assessing the value of spirituality relates to how individuals make themselves comfortable in a space. They may make room for a statue of the Buddha, a cross, a prayer shawl or prayer beads, or a spiritually inspiring poem, or they may ask for meaningful or soothing music. These may be most evident when making a home visit or when using a video platform. At a communal level, asking about use of rooms for prayer or meditation, interest in artistic or cleansing elements such as ponds or fountains of water, or open bowls with water may provide clues to needs.²⁴ Assessment of family spiritual needs and community religious networks may also acknowledge the wider environment of support

for the patient and the family that may sustain into the future. Finally, tattoos, that clients choose to wear permanently on their bodies, often have religious or spiritual meaning; inquiring about the significance and symbolism of these choices may lead to deeper understanding of the person's spiritual views.

Social Work Interventions with Spirituality

Despite recognizing spiritual needs and risk for spiritual distress, our respect for patient self-determination leads social workers to rely on patients and support networks to clarify whether and how these issues will be addressed. Some may choose not to discuss spiritual concerns, or they may explore these aspects of their life with others. Social work interventions will still address a myriad of other needs identified, and in the meeting of those needs they may metaphorically bring meaning and purpose to a patient's life and relationships. Toward this end, the remaining chapter will focus on how social workers may engage in spiritually sensitive practice and, in the process, support the delivery of spiritual care by interdisciplinary team members.

Applying a Relational Model

Spiritually sensitive social workers require the capacity to both recognize and intervene with relationships that are significant to patients across systemic levels. Positive relational experiences, like the therapeutic relationship, are expected to sustain life quality if not inspire growth. Negative relational experiences may inspire growth, but require intervention for patients to respond productively. Targeted social work interventions, such as reconciliation, where a realistic goal can help patients cultivate current relationships and/or build new ones, support a patient's experience of life meaning and resilience when life quality is threatened. (For additional information see Chapter 60, "Connections and Context," this volume.)

An Eclectic Foundation

Social workers can draw from an eclectic foundation to inform interventions that build on patient strengths for goal achievement. A patient's spirituality may be one of those strengths along with other dimensions of diversity, and this calls for social workers to be both spiritually and culturally sensitive, particularly when intersectionality has implications for care delivery (For more information, see Chapter 3, "The Importance and Impact of Culture in Palliative Care," this volume.) Along with relational, person-centered care, biographical meaning-centered work and mind-body interventions were the most cited in the literature, which can be applied by social workers across systemic levels. Additional spiritual interventions include creative arts, change in environment, patient education, psychopharmacology, and care coordination and referral.

Micro-level spiritual interventions may include meaning-making interventions, such as life review and dignity therapy, guided meditation, or progressive relaxation psychotherapy—such as narrative, existential, or cognitive-behavioral therapy. Mezzo-level interventions include patient/family education, mutual goal setting and intervention, and referral and care coordination—such as collaborative relationships across professionals. Finally, macro-level interventions include religious rituals, enabling access to personal items or resources that inspire, and ensuring the care environment is responsive to patient preferences.³⁸⁻⁴⁰ (For additional information, see Chapter 70, "Cognitive-Behavioral Therapy in the Palliative Care Setting," Chapter 79, "Meaning-Centered Therapies," and Chapter 82, "The Power of Narratives and Storytelling," this volume.)

The ecological-systems theory can help a social worker clarify what intra-, inter-, and transpersonal relationships contribute to a patient's experience of relational spirituality. The meaning of significant relationships on the intrapersonal (micro) level may manifest in the way patients engage with themselves, on the interpersonal (mezzo) level in the way patients engage with others (including pets), and on the transpersonal (macro) level in how patients

engage with the larger environment, or higher power. For example, having a religious affiliation suggests a patient identifies with a particular religion, engages with others of a similar tradition, and worships divine being(s). However, identification with a specific faith tradition does not necessarily mean that the individual's beliefs are fully aligned with the group's religious doctrine, and it is this element of complexity that invites diligent listening and inquiry. Spiritual relationships may be sustained due to being meaningful in some way; thus, they have the potential to be spiritual resources.

Optimum spiritual functioning is congruent with the experience of relationships that enhance life meaning. Goodness-of-fit is the extent to which the relational context is experienced as spiritually supportive. Interventions address the point of interface where systems can be adapted to be more supportive. Opportunities for relational spirituality can vary across systemic boundaries depending on which relationships are the target of intervention. Although the specific dynamics of significant relationships vary, social workers have the expertise in a range of generalist and clinical skills for intervention. New ways to engage in relationships can be developed which include, for example, helping patients detach from relationships that threaten to undermine life quality.⁴¹ Nevertheless, spiritually sensitive social work can help patients nurture themselves spiritually by facilitating meaningful connections within their environment.

