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Pain and Suffering

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Abstract

Objective—To review literature on the relationship of pain, spirituality, and suffering as it relates to the patient with cancer who is experiencing pain.

Data Sources—Peer-reviewed articles, textbooks, internet.

Conclusion—Pain and suffering are distinct and yet closely related in patients with cancer. Oncology nurses are important in assessing a patient's pain, including dimensions of spirituality and suffering.

Implications for Nursing Practice—Oncology nurses are the front line of pain management for patients. This includes recognizing existential distress and suffering and responding to suffering.

Keywords

Pain; Suffering; Spirituality

Pain and Suffering

The concepts and human experiences of pain and suffering are distinct yet also closely related in patients with cancer. Pain has been increasingly recognized as more than a physical problem or a neurological response to injury, but rather as a whole-person experience. Pain extends beyond the biologic response and impacts every dimension of life, including the psychological, social, and spiritual domains. Suffering is often described with emotionally laden terms such as distress, misery, agony, or anguish. Suffering is commonly associated as an aspect of pain such as "he suffered horrible pain" or "the bone metastasis caused such agony and suffering."

Building on the work of Eric Cassell, MD, who wrote about the nature of suffering and the goals of medicine,[1] Ferrell and Coyle described the goals of nursing care in response to suffering.[2] They identified the tenets of suffering and nurses' responses, including presence, listening, intimate care of the body, and other aspects unique to the nurse-patient relationship.

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Pain is an overwhelming, all-consuming experience and even pain of low or moderate intensity may evoke extreme suffering because the pain interferes with daily life and relationships or causes the patient to question why such pain and suffering is deserved.

The articles within this issue of *Seminars in Oncology Nursing* are dedicated to various aspects of cancer pain and its management. A common thread throughout these articles is that failure to recognize and respond to suffering will likely mean that the pain will not be relieved. Focusing only on existential concerns without attention to the physical is equally insufficient. This article describes pain and suffering as distinct concerns, yet highly related. Literature is synthesized to capture pivotal work in this area, and case examples are presented to illustrate the shared experiences of pain and suffering. Finally, the authors suggest strategies for the assessment of suffering and responding to it.

Literature Review

The words *pain* and *suffering* are often used interchangeably. For example, definitions of pain in the dictionary include bodily suffering, mental/emotional suffering, or distress, and suffering is defined as the bearing of pain or distress.[3] It is understandable that these words are intertwined in relation to cancer patients in pain. However, there are distinctions. Pain is a physical sensation or signal indicating an event within the body. Suffering is the interpretation of that event and involves thoughts, beliefs, or judgments,[4,5] and reflects the human experience of pain.

Pain can cause suffering when it is uncontrolled or persists. Uncontrolled pain can lead to further physical impact and to major disruption in quality of life (QOL). Uncontrolled pain has deleterious effects on one's outlook on life,[6] often creating a sense of hopelessness. Chronic pain not only affects QOL but may predispose one to further complications psychologically and physically.[5,7,8]

It is well known that pain does not occur in isolation but affects all aspects of QOL, including physical, psychological, social, and spiritual. Pain can cause or worsen other existing physical symptoms such as disturbing sleep, diminishing function, decreasing appetite, or increasing fatigue.[6,7,9–11] Psychologically, pain can cause or exacerbate depression, anxiety, uncertainty, or loss of control.[6,9,11] Pain is also associated with persistent depression in cancer survivors.[10] Socially, pain can impede interaction with others, sexual function, work, and relationships.[6–8] Pain can affect spirituality, causing existential questions of meaning, faith, and fatalism.[6,9]

Spirituality has been defined over the years in different ways. Frankl[12] emphasized meaning, and Pargament[13] stressed interconnectedness and transcendence. The most recent definition comes from a national consensus conference and states that "Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred."[14(p25)]

