

CLINICAL PRACTICE

Timing is everything: When to consult palliative care

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Abstract

Purpose: Consults promote additional perspectives and help with complex patient management. As the population ages and healthcare demands increase, providers are consulting palliative care (PC). Nurse practitioners (NPs) should understand when to consult PC.

Data sources: Information was obtained from an extensive search of the scientific literature to include Pallimed (<http://www.pallimed.org/>) and the author's clinical experience.

Conclusions: Based on the 2009 Clinical Practice Guidelines for Quality PC developed from the Hospice and PC Coalition, PC should be consulted at diagnosis. These findings have also been validated in a landmark randomized controlled trial by Temel et al. (2010). The goals of PC are to alleviate suffering and promote quality of life for people with illnesses. PC accepts and incorporates hospice philosophies, but is distinct.

Implications for practice: Many professional organizations are incorporating PC into their specialties and guidelines. In addition to incorporating PC at diagnosis, PC access needs to be improved. New and experienced NPs may appreciate collaborating with PC specialists. Such conversations and relationships will likely offer practical and supportive guidance to both patients and NPs. Overall, the future for PC is promising.

An increasing number of Americans are being diagnosed with chronic illnesses, including cancer, heart disease, HIV/AIDs, pulmonary disease, and renal disease. Palliative care (PC) strives to alleviate suffering and promote quality of life for people living with such life-limiting and chronic illnesses. By individualizing symptom management, PC is appropriate for patients throughout illness continuums, including cure, remission, control of disease, and end-of-life (EOL) care. Although PC accepts and incorporates the hospice philosophy of care, PC is separate from hospice care (Billings, 1998).

Unfortunately, many healthcare providers are slow to initiate PC consults. These delays contribute to unrelieved symptoms for patients, moral distress for bedside providers, and financial shortfalls for healthcare institutions. The purposes of this article are to: (a) identify the roles and benefits of PC, which include improved symptom management and cost reduction; (b) discuss barriers to PC consults; (c) identify proponents of PC; and (d) improve timely access to PC. This article will detail reasons to initiate PC consults at the time of diagnoses of

life-limiting illnesses, while addressing the roles of nurse practitioners (NPs).

Role of PC: Not just EOL care

PC providers strive to provide control to individuals suffering from life-limiting and chronic illnesses by managing their physical, spiritual, and emotional needs. PC providers expertly manage distressing symptoms for patients with life-limiting illnesses. When appropriate, PC providers facilitate "goals of care" conversations in addition to referring patients to hospice.

Unfortunately, widely held misconceptions of PC exist. Many believe that the main role of PC is to care for those who are at risk of imminent death. While PC providers do care for patients who are imminently dying, PC providers focus on quality-of-life issues that enable patients to live well with dignity and control.

Noting the prevalence of such misconceptions, four national PC organizations formed the Hospice and PC

Coalition in 2007. These organizations include the: (a) Hospice and Palliative Nurses Association; (b) American Academy of Hospice and Palliative Medicine; (c) Center to Advance PC; and (d) National Hospice and PC Organization. A subcommittee of this Coalition, the National Consensus Project for Quality PC (NCP), developed the *Clinical Practice Guidelines for Quality Palliative Care*. Revised in 2009, these guidelines stress the importance of initiating PC at the time of diagnosis of life-limiting and chronic illnesses (<http://www.nationalconsensusproject.org/>).

A landmark study by Temel et al. (2010) evaluated the effects of early PC integrated with standard oncology care versus standard oncology care in 151 newly diagnosed metastatic nonsmall cell lung cancer patients. Five statistically significant results were identified. First, the 77 newly diagnosed patients who received integrated PC at the time of diagnosis had an improved median survival of 2.7 months (11.6 months vs. 8.9 months, $p = .02$). Because patients with metastatic nonsmall cell lung cancer usually live less than 12 months following their diagnoses, such results are considered to be impressive gains against a deadly disease. Second, the integrated patients had improved quality of life as measured by the Functional Assessment of Cancer Therapy-Lung (FACT-L) scale (98.0 vs. 91.5, $p = .03$). Third, the integrated patients had less depressive symptoms (16% vs. 38%, $p = .01$). Fourth, patients within a subsample who received integrated PC were more likely to have their resuscitation preferences documented (28% vs. 53%, $p = .05$). Finally, of the 105 patients who had died at the time of analysis, 33% of the integrated patients received aggressive EOL care versus 54% of the standard care patients ($p = .05$). Although further studies are needed in various populations and settings, improved qualities of life and moods for this challenging patient population deserve acknowledgement.

