The National Agenda for Quality Palliative Care:

The Essential Elements of Spirituality in End-of-life Care

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This article demonstrates how guidelines and preferred practices for quality palliative/hospice care, written by the National Consensus Project and the National Quality Forum, may be operationalized. It focuses specifically on Domain 5 of the guidelines, "Spiritual, Religious and Existential Aspects of Care." Included are methods for assessing need for spiritual care and for communicating with patient/family about such need; role of the spiritual advisor on the interdisciplinary team and the advantages of including certified chaplains; need for sensitivity toward cultural/religious diversity in administering spiritual care; and relationship building with community clergy.

In December 2001, representatives for the leading end-of-life organizations came together to discuss palliative care guidelines. From this meeting emerged the National Consensus Project for Quality Palliative Care (NCP), consisting of members from the Hospice and Palliative Nurses Association (HPNA), the American Academy of Hospice and Palliative Medicine (AAHPM), the National Hospice and Palliative Care Organization (NHPCO), the Center for the Advancement of Palliative Care (CAPC), and the Partnership in Caring: America's Voice for the Dying. With the intention of describing optimal palliative care as well as providing a foundation for education and research in the United States, the NCP released the *Clinical Practice Guidelines for Quality Palliative Care* in April of 2004.[1] The guidelines delineate eight domains of quality palliative care with criteria for implementation. (See Table 1, p. 16.)

This article demonstrates how the guidelines and preferred practices may be operationalized in practice, focusing specifically on Domain 5 of the guidelines, "Spiritual, Religious and Existential Aspects of Care." This domain incorporates many pertinent aspects of hospice and palliative care related to addressing the spiritual needs of the dying patient and his/her family. In particular, the article addresses methods for assessing need for spiritual care,

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methods for communicating with the patient and family about spiritual care needs; role of the spiritual advisor on the interdisciplinary palliative care team; advantages of including certified chaplains on the palliative team; need for sensitivity toward culture and religious diversity in administering spiritual care and need for specialized palliative care spiritual advisors to build relationships with community clergy.

In 2006, the National Quality Forum (NQF) used the NCP guidelines as a basis for its document, *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report.*[2] Significantly, NQF accepted and endorsed NCP's definition of palliative care as "family- and patient-centered care that optimizes quality of life by anticipating, preventing and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social and spiritual needs and facilitating patient autonomy, access to information and choice."

This framework/practices document articulates thirty-eight evidence-based preferred practices developed from the eight domains of the guidelines. These preferred practices provide assessment criteria that allow for measurement and evaluation of quality of care, while identifying areas for research that apply both to hospice and to palliative care across settings of care, as well as to all members of the interdisciplinary healthcare team.

Domain 5 of the guidelines addresses spiritual, religious and existential aspects of care. Spiritual care providers are identified as integral members within the interdisciplinary palliative care team and therefore need to

Table 1

National Consensus Project for Quality Palliative Care
Clinical practice guidelines for quality palliative care

Domain 1: Structure and Processes of Care

Domain 2: Physical Aspects of Care

Domain 3: Psychological and Psychiatric Aspects of Care

Domain 4: Social Aspects of Care

Domain 5: Spiritual, Religious, and Existential Aspects of Care

Domain 6: Cultural Aspects of Care

Domain 7: Care of the Imminently Dying Patient

Domain 8: Ethical and Legal Aspects of Care

Table 2

National Quality Forum
Preferred practices associated with spirituality

20 – Develop and document a plan based on assessment of religious, spiritual and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.

21 – Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual counseling or through the patient's own clergy relationships.

22 – Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.

23 – Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy, and provide education and counseling related to end-of-life care.

24 – Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including, but not limited to, locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine perspectives on death, suffering and grieving and funeral/burial rituals.

understand both NCP guidelines and the NQF preferred practices. This article discusses five preferred practices associated with Domain 5. (See Table 2, p. 16.)

Overview of chaplaincy or spiritual care assessment

Preferred Practice 20: Develop and document a plan based on assessment of religious, spiritual and existential concerns using a structured instrument and integrate the information obtained from the assessment into the palliative care plan.

