Hospice and Palliative Care Nursing

Overview

Defined by the World Health Organization in 1990, palliative care seeks to address not only physical pain, but also emotional, social, and spiritual pain to achieve the best possible quality of life for patients with advanced diseases and/or terminal prognoses as well as their families. Such care is concerned with improving a patient’s quality of life rather than curing the underlying malady. This holistic approach to care is provided by an interdisciplinary team consisting of at least one primary physician, one nurse, and one social worker. When necessary, the services of a clergy member, dietician, physical therapist, and others may also be included.

Journals

The Journal of Hospice and Palliative Nursing (JHPN) is the official journal of the Hospice and Palliative Nurses Association (HPNA). The stated mission of this peer-reviewed bi-monthly journal is "promoting excellence in end-of-life care." JHPN may be the most important academic journal in this disciplinary field.

The American Journal of Hospice and Palliative Medicine (AJHPM) targets a diverse audience of caregivers: doctors, nurses, administrators, counselors, and pastors. The aim of this peer-reviewed bi-monthly journal is "the dissemination of medical science to broaden education and advance understanding of the complex issues encountered in these areas." Though not exclusively geared for nurse practitioners, AJHPM is also an important journal in the field of palliative care.

The Journal of Palliative Medicine (JPM) is the official journal of the American Academy of Hospice and Palliative Medicine (AAHPM) and is geared toward end-of-life caregivers.

The Journal of Pain and Symptom Management (JPSM) is the official journal of U.S. Cancer Pain Relief Committee and the National Hospice and Palliative Care Organization and like the AJHPM is directed to a broad audience, specifically clinicians and research in pain management, oncologists, neurologists, anesthesiologists, pharmacologists, therapists, nurses, and social workers. This highly regarded peer-reviewed monthly journal has an international readership and according to its website "boasts an international editorial board including leading researchers and clinicians, each board member is an active figure in pain or palliative care, and a major contributor to the literature." It ranks in the top third or better in Clinical Neurology titles, Health Care Sciences & Services titles, and Medicine, General & Internal titles.

The Clinical Journal of Oncology Nursing (CJON) is an official publication of the Oncology Nursing Society (ONS) and is targeted specifically to oncology nurses. The stated mission of this peer-reviewed bi-monthly journal is twofold: "(a) to provide practical information necessary to care for patients and their families across the cancer continuum and (b) to develop publication skills in oncology nurses."

Organizations

The National Hospice and Palliative Care Organization (NHPCO) is the largest nonprofit organization of its kind in the United States. It is not surprising, then, that every professional I spoke with during the course of this project was a member of this organization. Founded in 1978, the mission of the NHPCO is "to lead and mobilize social change for improved care at the end of life." To help illustrate just how significant this organization really is, consider this fact found on the NHPCO website: NHPCO members cared for almost 90 percent of the approximately 1.3 million patients served by hospice in 2006. Individual membership is free to those working for member organizations.

The Hospice and Palliative Nurses Association (HPNA) is the oldest and largest (9,200 members) organization of its kind. Launched in 1986 and expanded to include palliative care in 1998, the mission of the HPNA is to promote "excellence in end-of-life nursing" through the exchange of information, experiences, and research.

The American Academy of Hospice and Palliative Medicine (AAHPM) is an organization geared primarily to physicians, though membership is also open to nurses and other healthcare professionals interested in hospice and palliative medicine.

The Center to Advance Palliative Care (CAPC) is an organization designed to help healthcare professionals establish and maintain their own palliative care center in hospitals and other health settings by providing developmental tools, training, and assistance.
Genres

There are so many written and spoken genres in the field of hospice and palliative nursing (as there are in other disciplines as well) that you might begin to feel overwhelmed. Students in academia write essays, research proposals, research papers, data reports, field notes, to name just a few. Research professionals working in the field author scholarly articles. Floor nurses and home care providers participate in online discussion forums. Administrators compose program reports, staff evaluation reports, and perhaps even newsletters. Everyone uses email.

But what they do not tend to write are brochures, pamphlets, bulletins, pharmaceutical information letters, and so on. In short, nurses are not responsible for producing any of the documents actually distributed to hospice and palliative patients. These genres tend to be developed by other professionals in social work, public relations, pharmaceuticals. This is not to say it is unnecessary for hospice and palliative nurses to be familiar with the contents of these genres. Quite the opposite, really, since the nurse is usually the individual most often fielding questions from patients and families. But in terms of having a hand in the production of these genres, it just does not happen.

Observations of Professionals in the Field

I spoke to four individuals in the process of researching this project: the Director of the BSN program and Professor of Nursing at Malone University, the Clinical Coordinator of Palliative Care at Aultman Hospital, a RN working in the Palliative Care Unit at Akron City Hospital, and a RN working for Summa Hospice.

More than anything, what I learned from these interviews is that most professionals in the field of hospice and palliative care actually write very little. This is ironic since all of them noted how much writing was required of them throughout the course of their undergraduate and graduate studies. They wrote essays, articles, research proposals, reports, brochures, pamphlets, handouts, and so on, yet within their own professional careers, they write emails, field notes, and check boxes on the computer. There seems to be a disconnect between what and how students learn and what they actually need to do their jobs.

Yet interestingly, all four people I spoke with noted the importance of keeping informed of developments in their field through scholarly journals, membership in professional organizations, and conference participation. And all four agreed that for the hospice and palliative care professional the most important skill is not writing. It may not even be a teachable skill. The most important skill is to be empathetic while still maintaining an emotional distance. If we can figure out how to teach that, then we really might be on to something.

Additional Resources

**Growth House, Inc.** is an absolutely wonderful website for those interested in gathering international resources pertaining to end-of-life care. The mission of this award-winning search engine is "to improve the quality of compassionate care for people who are dying through public education and global professional collaboration." More than 19,000 healthcare professionals have opened accounts personal accounts in order to access to "the Internet's most comprehensive collection of reviewed resources for end-of-life care." The website offers dozens of links available on a wide variety of topics as well as professional forums, blogs, featured books (which can be purchased through the website's bookstore), reviews, and newsletters to name just a few of its services.

**palliativedrugs.com** is a free online nursing forum out of the United Kingdom. Commended by the British Medical Association in 2008, this website focuses primarily on drug issues related to palliative care (e.g., interactions, administration, addictions, and so on). Recently, the forum has been expanded to include non-drug issues as well.

**Medscape Nurses** is an excellent general information online resource for nurses regardless of their individual medical field. The site provides a resource center for a diverse array of disciplines, including palliative care, pain management, mental health, and geriatrics. The site also allows access to select articles from over 200 different scholarly journals from around the world. Additionally, there is an "Ask the Expert" section, a current affairs and news section, and blogs.