Benefits of PC

The benefits of PC continue to emerge in professional literature. PC responds to the needs of patients and their families regardless of disease state. Integrated PC services have been shown to decrease the number of palliative patients seen in an emergency department (29% vs. 36%, $p < .001$; Lawson, Burge, McIntyre, Field, & Maxwell, 2009). Also, a case report indicated that a patient undergoing induction chemotherapy for acute myelogenous leukemia derived symptom management benefit from PC (Santamour, 2008).

Early consultation with PC providers facilitates the development of trusting and therapeutic relationships with patients and families. PC providers routinely assess pa-

tients and communicate new and relevant findings to providers treating the patients' diseases. In addition, PC providers help patients and families identify immediate and long-term goals. When appropriate, skilled PC providers may initiate EOL conversations. These conversations are essential to provide quality of life and dignity to those with chronic illnesses (NCP, 2009).

PC may improve patients' symptoms. The MD Anderson Palliative Care Team has published several positive outcomes associated with PC. In one study of 922 hospitalized patients seen by the PC Team (92% in a noncritical care setting), many patients experienced undiagnosed opioid toxicity and delirium prior to PC consultation. Once consulted, the PC Team helped these patients by rotating opioids and adding medications such as laxatives, neuroleptics, and steroids (Dhillon et al., 2008). In a separate retrospective review of consults, the Team provided counseling and spiritual support to family members. The Team facilitated code status conversions for 70% of EOL patients (Delgado-Guay, Parsons, Li, Palmer, & Bruera, 2009). Today, MD Anderson, a premier cancer center, encourages patients to receive simultaneous oncology and PC beginning at the time of their diagnoses (<http://www.mdanderson.org/patient-and-cancer-information/cancer-information/cancer-topics/cancer-treatment/palliative-care/index.html>).

Patient and family satisfaction may be improved with PC. According to Byock (2009), patients concurrently seen in a PC clinic and an oncology clinic demonstrated statistically significant improvements in symptom management and satisfaction with care than those patients solely seen in an oncology clinic. Gelfman, Meier, and Morrison (2008) discovered that PC patients had a statistically significant difference in met emotional and spiritual needs (65% vs. 35%, $p = .004$). In a multicenter, randomized, controlled trial conducted within the Kaiser Permanente system, no survival difference was discovered between the patients who received PC consults and those who continued with usual care without PC consults. However, patients who received an interdisciplinary PC consult were more satisfied with their care and their providers' communication ($p < .001$; Gade et al., 2008).

PC helps actualize patient wishes related to care. According to a literature review by Higginson and Sen-Gupta (2000), more than half of patients with progressing illnesses wanted to die at home. Accordingly, inpatient PC teams may help patients be discharged to their homes from hospitals. Oregon Health and Science University (OHSU) studied 292 patients seen by the inpatient PC team over the course of 1 year. Overall, 63% of patients (183) were discharged alive. More than half of the patients were discharged home. Furthermore, 38%

of discharged patients died within 2 weeks of discharge. More importantly, only 10% of patients seen by the consult service were readmitted within 30 days. Eventually, only 5% of those discharged alive from OHSU died in hospitals. The authors concluded that the small percentage of readmissions and deaths in hospitals were a result of the OHSU PC team's reasonable and effective discharge planning (Fromme et al., 2006).

While not all PC patients are admitted to hospitals and/or assessed as death imminent, PC helps to prepare patients for death. Schapira, Moynihan, von Gunten, and Smith (2009) wrote, "In listening to our patients, we hear their hopes and wishes, their dreams and dilemmas. Patients have taught us they frequently hope to have some control over their time remaining, to minimize the burden of their situations on loved ones, and to preserve their dignity until the very end" (p. 308). Furthermore, Schapira and colleagues (2009) believe that patients enrolled in phase I and II trials may benefit from PC's abilities to manage systems, set goals, and communicate honestly.