Spiritual care is considered a basic tenet of palliative care. The provision of continual end-of-life spiritual care is the responsibility of the entire palliative care/hospice team. Nonetheless, the clinical assessment of a dying person's spiritual, religious, and existential needs must first be discerned before the appropriate interventions may be made.

The palliative care team should complete an assessment during an initial evaluation. While the Joint Commission mandates spiritual assessments of patients and families, there are no specific requirements for a spiritual assessment. Thus, the specifics as to how spiritual assessments are performed and the response to spiritual issues are determined by the individual healthcare organization.

During their initial meeting, a palliative care team member should ascertain the patient's and his/her family's spiritual/religious/existential beliefs, practices, preferences and needs. This is often referred to as "taking a spiritual history." A variety of formal assessment tools and guides have been designed to measure and assess existential, religious and spiritual beliefs and practices along with any associated community support of such practices.

One of the best known interviewing tools for taking a spiritual history is the four-point FICA (Faith, Importance/Influence of beliefs, Community involvement, and Addressing issues in providing care).[3] Another is the six-point SPIRITual History assessment (identifying Spiritual beliefs, Personal spirituality, Integration in spiritual community, Ritualized practices, Implications for medical care, and Terminal event planning).[4]

Standardized structured formats that are self-administered include the FACIT-Sp (the 12-item Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being which focuses on meaning/peace and faith) and SBI-15R (Systems of Belief Inventory which focuses on beliefs/practices and religious community/support).[5]

Each of these spiritual assessment tools adequately identifies and addresses the most frequent and important qualitative questions raised by serious illness: those of meaning/purpose, death/dying, illness/pain, value/dignity, and relationship/forgiveness.[6] Information entered into the patient's medical record should be reviewed by a chaplain/spiritual care specialist. The chaplain then devises and implements a patient-focused spiritual care plan, which may or may not include faith/denomination-specific interventions.[7]

While these assessment tools are useful in providing valuable information to the healthcare team, there remains the underlying conundrum of using a clinical model to assess or address the non-clinical realm.[8] Gordon and Mitchell offer a four-level competency model for spiritual assessment and care based on the individual competence of all healthcare professionals and volunteers involved in patient/family care as follows:

- Level 1 – all staff and volunteers with casual contact with patients/families.
- Level 2 – all staff and volunteers whose duties require contact with patients and families/caregivers.
- Level 3 – staff and volunteers who are members of the multidisciplinary team.
- Level 4 – staff or volunteers whose primary responsibility is for the spiritual and religious care of patients, visitors and staff.[9]

This core competency framework allows for spiritual/religious/existential concerns to be thoroughly integrated into all aspects of care rather than function as a subset of care. Tools for training and measuring competencies at each level include but are not limited to the following: case reviews, seminars and chart reviews. They are facilitated by the healthcare team's chaplain/spiritual care specialist.

Availability of services

Preferred Practice 21: Provide information about the availability of spiritual care services and make spiritual care available either through organizational spiritual counseling or through the patient's own clergy relationships.

In order to meet the various spiritual needs of both patients and

families, it is essential to provide information about available services. This should be multidimensional, reflecting the various formats available for adult learning, e.g., written materials, Web sites with healthcare networks, and should incorporate verbal descriptions from healthcare professionals. Any brochure or written information about supportive care programs should include mention of the availability of spiritual care services as well as how to access them.

Ideally, the chaplain will meet every new patient to assess whether spiritual care may be welcome and helpful; however, the reality of staffing may preclude this. In the latter case, a palliative care team member should routinely offer these services to the patient/family during the initial visit, just as they offer services from other disciplines. Documentation of the patient's and/or family's responses should be made in the medical record as well as at team meetings.

If the patient or family declines spiritual care services at admission, it may be appropriate to again offer such services at a later date, particularly at times when the patient begins working on such themes as love, forgiveness, hope, trust and meaning. This may be accomplished through open queries such as the following: "Sometimes it really helps to explore those important spiritual questions with a trained chaplain. Would you like me to ask our team's chaplain to come by and visit?" In situations where the family is looking for resources to support them as their loved one grows closer to death, a member of the team may again offer spiritual care: "Our chaplain is really good at helping people figure out what spiritual resources work for them. Would you like me to have her call?"