The importance of spirituality for cancer patients cannot be overstated. This was demonstrated in the work of Alcorn et al[15] and later expanded by Balboni and colleagues,[16]

where most patients reported spirituality or religion as important to their cancer experience. Five themes emerged from interviews: (1) coping (able to endure); (2) spiritual practices (praying and prayer for strength as most prevalent); (3) beliefs (in terms of personal beliefs); (4) transformation (changes in spiritual/religious beliefs related to the cancer experience); and (5) community (spiritual support). Further studies in various settings and languages reported similar findings.[17–19] In Astrow and colleagues'[17] work with 727 patients with differing ethnicities, languages, and religions in four outpatient settings, most patients reported at least one spiritual need. Needing help with finding hope, prayer, or meditation, meaning in the illness experience, and relationship with God or other were the most frequently cited needs. Over half of the respondents considered themselves spiritual but not religious, and those patients had greater spiritual needs. Associated with higher spiritual needs were a perceived lower quality of care and less satisfaction with care. Over half of the patients thought it was acceptable for a physician to inquire about a patient's religious beliefs when taking their social history and just under half thought it acceptable to ask about spiritual needs.

Selman and colleagues[19] conducted focus groups in nine countries in Europe, the United States, and Africa with 74 patients and caregivers. Common patient spiritual concerns included asking "why?," searching for meaning and purpose related to illness, and in life, as well as questions about God and personal faith. Using five prominent databases, Mesquita et al[18] reviewed and synthesized literature on spiritual needs of cancer patients receiving palliative care. From 695 records screened, 16 primary studies met the study criteria. Eight groups of spiritual needs were identified and were similar to the aforementioned. They included needs for meaning and purpose of life; meaning in the disease experience; connecting to God, others, and nature; religious and spiritual practices; well-being physically, psychologically, socially, and spiritually. Additional spiritual needs specific to this study included conversations about death and dying; making the best of time left; and being treated as a normal, independent person.

Unmet spiritual needs are known to impact QOL and cause suffering. Patients struggling spiritually (eg, feeling abandoned by God) and seeking spiritually (eg, meaning of life) have worse overall psychological well-being and QOL.[20,21] A spiritual concern negatively affecting psychological well-being is doubting one's belief in God.[21] Not receiving desired spiritual care is associated with symptoms of depression and diminished meaning and peace.[20] Conversely, spirituality and religiousness, specifically meaning, hope, and peace, were associated with fewer symptoms of depression.[22]

The word *suffering* has varied connotations and is frequently viewed as deserved or undeserved. It is common to see the terms suffering and pain used synonymously. Yet, while suffering and pain are related, they also represent separate concepts.[23] Cassell[24(p221)] defines suffering as "the specific distress that happens when persons feel that their intactness or integrity is threatened or is disintegrating, and it continues until the threat is gone or intactness or integrity is restored." Cassell further asserts that suffering is caused not only by the event itself but also what that means to the person with regard to the future. For Frankl,[12] what was worse than suffering was suffering without meaning, and this he called *despair*. He frequently cited Nietzsche's[25] words "He who has a "why" to live for can bear with almost

any how...”[12(p76)] These words apply to cancer patients who desperately search for meaning in their illness experience or as they face pain.

Patients with cancer experience multiple losses leading to suffering. Physical losses may include loss of function(s), independence, and normalcy, and experiencing pain can add to those losses.[2,6,11,26,27] Existential losses may include loss of dignity, hope, and faith, as well as raising existential questions about meaning of life, meaning of the illness experience, and God’s perceived abandonment.[6,28,29] Pain can add to these losses as well. Liu et al[6] cited a patient expressing the wish to die because life had become meaningless as a result of uncontrolled pain, and another patient feeling tortured from pain. In another study, pain was found to be the most substantial cause of suffering for patients with cancer.[30] As Cassell[24(p219)] states, “Suffering is suffering.” In some studies, spirituality has been associated with lower pain levels and decreased symptoms, as well as buffering against a reduced QOL.[31] Psychological suffering from cancer may occur from loss of a sense of self, a loss of control, or feeling helpless.[6,27,28]