The biopsychosocial-spiritual model provides additional insight for application in a palliative care setting. Based on Sulmasy's approach,⁴² people are beings-in-relationship through which life quality is derived. Changes in functional capacity can compromise interpersonal relationships (e.g., family, friends, communities, political order) and relationships with the physical environment and transcendent or higher power. Even if an individual does not identify as a spiritual person or recognize a transcendent connection, the process of determining what informs life meaning and associated life quality is considered a

relational process that influences biopsychosocial-spiritual functioning. For example, chronic health conditions can influence biopsychosocial-spiritual functioning in a way that necessitates palliative care. A meaningful connection with close friends and support networks can help a patient transcend difficulties and maintain life quality. Since a patient frequently relies on a support system in varied ways as illness evolves, the essential outcome of these relationships is the continuation of quality life. Every dimension of the patient must be considered as social work health professionals work together in and through relationships to support a patient's quality of life, even when it is not possible to extend the patient's life.

Composite Patient Narrative

A composite patient narrative in Box 4.1 provides an example of how relationships can enhance life meaning through the delivery of spiritually sensitive social work. This experience entailed clinical social work with a client named Sue who experienced a change in mental health status with behavioral disturbances (i.e., anxiety, depression, and social withdrawal) after the death of her husband and her subsequent placement in a nursing home. Intervention began with an assessment of influential systemic factors and potential for relationships to moderate her distress.

[Insert Box 4.1 here]

Anticipated Outcomes

Spiritually sensitive social workers evaluate the extent to which significant relationships enhance a patient's experience of life meaning as an indicator of relational spirituality. Evidence of success may be indirect, for example, a patient's experience of enhanced spiritual well-being drawing from mindfulness meditation, therapeutic life review, and other spiritual self-care practices.⁴³ As mentioned in the "Spiritual Assessment" section, there are numerous measurement instruments that can help social workers evaluate patient outcomes and more in development stages. Assessment becomes outcomes measurement when it is

conducted again periodically throughout the intervention. Then the first assessment measurements can be compared to later assessment measurements, to document the impact of social work intervention.

Ensuring Access to Spiritual Care

Spiritually sensitive social workers ensure patients, families, and their intimate networks have access to spiritual care, particularly when there is evidence of spiritual needs or distress. This may include coordination with a spiritual care specialist, like a board-certified chaplain, whose primary responsibility is to engage in the delivery of spiritual care. Board-certified chaplains typically have an advanced theological degree, clinical pastoral education, supervised training, and have met specific certification requirements which entail compliance with a professional code of ethics that includes respect for diversity and continuing education. Chaplains may engage in pastoral counseling, which is more theological than psychological in nature, but they may offer interventions that overlap with social work such as asking patients questions about life purpose, advance care planning, problem solving, and crisis intervention. This can blur professional boundaries and, thus, necessitate open communication and careful coordination. Collaboration within a high-functioning team requires coordinated intervention to ensure that needs and concerns are approached in a consistent way, without repeating interventions and with the inclusion of the patient and family's personal spiritual caregiver or faith leader from their religion to explore specific religious questions. (For additional information, see Foreword by George Handzo.)

Guidelines for Referral

Interdisciplinary hospice and palliative care teams have been challenged by turf battles and lack of consensus regarding individual roles in addressing spirituality. It is clear, though, that all members of the team must respond to client requests to discuss spiritual issues. The first time the first author was faced with a hospice patient's question, "Why would God do this to

me?” she answered, “Let me refer you to the hospice chaplain.” The sad fact that led her on this course of study was that the patient died before the chaplain could get there, the question remaining unexplored. Thus, it is advisable to address spiritual questions when they are brought up by patients. Although the focus in this chapter has been on social workers, all palliative care professionals should develop a comprehensive skill set for the provision of spiritual intervention which may require continuing education in this area. Some cultural groups, like African Americans who are Christian, may prefer seeking guidance from a family pastor or minister in serious illness and end-of-life care.⁴⁴ In the Jewish faith, it may be the community rabbi, who is the trusted spiritual provider with whom profound questions are most comfortably explored.

Conclusion

The diagnosis of a serious illness may heighten the therapeutic and spiritual value of meaningful relationships. Relational spirituality is the product of meaningful relationships that may pre-exist illness, inform and perhaps transform a person. Spiritually sensitive social workers recognize the spiritual significance of relationships and their potential to enhance life meaning. Since relational processes are central to social work intervention, the therapeutic relationship has the potential to enhance a patient’s experience of life meaning. Other significant relationships are reflected by how patients treat themselves (intrapersonal relationships), people for whom they care (interpersonal relationships), and that which defines the larger environment (transpersonal relationships). Interventions can help bolster a patient’s capacity to nurture relationships as a spiritual strength. Spiritually sensitive social workers further draw from traditional social work theory and evidence-based interventions to spiritually support patients. In the end, however, it is the patient’s perception of enhanced life meaning that defines spiritually sensitive social work.