If at any point the patient or family requests that spiritual care services *not* be offered, this request should be documented in the chart and honored. The clinician might say, "We will be glad to honor your request. At any point you may ask for the service, and we will provide it, but we will not offer it again."

The second element of this preferred practice pertains to the actual provision of professionals to provide spiritual care. The best method is for the palliative care or hospice program to hire a professional chaplain or spiritual care specialist. This provides the organization control over the quality of spiritual care, as well as a guarantee of responsiveness and availability. Moreover, staff chaplains may collaborate with the other disciplines in the care of patients and families and fully document their contributions in the medical record.

Utilizing the patient's own clergy relationship for primary spiritual care may be helpful to the patient and family if those relationships are positive and strong. Being known by the clergyperson may help the patient feel safe and understood. Prayer and ritual may be offered in the exact vernacular of the patient. Moreover, knowing that the clergyperson will continue to support family members through their bereavement often is comforting to the patient.

A number of risks, however, are inherent in relying solely on community clergy. The patient/family may not have a solid congregational connection. The clergyperson may neither feel comfortable in healthcare settings, nor be equipped with the specialized spiritual care skills needed to support the dying and their families. This may result in their failing to respond to requests or doing so in a manner that is unhelpful to the patient/family. Many clergy have minimal training in supporting people through bereavement. Clergy who lack the skills and/or confidence to minister in end-of-life situations, but who have pastoral relationships with patient/family members may be amenable to mentoring by the chaplain. This is an excellent role for a staff chaplain.

Training in palliative spiritual care

Preferred Practice 22: Specialized palliative and hospice care teams should include spiritual care professionals appropriately trained and certified in palliative care.

Specialized palliative care and hospice teams should include professionally certified chaplains. Professional chaplains are trained to work within the worldview of the patient or family member, be that secular or religious, similar or dissimilar to their own religious beliefs. They are capable of working across religious lines, with knowledge about spiritual care in many forms, rites and rituals. Chaplains are the spiritual care specialists on the team. However, if they are appropriately trained and comfortable with the role, team members from other disciplines may serve as spiritual care generalists.[10]

In the United States there are currently three major professional organizations that certify chaplains: the National Association of Jewish Chaplains (NAJC), the National Association of Catholic

Chaplains (NACC) and the Association of Professional Chaplains (APC). The first two certify chaplains only within their respective faith traditions. The APC certifies chaplains from all faith traditions listed in the Yearbook of American and Canadian Churches, plus others by application and approval. Standards for certification in any of these organizations include the following: master's level theological education, endorsement from one's religious group, at least four units of clinical pastoral education (CPE) and a rigorous committee review process. Certification for palliative care specialists does not yet exist for chaplains. Although some CPE students choose to focus their advanced CPE learning on a specialty area, such as end of life, such clinical specialization is not required for certification.

Certified chaplains are required to pursue at least fifty hours of continuing education each year. Those working within palliative care should focus on educational experiences that further their development of a clinical specialty in end-of-life care. This may include work in hospices, palliative care services, cancer centers or within settings that serve patients with life-threatening illnesses.

Across the healthcare continuum, the cultural and religious diversity of patients/families is significant. It is important that chaplains develop a nuanced knowledge of the beliefs and behaviors of the populations served by their team. This knowledge will help chaplains to individualize care that addresses each person's uniqueness. This degree of expertise, comfort and creativity is less likely to be found in a noncertified chaplain.

Specialized spiritual care

Preferred Practice 23: Specialized palliative and hospice spiritual care professionals should build partnerships with community clergy and provide education and counseling related to end-of-life care.

The strength of the team approach in hospice/palliative care extends to building relationships with various faith/religious groups in the surrounding community. Patients and families often have very specific religious needs. For many, the ability to attend services, receive sacraments and/or participate in meaningful rituals and community gatherings is greatly curtailed as a disease progresses.

In order to meet both individual and communal needs, the chaplain establishes and facilitates contacts with community faith group leaders, e.g., minister, rabbi, imam, elder, monk, and programs, e.g., mediation groups, AA, other twelve-step programs, that connect, and in some cases reconnect, patients with their chosen faith/religious traditions. Utilizing the resources in their communities, chaplains direct patients and families to those with special competence and comfort in end-of-life issues.

