Integrating Palliative Care into Primary Care

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KEYWORDS

• Primary care • Palliative care • Chronic disease • Symptom management
• Communication

KEY POINTS

- All nurses who provide consistent care are considered primary care providers (PCPs) and should be knowledgeable in the benefits of palliative care (PC) and adept at initiating PC.
- The focus of PC is the management of physical and psychological symptoms and spiritual distress in accordance with a patient's goals of care obtained through effective communication. The holistic care provided by nurses makes PC an integral part of practice.
- Improving access to PC for the nonhospitalized seriously ill would have a positive impact on the present health care system.
- Nurses have an ethical responsibility to advocate for end-of-life (EOL) care and serve as resources for patients and their families.
- PC is not the same as hospice; both are important in the management of serious disease.

PC is specialized care focused on the management of physical, psychosocial, and spiritual needs of patients and families experiencing serious illness. PC is about living and quality of life (QOL); it offers dignity and control. PC can continue until a patient approaches EOL and then transitions to hospice. PC can and should be instituted at any stage of illness and is appropriate concordantly with treatment to prolong life. Patients requiring PC can range from those requiring treatment of cancer to those with multiple chronic diseases. Even if full recovery is anticipated, PC can be appropriate. Currently, hospital-based PC specialists provide the majority of PC.

Because the focus of PC is on the management of physical and psychological symptoms and spiritual distress, PC may be appropriate multiple times throughout the trajectory of a serious illness. It is, therefore, essential that PCPs recognize the benefits of PC and become adept at initiating and providing generalist PC. In addition, PCPs need to be familiar with how and when to refer a patient to a specialist PC provider. Introducing PC in the emergency department (ED), the hospital, or the ICU

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is beneficial but often too late. Patients should not be subject to unmanaged symptoms or unnecessary care because it was never discussed. Inpatient PC should not be the gateway; PC should begin in primary care. PCPs and patients must be cognizant that PC is not synonymous with hospice care, and both are important in the management of serious disease.

PRIMARY CARE PROVIDERS

Primary care in the United States, as defined by the Institute of Medicine, is "the provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community."[1]

Primary care in the United States is the foundation of medical care and ideally the primary point of entry into the health care system. PCPs provide health promotion and preventive care, treat acute and chronic illness, and coordinate specialist care as needed. The goal for a PCP is patient-centered continuity of care that leads to long-standing relationships and effective communication. An established relationship with a PCP should ensure that changes in a patient's condition warrant evolving discussions about the specific impact of treatment and patient goals of care. Professionals caring for individuals who exhibit progression of illness are obligated to discuss prognosis and have a goals-of-care discussion with the development of a care plan reflective of these goals. This is an integral part of providing generalist PC. Research supports that EOL discussions are not associated with increased emotional distress. On the contrary, those who did not have EOL discussions had worse outcomes and their caregivers had increased emotional distress.[2,3] Lack of awareness regarding advance directives (ADs) was cited in a large study that reported only 25% of respondents having an AD.[4] Iterative discussions over multiple visits have shown to improve the completion of ADs.[5] An informed PCP considers the synergistic symptom burden, together with a patient's values and goals, and counsels patients accordingly, resulting in further discussions and shared decision making. Patients should be aware that treatment decisions left to a surrogate may cause significant burden. Additionally, often medical decisions regarding EOL made by a surrogate may be inconsistent with a patient's wishes.[2]

Primary care occurs in multiple settings, including offices, hospitals, outpatient clinics, rehabilitation facilities, long-term care facilities, assisted living facilities, and home care. This article specifically focuses on PCPs; however, all practitioners providing consistent ongoing care (ie, cardiology, nephrology, neurology, pulmonology, and oncology) should be knowledgeable and proficient in generalist PC and be cognizant of where and when to refer patients for specialist PC services.

Based on population growth, the aging population, and expanded health care coverage under the Affordable Care Act, the Association of American Medical Colleges predicts a shortfall of primary care physicians, ranging between 12,500 and 31,000, by 2025.[6] Although the number of primary care physicians is decreasing, the number of primary care trained nurse practitioners (NPs) is on the rise.[7]

The role of the NP is continually evolving, and NPs have the potential to fill the need for PCPs. NP care is safe, effective, timely, equitable, efficient, and patient centered. Literature supports NPs' contributions to high-value primary care.[8] Research by the Kaiser Commission on Medicaid and the Uninsured provides evidence that NPs are more likely to provide care to the uninsured and provide care in underserved areas and to the Medicaid population.[9] This is significant because an increased symptom burden is associated with poverty.[10] NPs' integration of PC is essential to the delivery