Resources/Additional Reading

City of Hope Professional Resource Center: Serves as a clearinghouse of information and resources that assist others in improving the quality of pain management and end-of-life care.

Edward Canda: Website for the Spiritual Diversity and Social Work Initiative.

The George Washington Institute for Spirituality and Health: Conducts research, educates practitioners, and impacts healthcare policy worldwide.

Society for Spirituality and Social Work: A network of social workers and other helping professionals dedicated to spiritually sensitive practice and education.

Learning Exercises

Spiritual Self-Reflection

The purpose of this exercise is to reflect on your own experience of spirituality, spiritual resources, and spiritual needs. Review the following article:

- Hodge, D. (2005). Developing a spiritual assessment toolbox: A discussion of the strengths and limitations of five different assessment methods. *Health & Social Work, 30*(4), 314–323.⁴⁵

Select a spiritual history tool to complete on your own experience. After completing this tool:

- Reflect on insights gained about yourself.
- Assess the utility of this tool for practice.

Selecting a Spiritual Assessment Tool

A recent Quality Improvement project included a chart audit that identified the lack of consistency regarding the documentation of spiritual care concerns. In collaboration with your chaplain colleagues, you are assigned the task to select a tool to guide spiritual assessments. You are considering the use of the SWAT,²⁷ FACIT-Sp-12,³⁴ or the recently developed PC-7 (which explores concerns related to meaning in suffering;

integrity/legacy/generativity; relationships; fear of dying/death; treatment decisions; religious/spiritual struggle; and “other” dimensions—such as requests for rituals).⁴⁶ After reviewing these tools, consider what factors (cost of use, availability in multiple languages, confidence in its clinical utility, psychometric soundness, applicability for your population, ease of use, etc.) would guide your recommendation for a standardized process to be used by your palliative care service.

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Box 4.1

Patient Narrative

It is Monday morning, and the first person I see is Sue. As I enter the nursing home, there she sits in a wheelchair with a blanket and a huge smile. Sue often sits in her favorite place in the lobby from where she greets visitors. Today Sue is wearing a pink cowboy hat decorated with metal studs that form a cross on the front. People have given Sue hats over the years to add to her collection. She proudly displays them on the walls in her room. Sue is also an artist and has numerous sketch pads and art supplies she uses when she is not enjoying activities like bingo with other residents. Later that afternoon, I find Sue alone in her room watching television. She gracefully allows for my intrusion and begins our psychotherapy session by describing meaningful experiences that day.

This narrative suggests the therapeutic value of meaningful relationships. Spiritually sensitive social work enables the capacity to recognize and mobilize these relationships as part of the traditional provision of care. Clinical work with Sue involved relationships that gave her life meaning, cultivating and maintaining meaningful relationships that were

challenged by the death of her husband and serious illness that necessitated placement in a nursing home. These significant relationships spanned across the intrapersonal (micro), interpersonal (mezzo), and transpersonal (macro) levels. All of these relationships informed life meaning, but as Sue's needs changed, her relationships had to change to maintain goodness-of-fit.

Micro Level: Intrapersonal Relationships

Intrapersonal relationships are defined by internal processes that inform one's relationship with the self. Patients may engage in deep breathing, prayer/meditation, crafts, reading, watching television, using the computer, spending time alone, or exercising. Although the activities of interest may vary, they provide patients a way to nurture self-care. Sue had been struggling with anxiety about leaving her room to join a craft group she would have otherwise enjoyed. Sue learned to engage in deep breathing exercises when she started feeling anxious before going to the group, which inspired self-confidence in her capacity to cope and made her feel more comfortable about participating. Sue also needed a path to creating private time to grieve the death of her husband that did not depend on her roommate leaving their room for an activity. In consultation with staff, Sue was assured a time to sit on the front porch in the morning where she read from her Bible. This grieving process led to questions about her faith, and about an afterlife, necessitating a visit with her minister.

Mezzo Level: Interpersonal Relationships

Interpersonal relationships are central to the provision of nursing home care, occurring one on one or in groups with other patients, staff, and visitors (including by an emotional support animal for pet therapy). At a minimum, patients rely on staff for assistance with personal care. Sue was paralyzed with only partial use of one arm, so she relied extensively on staff for most activities of daily living, including getting out of bed, changing her clothes, and maintaining personal hygiene; but these needs exacerbated her anxiety, and she wanted more

autonomy. This led to problem solving and practice in assertiveness so Sue would feel comfortable in advocating for her preferences in personal care, including arranging a later time to shower so she was able to stay in bed longer in the morning. When Sue’s favorite nursing assistant announced plans to leave the nursing home, Sue processed her feelings of loss and reflected on how she could express her appreciation for their relationship to facilitate closure on the nursing assistant’s last day.