Schapira et al. (2009) acknowledged:

Failure to prepare patients for death deprives them and their survivors of meaningful interactions that can never be replaced. Recent research shows quite clearly that talking about imminent death does not lead to despair or depression and allows for appropriate care near the end of life—avoiding futile chemotherapy, intubations, and hospitalizations, and leading to longer enrollment in hospice. Other research also shows clearly that patients who overestimate their prognosis do not live longer, but rather just have more chemotherapy, intubations, and deaths in the hospital. (p. 307)

PC reduces costs

Angus et al. (2004) estimate that 540,000 Americans die after receiving intensive care each year. Yet, terminal intensive care is associated with increased lengths of hospital stays (8.9 vs. 12.9 days) and costs (\$8548 vs. \$24,541; Angus et al., 2004). Studies have demonstrated that the use of PC reduces healthcare costs. In the Kaiser study, PC patients experienced fewer ICU admissions, saving an estimated \$4855 per patient. Subsequently, the Kaiser PC patients were less likely to be readmitted to hospitals. Thus, readmission costs were reduced by \$6854 per patient (Gade et al., 2008). Decreased hospital deaths, decreased admissions to critical care during the last 6 months of life, and decreased total Medicare reimbursements have also been identified in states with multiple PC programs (Goldsmith et al., 2008).

In the largest study of its kind to date, eight American hospitals with mature PC consult programs participated in a retrospective case control study to evaluate costs.

Hospital bills for 4908 patients who received PC consults were compared to hospital bills for 20,550 patients who did not receive PC consults. The researchers concluded that PC consults were associated with a cost reduction of approximately \$1700 per admission for live discharges (\$174 per day) and \$5000 per admission for patients who died in the hospitals (\$374 per day). Although costs remained consistent for both groups for 1–2 days after the consult, costs subsequently decreased for PC patients and increased for usual care patients. The authors calculated that a PC service completing 500 consults annually would save a 400-bed hospital approximately \$1.3 million (Morrison et al., 2008).

Barriers to PC consults

Despite the benefits, PC is not consulted for a variety of reasons. Although PC programs are increasingly being created, many individuals still do not have direct access to PC. Essentially, 80% of for-profit hospitals, 70% of sole community provider hospitals, and 59% of public hospitals lack hospital-based PC programs. Also, residents of Alabama, Mississippi, and Oklahoma have limited access to PC providers and services (Goldsmith et al., 2008).

Assuming PC providers are available, many patients and providers struggle to accept PC when making decisions regarding their illnesses. Some reasons include: (a) lack of conversations regarding patients' statuses and prognoses; (b) challenges associated with rapid transitions from cure to comfort; (c) overwhelming numbers of choices given to terminal patients and their families; (d) confusion between scientific and cultural facts; and (e) lack of appreciation for symbolism for artificial nutrition and resuscitation in EOL situations (Gillick, 2009). Additionally, many providers may perceive PC referrals as personal failure (Duke & Northam, 2009). Notably, many providers and patients have inconsistent trajectories of their chronic illnesses (Fried, O'Leary, Van Ness, & Fraenkel, 2007).

Because PC providers refer patients to hospice and assist other healthcare providers with hospice referral, many providers believe that PC providers only care for "death imminent" patients. Such a belief exists in spite of hospice care likely representing a fraction of all care related to patients' chronic illnesses. Notably, a limited number of providers know that PC manages symptoms for patients with life-limiting illnesses. Some providers have referred to PC as the "death service" for discontinuing treatments. Other providers believe that they provide equivalent PC interventions and thus, do not require PC services (Rodriguez, Barnato, & Arnold, 2007).

In a separate survey conducted at New York Presbyterian Hospital, nonreferring physicians also believed that

all physicians should have expert knowledge in managing symptoms associated with advanced disease (75% vs. 50%, $p < .05$). However, 80% of those surveyed believed that the majority of physicians lacked such expertise. A limited number of physicians claimed to have gained adequate PC knowledge during their training. Although the majority believed that PC should begin earlier in illness continuums, physicians also perceived that patients and families associated PC with hospice care and quitting (Snow et al., 2009).

Proponents of PC

Despite the opposition, many organizations support PC. Because PC has successfully transitioned complex patients to home and decreased readmissions, PC has received national attention from the American Board of Internal Medicine Foundation, the Society of Hospital Medicine, the Centers for Medicare and Medicaid Services, and the Joint Commission. In the near future, two current national research efforts (the Care Transitions Program coordinated by Dr. Coleman of the University of Colorado Hospital and the Transition Care for Elders project coordinated by Dr. Naylor of the University of Pennsylvania School of Nursing) will provide evidence for PC transitions (Meier & Beresford, 2008a). Many supporters of healthcare reform favor improved care coordination (Wennberg, Bronner, Skinner, Fisher, & Goodman, 2009).

