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Review Article

Spiritual Care in Hospice and Palliative Care

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Spiritual care is at the center of hospice and palliative care. Patients facing serious and life-threatening illness have important needs in regard to faith, hope, and existential concerns. The purpose of this article is to review the key aspects of this care, including the definitions of spirituality, spiritual assessment, and spiritual care interventions. A review of the current literature was conducted to identify content related to spiritual care in hospice and palliative care. A growing body of evidence supports the importance of spiritual care as a key domain of quality palliative care. The literature supports the importance of spiritual assessment as a key aspect of comprehensive patient and family assessment. Spirituality encompasses religious concerns as well as other existential issues. Future research and clinical practice should test models of best support to provide spiritual care.

Key Words: Spirituality, Hospice care, Needs assessment, Existentialism

INTRODUCTION

The field of hospice and palliative care is based on the principle of whole person care. Quality care is dependent on meeting physical, psychological, social, and spiritual needs. A hallmark of hospice and palliative care is the focus on spirituality, which is essential as patients face serious illness and the end of life (1,2). Spirituality is also important to family members as they face the loss of their family member and envision a future life without that person. There have been significant efforts in recent years to expand the focus on spiritual care through the assessment of spiritual needs and education of clinicians regarding spiritual care (3). This article reviews the key concepts including a consensus definition of spirituality, spiritual assessment, and spiritual interventions.

As illustrated in Figure 1 (4), spiritual well-being is one of the domains of quality of life (QOL) with various elements in this domain, including faith or religion, hope, and existential concerns (5). The domains of QOL are separate but also very

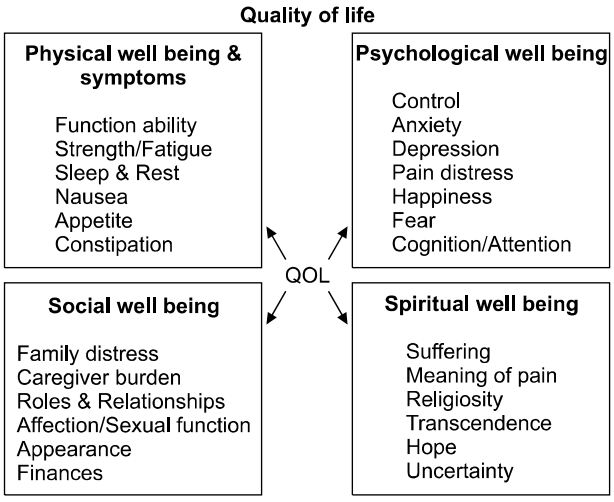

Figure 1. The City of Hope quality of life (QOL) model.
Source: prc.coh.org [Internet]. Duarte, CA: City of Hope Pain Resource Center; 2017 [cited by 2016 Oct 28]. Available from: http://prc.coh.org.

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interrelated. Spiritual well-being influences the patient's experience of symptoms and other aspects of physical well-being (6). Psychological symptoms such as anxiety and depression may be related to a patient's spiritual distress, regrets, fears, or need for forgiveness (7-9). The social domain includes changing roles and relationships and other aspects of

Table 1. Clinical Practice Guidelines for Quality Palliative Care.

Guideline 5.1. The interdisciplinary team assesses and addresses spiritual, religious, and existential dimensions of care.

Criteria

Spirituality is recognized as a fundamental aspect of compassionate, patient and family centered care that honors the dignity of all persons.

- Spirituality is defined as, "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/or to the significant or sacred." It is the responsibility of all IDT members to recognize spiritual distress and attend to the patient's and the family's spiritual needs, within their scope of practice.
- The interdisciplinary palliative care team, in al settings, includes spiritual care professionals; ideally a board certified professional chaplain, with skill and expertise to assess and address spiritual and existential issues frequently confronted by pediatric and adult patients with life-threatening or serious illnesses and their families.
- Communication with the patient and family is respectful of their religious and spiritual beliefs, rituals, and practices. Palliative care team members do not impose their individual spiritual, religious, existential beliefs of practices on patients, families, or colleagues.

Guideline 5.2. A spiritual assessment process, including a spiritual screening, history questions, and a full spiritual assessment as indicated, is performed. This assessment identifies religious or spiritual/existential background, preferences, and related beliefs, rituals, and practices of the patient and family; as well as symptoms, such as spiritual distress and/or pain, guilt, resentment, despair, and hopelessness.