Macro Level: Transpersonal Relationships

Transpersonal relationships with the environment and/or higher power can also inform life meaning. Relationships with a higher power can be shaped by a patient’s spiritual or religious beliefs and practices. While religious affiliation may inform a patient’s worldview, spiritual sensitivity requires spiritual assessment if not consultation with a chaplain or religious leader associated with the patient’s faith. The quality of transpersonal relationships may also be influenced by the building’s design, room decorations, and access to the natural world. Sue decorated her room with her hat collection and artistic creations. Sue also enjoyed sitting in her favorite place in the lobby. There, Sue felt she was part of the milieu, while others would come and go. Sue also valued feeling connected to the larger environment. Although Sue could no longer garden, she could still enjoy watching the birds and the setting of the sun. Bird feeders as well as evergreen trees and berry bushes surrounded the building. Sue would sit by the window to watch the seasons change and enjoy trips arranged by activities staff. This helped Sue connect with the transcendent despite mobility issues that normally kept her inside.

Table 4.1

Examples of Spiritual Concerns

Spiritual Concern	Primary Condition	Illustration
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Anger toward God or others	Projects anger toward religious figures or clergy, inability to forgive	<i>Why would God allow this cancer? I've been good.</i>
Existential concerns	Poses questions about life meaning, what will happen after death, what is the purpose of suffering	<i>My life has no meaning. What happens when I die?</i>
Being forgotten	Worries that one's death won't matter	<i>No one will care when I die.</i>
Guilt/shame	Deep regrets, lack of self-worth	<i>I'm so sorry I hurt him.</i>
Isolation	Shows feelings of loneliness	<i>I feel so alone.</i>
Loss/grief	Feels deep sorrow loss of good health/home, loss of other support systems	<i>I don't know how to go on without my sister.</i> <i>I wish I could still walk every day.</i>
Relationship with God/doubt	Does not sense God's presence, or presence of the Ultimate	<i>Where is God now?</i> <i>Why can't I feel him/her?</i>
Religious or spiritual struggle	Displays deep level of discomfort with spiritual questions which are pervasive	<i>Why am I feeling this way?</i>
Hope and/or belief a miracle will occur	May reflect ethnic or religious group's beliefs and expectations	<i>We are praying for a miracle. Thank you, God, for performing a miracle.</i>

Source: Adapted and condensed from Nelson-Becker, 2018.²⁴

Table 4.2

Spiritual Screening and Assessment Tools

Assessment Tool	Brief Content	Author
Daily Spiritual Experiences Scale	16-item scale addressing deep peace, awe, gratitude, mercy, sense of connection with the transcendent and compassionate love	Underwood, Fetzer Institute, 2019 ³¹
SPIRIT	Spiritual belief system Personal spirituality Integration with a spiritual community Ritualized practice and restrictions Terminal event planning	Maugans, 1996 ³²
HOPE	<i>H</i> (sources of hope and meaning) <i>O</i> (organized religion) <i>P</i> (personal spirituality and practices) <i>E</i> (effects of medical care and end-of-life decisions)	Anandarajah & Hight, 2001 ³³
Functional Assessment of Chronic Illness-Spiritual well-being scale (FACIT-SP12).	12-item scale has two subscales assessing meaning and peace and the role of faith	Peterman, Fitchett, Brady, Hernandez, & Cella, 2002 ³⁴

Domains of Spirituality (11 possible areas)	<i>Spiritual Affiliation</i> (formal/informal groups) <i>Spiritual Beliefs</i> (spiritual philosophy) <i>Spiritual Behavior</i> (daily practices or events) <i>Emotional Qualities of Spirituality</i> (feelings) <i>Values</i> (moral principles, ethical guidelines) <i>Spiritual Experiences</i> (sacred meaning) <i>Spiritual History</i> (development trajectory) <i>Therapeutic Change Factors</i> (resources) <i>Social Support</i> (environment) <i>Spiritual Well-Being</i> (subjective balance) <i>Extrinsic/Intrinsic Spiritual Focus</i> (identity)	Nelson-Becker, Canda, & Nakashima, 2015 ³⁵
FICA	Faith, Belief, Meaning Importance and Influence Community Address/Action in Care	Puchalski, 2006 ³⁶
Spiritual Distress Assessment Tool (SDAT)	<i>Need for Life Balance?</i> <i>Need for Connection?</i> <i>Need for Values Acknowledgment?</i> <i>Need to Maintain Control?</i> <i>Need to Maintain Identity?</i>	Monod, Rochat, Büla, 2010 ³⁷
Social Work Assessment Tool (SWAT)	One item in a general assessment tool developed for hospice and palliative care assesses the two dimensions of spirituality: Philosophy of life Unity consciousness	Reese, Raymer, Orloff, Gerbino, Valade, et al., 2006 ²⁷