Suffering can be exacerbated further by those entrusted to provide care. Liu et al[6] reported inadequate knowledge of pain management exacerbated the patients’ pain and suffering. A study by Berglund et al[32] described four areas of suffering: (1) feelings of being mistreated; (2) fighting for health care needs including pain medications; (3) feeling powerless; and (4) feeling objectified. Feelings of being mistreated stemmed from not being listened to, when symptoms were ignored, when no time was provided for questions, or when the patient felt he or she was not being taken seriously. Other patients felt powerless when health care professionals did not encourage them to be part of their own care. Additionally, when patients felt secondary to their disease and their experiences were not considered, they felt objectified. Best et al[27] highlighted the difficulty patients have in articulating their suffering. If health care professionals do not acknowledge existential distress either from lack of knowledge or discomfort, they will miss their patient’s suffering.

Assessment of Spirituality and Suffering

Pain, spirituality, and suffering are experienced by patients with cancer. The following case examples illustrate this complex matrix.

Case 1

Roberto is a 48-year-old man who was diagnosed with metastatic colon cancer. He is a quiet, humble man and cared for by two teenaged sons and his wife. He has had a very difficult last few months, reporting a pain of “15 out of 10” throughout his abdomen, lower spine, and rectum. The pain has greatly decreased his function, caused insomnia, and it has been difficult to manage his opioid requirements and bowel regimen. Roberto is from Honduras, and he has become very close with a technician in the radiology department who he discovered was also from Honduras. The oncology team had finally been able to get a plan in place with a combination of analgesics and radiation and, while his physical pain seems improved, the staff and Roberto’s wife share their observation that he remains very distraught.

Today, after Roberto left the clinic, the radiology technician shared with the clinic nurse that "Roberto is suffering so badly." Upon further conversation, the technician explained that Roberto has spoken about his deep regret that he has not been a good father, a good husband, or a good son, all deeply important as a Honduran man, and that he knows he will never see his mother again, and that is the worst part of all.

Case 2

Gwen is a 56-year-old divorced woman who had recently relocated to the West Coast after living in the South for most of her life. She was diagnosed with advanced breast cancer, admitting that she knew the tumor was in her breast, but she had no health insurance when she left her former job, so she delayed care. She has shared with the Social Worker that her marriage and her job ended because she had "a drinking problem," and she also has commented that "it's all coming around – me getting this cancer," and that she knows she deserves "the pain and suffering she is living with" now. She has declined prescription analgesics despite her worsening pain, and the clinic nurse noted today that Gwen has lost more weight and seems depressed.

Spiritual Assessment Tools

Care for the patients in the above cases begins with spiritual assessment. This assessment by a nurse can inform the health care team about the patient's existential needs and coping strategies.[33] Typically, spiritual assessment tools are used within an initial, comprehensive evaluation in which, along with other assessments, the spiritual history is taken. This approach uses a sequence of targeted questions that capture a patient's spirituality, resources, and needs. Although these tools are often used on an initial assessment, they should also be used throughout the patient's illness experience.[34] In situations of suffering in patients with pain, an in-depth spiritual assessment by a chaplain or person with advanced training in spiritual or psychological care may be necessary.[35] Probing into suffering and asking questions that cause the patient to think deeply about his or her experience can be overwhelming but helpful when done with sensitivity. It is important to first assess openness to answering questions regarding spirituality. Gaining trust and rapport allows the patient to feel more comfortable discussing such an intimate topic. It may then be helpful for the nurse to start with one open-ended question to assess the patient's comfort with spirituality and whether further conversation about their spirituality is welcomed.[35,36] Table 1 gives examples of nonthreatening questions that can be used in spiritual assessment. The best open-ended questions begin with how, what, when, or phrases such as "tell me about." Questions that begin with why may come across as threatening (eg, Why do you believe that?).[37] Once a question is asked, it is important to listen to and observe the patient's response and nonverbal communication.[38]

There are several spiritual assessment tools using mnemonics to guide assessment.[50,51] Table 1 lists several spiritual history tools that have been used by nurses and other health care professionals to assess spiritual needs and engage in meaningful conversations. In addition to these mnemonic tools, quantitative scales are used to measure religious/spiritual components of QOL in patients with cancer. Commonly used research tools include the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-being Scale (FACIT-

Sp), which focuses on meaning, faith, and purpose,[39,40] and the SNAP developed by Astrow and colleagues (Table 1).[41] The SNAP questionnaire consists of 23 items useful for the clinician to gain a comprehensive picture of the patient's suffering. It has three subscales: spiritual, psychological, and religious needs.