Criteria

- The IDT regularly explores spiritual and existential concerns and documents these spiritual themes in order to communicate them to the team. This exploration includes, but is not limited to: life review, assessment of hopes, values, and fears, meaning, purpose, beliefs about afterlife, spiritual or religious practices, cultural norms, beliefs that influence understanding of illness, coping, guilt, forgiveness, and life completion tasks. Whenever possible, a standardized instrument is used.
- The IDT periodically reevaluates the impact of spiritual/existential interventions and documents patient and family preferences.
- The patient's spiritual resources of strength are supported and documented in the patient record.
- Spiritual/existential care needs, goals, and concerns identified by patients, family members, the palliative care team, or spiritual care professionals and addressed according to established protocols and documented in the interdisciplinary care plan, and emphasized during transitions of care, and/or in discharge plans. Support is offered for issues of life closure, as well as other spiritual issues, in a manner consistent with the patient's and the family's cultural, spiritual, and religious values.
- Referral to an appropriate community-based professional with specialized knowledge or skills in spiritual and existential issues (e.g. to a pastoral counselor of spiritual director) is made when desired by the patient and/or family. Spiritual care professionals are recognized as specialists who provide spiritual counseling.

Guideline 5.3. The palliative care service facilitates religious, spiritual, and cultural rituals or practices as desired by patient and family, especially at and after the time of death.

Criteria

- Professional and institutional use of religious/spiritual symbols and language are sensitive to cultural and religious diversity.
- The patient and family are supported in their desires to display and use their own religious/spiritual and/or cultural symbols.
- Chaplaincy and other palliative care professionals facilitate contact with spiritual/religious communities, groups or individuals, as desired by the patient and/or family. Palliative care programs create procedures to facilitate patients' access to clergy, religious, spiritual and culturally-based leaders, and/or healers in their own religious, spiritual, or cultural traditions.
- Palliative professionals acknowledge their own spirituality as part of their professional role.
  Opportunities are provided to engage staff in self-care and self-reflection of their beliefs and values as they work with seriously ill and dying patients. Core expectations of the team include respect of spirituality and beliefs of all colleagues and the creation of a healing environment in the workplace.
- Non-chaplain palliative care providers obtain training in basic spiritual screening and spiritual care skills.
- The palliative care team ensures postdeath follow up after the patient's death (e.g. phone calls, attendance at wake or funeral, scheduled visit) to offer support, identify any additional needs that require community referral, and help the family during bereavement (see Domain 3: Psychological and Psychiatric Aspects Car, Guideline 3.2)

Source: National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care. 3rd ed. Pittsburgh, PA: National Consensus Project for Quality Palliative Care; 2013 [cited by 2016 Oct 28]. Available from: http://www.nationalconsensusproject.org.

the patient and family life which is also greatly influenced by spirituality (10-12). Thus, it is evident that attention to spirituality influences all aspects of the patient's life (13-16).

In the United States, national palliative care guidelines include spiritual care as one of 8 domains (3). Table 1 presents the recommendations from these guidelines for spiritual care. These guidelines, based on available evidence, have as a first recommendation the need for the entire inter-disciplinary team to be accountable for spiritual care. The guidelines also emphasize spiritual assessment with attention to spiritual history, spiritual distress, and rituals that might be important in the patient's care. The recommendations address spirituality in the broadest sense, and are not limited to religiosity. The guidelines include attention to existential concerns, life review, and meaning of life. The third area of the recommendations focuses on practices and rituals near the end of life. An important aspect of these recommendations is that quality spiritual care also requires that clinicians acknowledge their own spirituality.

SPIRITUALITY DEFINED

The term spirituality is often viewed as synonymous with the term religion or faith in a higher power. However, the field of palliative care has broadened this concept to include other dimensions. In 2009, a meeting was convened bringing together experts in spiritual care and those in palliative care to reach a consensus definition of the term spirituality and recommendations for care (17). The definition they settled on is, "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" (17).

This definition has been widely adopted in the field of palliative care and guides clinicians to explore the many aspects of a patient's life (3). Spirituality is also often related to the relief of suffering, which is a primary goal of palliative care. Most definitions of spirituality recognize that it encompasses beliefs, rituals, and practices regarding a higher power and that spirituality is also strongly associated with cultural beliefs (18). The founder of the hospice movement, Dame Cicely Saunders, wrote and spoke extensively about spiritual pain, spiritual distress, and the sacred work of care at the end of life (19). The literature emphasizes spiritual care throughout serious illness with special attention at the end of life (17). The above definition, which originated from a United States Consensus meeting, has since been disseminated internationally (20,21).

SPIRITUAL ASSESSMENT

Expert patient care is contingent upon accurate assessment in order to determine the patient's needs. Spiritual assessment is as important as the assessment of physical symptoms to meet the goals of palliative care. Unfortunately, many clinical settings do not include spirituality as a part of routine assessment and many settings limit spiritual assessment to simply documenting religious affiliation. Another significant trend in palliative care is the recognition that spiritual care is led by the specialists in the field, religious leaders and chaplains, but that all clinicians should be dedicated to spiritual care and be skilled in spiritual assessment (22). Nurses, physicians, social workers, volunteers, and nursing assistants should all contribute to the assessment and monitoring of spiritual needs.