In order to support community clergy in their provision of spiritual/religious care, the chaplain should implement multifaith outreach programs both to promote open dialogue and to provide educational opportunities focusing on end-of-life care. Some clergy may have completed a unit of CPE as part of their ordination process. Others may have extensive experience providing pastoral care to patients and families within their congregations. Collaboration with local clergy may lead to sustained partnerships within a compassionate community that continues to offer supportive spiritual care not only at life's end but also into the family's bereavement.

Preferred Practice 24: Incorporate cultural assessment as a component of comprehensive palliative and hospice care assessment, including, but not limited to, locus of decision making, preferences regarding disclosure of information, truth telling and decision making, dietary preferences, language, family communication, desire for support measures such as palliative therapies and complementary and alternative medicine perspectives on death, suffering and grieving, and funeral/burial rituals.

Optimal spiritual care should strive to conform to the personal and communal needs of the individual, especially at the end of life. Although spiritual/religious/existential concerns vary from person to person and family to family, all necessarily entail a connectedness to something or someone that imbues life with a sense of purpose or meaning.[11]

Cultural diversity mandates honoring the differences presented in the world community. Rather than an attempt to direct another's life decisions, it is a convergence of mutual support, which respects the individual's belief system, a fundamental principle of empowerment. The hospice/palliative team should use the patient's personal goals as measurement, accepting that the patient's goals often are quite different than theirs. For example, some culturally specific interventions that address and honor belief in the healing power of God's will,

rather than a biomedical approach, may empower and contribute to the self-esteem, sense of control, and well-being of patients, especially religious African Americans and Latinos.[12]

The chaplain should be well-versed in faith traditions represented in the local patient demographic; nevertheless, variations within an ethnic group may be as wide as those between groups. Asking the patient or family directly, "what is important to you at this moment?" helps to cross ethnic and cultural barriers. Awareness of the importance of cultural expressions and symbols of religious and spiritual devotion, e.g., icons, prayer beads, should be encouraged and welcomed in the palliative care/hospice setting.

The use of integrative therapies in patient care may include dietary restrictions, herbal remedies and other homeopathic treatments. The use of such therapies should be respected unless the healthcare team determines the patient would be harmed or that its use would interfere with proven beneficial therapies.[13] Some patients and families with certain cultural backgrounds may have different views on the appropriateness of medical disclosures. They may request that the family become the gatekeepers of information, linking beneficence to family decision making over the value of personal autonomy.[14] This is quite often the case with death rituals and funeral customs. For many cultures, death is viewed not as an instantaneous or individual act but as an organic and communal one, a natural connection that affects not only the immediate family of the deceased but the entire community.

Conclusion

The goals of palliative care are to prevent and relieve suffering and support the best possible quality of life for patients and their families. Spiritual care is an essential aspect of the delivery of palliative care. The diagnosis of a life-threatening illness often results in the person reflecting on the meaning of life with concomitant spiritual, religious and existential questions. In fact, spiritual and religious needs and concerns may be equally, and sometimes more, important than those physical in nature. The NCP's Domain 5, Spiritual, Religious, and Existential Aspects of Care, and the associated NQF's Preferred Practices underscore the importance of the spiritual domain as an integral and vital component of palliative care clinical practice.

The multidisciplinary team requires a specific skill set to support patients and families from various faith traditions and belief systems throughout the course of illness, the process of dying and its immediate aftermath. It is important that the palliative care staff be capable of recognizing a person's spiritual and existential concerns, and that they be supported and trained by the professional chaplain or spiritual care specialist on the team. Several assessment tools have emerged to help practitioners at many levels.

Following the initial assessment, it is critical that professionally trained chaplains be available to provide continuing support to patients and families, especially those with complex issues. In order to support patients along the continuum of sites of care, chaplains should have a thorough knowledge of community resources outside the healthcare system. All of these interventions provide a holistic approach to help promote a collaborative process in attending to the various physical, psychological, social, and spiritual needs of patients at the end of their lives.

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