Spiritual assessment: case example 1

Following is an example of taking a spiritual history using the FICA Spiritual History Tool,[42,43] which has been evaluated in patients with cancer.[44] By addressing spiritual issues through the FICA tool, an environment of trust is established, leading to the relief of suffering by revealing essential information about world views and sources of personal meaning.[42] FICA prompts the clinician to assess **F**aith, belief, and meaning, the **I**mportance and Influence of faith or belief, who or what is their spiritual or religious **C**ommunity, and how they would like the health care provider to **A**ddress their issues (see Table 1).

In Case 1 described above, Roberto remains distraught even after his physical pain has improved. Through observation and conversation with his wife and other members of the health care team, it is evident that his illness has impacted his physical, psychological, social, and cultural contexts of his life. Roberto has deep regret that he has not been a good father, a good husband, or a good son, things that are important to him. With further questions, the nurse can assess Roberto's spirituality and how it impacts his illness experience, pain, and meaning in life. A simple open-ended question for introducing the topic of spirituality may be, "What do you rely on during times of illness?" "Is faith/religion important to you in this illness?"[35] Or the simple phrase, "Tell me about your spirituality." After opening this conversation, the nurse will want to give the patient time to talk and truly listen to what the patient says. Roberto shares that he relies on God, believing that "his life is in God's hands," and that his faith is important to him. The nurse can probe deeper into a spiritual assessment and then invite chaplaincy to assess further.

Assessment (using FICA): applied to case 1

F: Faith or beliefs: States he is a Christian and believes his illness is in God's hands and God knows best. Although he has regrets of his past, and not being a good father, he states "God has a purpose for my life, I just don't understand what that purpose is." He is hoping he will be around long enough to meet his first grandson and will be the best grandfather to him.

I: Importance and Influence: Verbalizes his faith is important. Has hopes that God will forgive his past but hopes his family will forgive him also.

C: Community: He is of Christian faith, was raised Catholic but has not attended church since he was first married. He reveals his family is most important to him.

A: Address/Action in care: Openly accepts a chaplain to visit him, declines the Bible or other spiritual materials. Asks the nurse to keep him and his family in his prayers.

The need for forgiveness

In the above assessment, the concept of forgiveness is illustrated. Individuals facing life challenges such as serious illness often experience feelings of regret and desire for forgiveness. They may reflect on their lives and relationships and confront unresolved conflicts from their past.[2] Forgiveness is not always resolved quickly; however, if not dealt with, it can lead to increased distress. Forgiving self and others can lead to acceptance and peace.[45] Psychological distress can impact physical pain and the suffering associated with it.

Nursing Response to Suffering through Interdisciplinary Collaboration

Nurses respond to suffering through numerous interventions, including interdisciplinary collaboration, compassionate presence, psychotherapy, and mind-body interventions to relieve spiritual and psychological suffering and pain.[34,46,49,52] Through dialogue between the nurse and patient, the nurse can document and share information with other members of the health care team and include the chaplain for further assessment and intervention. The active participation of professionals from psychosocial and spiritual disciplines (eg, chaplains, psychologist, and social workers) is of great importance in responding to suffering.[34] In situations of spiritual distress or suffering, an in-depth spiritual assessment by a chaplain or person with advanced training in spiritual care may be warranted. Knowing that Roberto struggles with forgiveness, the nurse plays a major role on the interdisciplinary team in communication and facilitating a patient-centered plan that will address his concerns. In circumstances of worsening condition, such as physical pain, self-blame, and depression, as in Case 2 of Gwen, a team approach is critical. Whatever the source of suffering, the nurse is empowered to respond and support the patient and family.