Extensive reviews have been published describing many spiritual assessment tools, their psychometric properties, and the associations between spirituality and other patient outcomes (23-28). Many of these tools have been developed for research purposes, but several can also be applied to clinical practice. There are a few basic principles that are prioritized as follows as key messages for hospice and palliative care clinicians.

The first principle is the need for spiritual screening performed early in the course of care, in order to identify the patient's needs. Initial screening can also identify those patients who have urgent needs that are critical to the patient's well-being. These spiritual needs may include a desire for forgiveness, a spiritual longing, or a feeling of separation from the divine, those with fears about an afterlife, or in need of religious rituals such as confession or baptism. Several assessment tools are available for clinicians to use. Two simple tools include the single question "Are you at peace?" developed by Steinhauser et al. (29), and the FICA tool developed by Pulchalski et al. (30). The FICA tool asks open-ended questions about the patient's faith community,

the importance of spirituality, and how the patient would like to have spirituality addressed as part of their care.

The second principle concerns spiritual history-taking. Patients facing life-threatening illness often come to this experience with lifelong beliefs and values that influence decisions about their treatments and preferences at the end of life. Spiritual history-taking goes beyond the initial screening or assessment of urgent needs in order to better understand the patient's life and story (31). Patients frequently share a history of having had strong religious affiliation in childhood, but having moved away from religion as adults. As they now face serious illness, there is often a strong desire to re-connect with the faith affiliation of their early lives.

The third principle identified in the literature is the need in some cases for a more comprehensive spiritual assessment, in a similar way that all patients need initial screening for physical symptoms. Some patients will be identified to have complex pain, difficult to manage dyspnea, or constipation resistant to the usual treatments and require more detailed evaluation (31,32), thus pain or palliative care specialist clinicians are consulted. In a similar way, if a patient voices spiritual distress and a feeling of being abandoned by God or punished by a terminal diagnosis, the clinicians would arrange for chaplaincy involvement as soon as possible, in order to conduct a more thorough spiritual assessment and to provide spiritual care (33,34).

SPIRITUAL INTERVENTIONS

Most of the literature regarding spirituality to date has consisted of descriptive studies of spiritual needs with limited research or literature devoted to spiritual interventions. Spiritual interventions can only be provided based on patient assessment in order to know what practices, such as prayer or religious rituals, are needed (35-37), and are culturally acceptable to the patients and their families (38,39).

There is also strong support for practices that can be employed by all members of the interdisciplinary team, such as presence and listening attentively to the patient's story, their suffering, and to witness the intensely personal work at the end of life, as patients seek to leave a legacy and to know that their life had meaning. This supportive care also assists patients in managing uncertainty and maintaining hope, even in the midst of a terminal prognosis. Breitbart et al. (40), Chochinov et al. (41,42), and others have tested interventions to support patient dignity and what has become known as meaning-focused psychotherapy. This literature has documented that all members of the team can participate in these therapies.

Spiritual care interventions are increasingly incorporated within the overall plan of care for patients in hospice or palliative care settings. Key educational efforts such as the End-of-Life Nursing Education Consortium (ELNEC) (43), www.aacn.nche.edu/elnec, which has prepared over 25,000 trainers in 95 countries, have included spiritual care training as a part of palliative care education. The ELNEC curriculum has been widely used in South Korea and throughout Asia. Similar efforts have been made in medical education (44), http://www.GWISH.org.

DISCUSSION

Quality palliative care is not possible without quality spiritual care which begins with an assessment of spirituality and requires attention by the interdisciplinary team (45-49). Spiritual needs vary for each patient and family and also may change across the trajectory of illness and at the time of death. Palliative care will continue to evolve and expand globally to serve the pressing needs in healthcare. Spiritual care will remain central to palliative care.

요 약

영적간호는 호스피스 완화의료의 중심에 있다. 심각하고 생명을 위협하는 질병에 직면한 환자는 신앙, 희망 및 실존적 관심과 관련하여 중요한 요구를 가지고 있다. 이 논문의 목적은 영성, 영적 평가 및 영적간호 중재의 정의를 포함하여 이러한 간호의 핵심 측면들을 검토하는 것이다. 호스피스 완화의료에서 영적간호와 관련된 내용을 파악하기 위해 현재의 문헌 자료들을 조사했다. 점점 더 많은 증거들이 양질의 완화의료의 핵심 영역으로서 영적간호의 중요성을 뒷받침하고 있다. 문헌은 포괄적인 환자 및 가족 평가의 핵심 측면으로서 영적 평가의 중요성을 뒷받침한다. 영성은 다른 실존적 문제들뿐만 아니라 종교적인 관심도 포함한다. 향후 연구 및 임상시험은 영적간호를 제공하기 위한 최선의 지

원 모델을 검증해야 한다.

중심단어: 영성, 영적 평가, 영적간호, 실존적 관심

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