Responding to Suffering through Compassionate Presence

Nurses can support the patient through compassionate presence, listening, providing communication that enables patient expression, and by eliminating sources of suffering such as physical pain.[26] Compassionate presence is one of the most significant responses the nurse can provide.[47] Kostovich and colleagues[47] describe presence as a phenomenon that incorporates the emotional connection between nurse and patient, and technical skills performed by the nurse. Compassionate presence is defined as being fully present, attentive to the patient, and being supportive in all of their suffering: physical, emotional, and spiritual.[33,48] It involves “body, mind, and spirit” focusing the attention on the patient and showing empathy in that moment.[41] Nursing presence includes verbal communication, nonverbal communication, and therapeutic touch.[48] Deep listening is essential in supporting patients who are suffering. To listen deeply means trying to understand the emotions and feelings behind the words.[41]

Conclusion

Caring for cancer patients with pain requires responding to the patient’s suffering in its broadest sense. Pain impacts all dimensions of QOL and pain management should also address all dimensions. Nurses working collaboratively with interdisciplinary colleagues can respond to suffering.

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Table 1

Examples of spiritual assessment interview questions and tools

Open-ended questions	What is helping you to cope? What do you see as the purpose of your life now, given that your body isn't allowing you to do all you used to do? What hopes and dreams do you have for your future? For your family? What do you rely on during times of illness? Is faith/religion/spirituality important to you in your illness? Tell me about a time during your life where you faced a huge challenge. What got you through? Is that resource available to you now? What comforts are more satisfying for you now? Do you have someone to talk to about religious matters? Would you like to explore religious matters with someone? Are you at peace? How important is spirituality or religion to you? What is your understanding of where things stand now with your illness? What are your hopes (your expectations, your fears) for the future? As you think about the future, what is most important to you?
FICA	The FICA tool stands for Faith, Import or Influence, Community and Address/Action in Care. Examples of the questions to use with this tool are: What spiritual beliefs are important to you now? What importance does your faith or belief have in your life? Are you part of a spiritual or religious community? How would you like me to integrate or address these issues in your care?
SPIRIT	The SPIRIT tool stands for Spiritual belief system, Personal spirituality, Integration with a spiritual community, Ritualized practices and restrictions, Implications for medical care and Terminal events planning. This tool is used to inquire about formal religious affiliation and the importance of religion in daily life. In addition, this tool is used to learn about forbidden areas of care/practice and to plan for end-of-life care.
HOPE	The HOPE tool helps identify the patient's sources of Hope, Organized religion, Personal spirituality or spiritual practices, Effects on medical care and/or end-of-life issues. Examples of questions that could be used with this tool are: What do you hold on to during difficult times? What in your life gives you internal support? Do you consider yourself part of an organized religion? Do you have any personal spirituality practices independent of organized religion? Has being sick affected your ability to do the things that usually help you spiritually?
FACT	The FACT tool helps assess for the patient's Faith, Availability of what he or she needs now, whether those spiritual beliefs helps the patient Cope or serves as a Comfort, and how the health care team in their Treatment can help support the patient spiritually.
MVAST	MVAST includes Moral authority, Vocational, Aesthetic, Social, and Transcendent. This tool helps the health care provider assess what guides the patient in his/her determination of right and wrong, what mission they feel passionate about, how they express their creativity, what faith community they feel they belong to, and whether they believe in a sacred being or order.
BELIEF	Belief system, Ethics or values, Lifestyle, Involvement in spiritual community, Education, Future events of spiritual significance. This tool helps assess spiritual belief, values, rules of life, spiritual habits including those that pertain to diet, connection to faith community including current religious education or upcoming religious ceremonies.
SNAP	Spiritual Needs Assessment is a tool that probes a patient's spiritual, psychological, and religious needs. The spiritual realm may include finding meaning, coping with suffering and dying and death, and finding peace of mind. Psychological needs may include getting in touch with other patients with similar illnesses or finding ways to relax or cope with stress, feelings of sadness, worries about his/her family, and identifying a means to share thoughts and feelings with those with whom they are close. Religious needs may include visits from clergy, members of their faith community, or the hospital chaplain, as well as religious rituals such as chants, prayers, or religious texts.