Many professional organizations are incorporating PC and EOL into their specialties. In 2003, the American Academy of Family Physicians adopted a policy statement addressing EOL care. In addition, the American Psychological Association adopted a resolution on EOL care and endorsed the Institute of Medicine's EOL work. PC and EOL guidelines related to chronic kidney disease were published in the 2005 *American Nephrology Nurses' Association Nephrology Nursing Standards of Practice and Guidelines for Care* (Haras, 2008). Also, the American Academy of Critical Care Medicine acknowledges that EOL care is emerging as an area of expertise in intensive care (Truog et al., 2008). These efforts are all supported by the American Hospice Foundation Guidelines, which recommend incorporating PC concepts into diagnosis and treatment aspects of diverse medical conditions (Emanuel et al., 2004).

Notably, the oncology community supports early PC consults. Since 1998, the American Society of Clinical Oncology (ASCO) has advocated that, "Cancer care optimizes quality of life throughout the course of an illness through meticulous attention to the myriad physical, spiritual, and psychosocial needs of the patient and family" (Byock, 2009, p. 171). ASCO, the National Cancer

Policy Board, and the National Comprehensive Cancer Network recommend concurrent palliative care for "patients undergoing disease-modifying treatments for advanced cancer" (Byock, 2009, p. 170).

Improving access to PC: The role of NPs

NPs remain committed to the care of vulnerable individuals including the elderly, the poor, nursing home residents, and those living in rural areas. For these patients, PC may not be readily available (Kuebler, 2003). Thus, communication with one of the nation's 4500 hospice programs (NCP, 2009) and/or the use of telemedicine technologies with neighboring PC providers become important links. By consulting with PC providers for assistance with managing complex patients, NPs gain specialty guidance that strives to improve patient care and outcomes.

Today, proactive healthcare institutions conduct reviews to determine appropriate PC patients. By using audit tools that address key elements of PC, many institutions identify patients who may benefit from PC services. Audit elements include assessing and managing symptoms, communicating prognoses, determining goals, supporting patients and families, and planning for discharge (Slaven, Wylie, Fitzgerald, Henderson, & Taylor, 2007). Hospital-based acute care NPs may want to use the Hamilton Chart Audit Tool (confirmatory validation studies needed) to identify inpatients who could benefit from PC consults (Slaven et al., 2007).

The time is now: Weaving PC into NP practice

Novice acute care, family, and pediatric NPs may experience anxiety, disconnectedness, and insecurity (Kelly & Mathews, 2001) because of shrinking appointment times, increased workload, seriously ill patients, and complex family dynamics. If PC consults are initiated as part of a systematic management plan at the time of diagnoses, distress and insecurities related to misunderstandings about PC's role may be decreased. NPs, especially those who are beginning their roles as providers, may appreciate collaborating with PC specialists. Such conversations and relationships will likely offer practical and supportive guidance to both patients and NPs.

Although experienced NPs may consider early PC consults to be unnecessary, nursing education is changing. Historically, PC has not been widely discussed and encouraged. Prior to 2006, PC received limited attention in textbooks. Ferrell and colleagues determined that only 2% of textbook content addressed EOL care (as cited in Paice et al., 2006). Thus, many experienced NPs have likely cared for patients with life-limiting illnesses with

minimal PC knowledge and without the input from PC providers. Today, nurses may refer to the *Oxford Textbook of Palliative Nursing (Third Edition)*. Furthermore, consensus statements, position statements, and standards seek increased quantities of PC and EOL content in nursing curricula. Currently, leading academic programs now teach medical and NP students about PC and EOL issues in their respective programs. Anderson, Williams, Bost, and Barnard (2008) discovered that exposure to death during medical school was associated with positive attitudes and greater knowledge about EOL care. When medical students and NP students learn about PC and EOL care, their attitudes toward PC and EOL improve.

Additionally, experienced NPs may not have benefited from the American Association of Colleges of Nursing's End-of-Life Nursing Education Consortium (ELNEC-Graduate) curriculum in their graduate programs. To date, 300 graduate faculty from 278 graduate programs in all 50 states have attended one of four ELNEC-Graduate courses. These courses have prepared graduate faculty members to readily incorporate PC and EOL concepts into their curricula (<http://www.aacn.nche.edu/ELNEC/Graduate.htm>).

NPs may help their patients by gaining new knowledge about symptom management and PC. Continuing education programs, journal articles, and professional interactions will improve the understanding and incorporation of PC concepts for NPs. Paice et al. (2006) noted that PC professionals are very willing and able to collaborate. PC providers may share techniques for expertly managing patients' symptoms, encouraging conversations about advance care planning, and potential palliative interventions.

A key PC characteristic includes accessing an interdisciplinary team to care for patients and their loved ones. Most PC providers have established relationships with chaplains, pharmacists, social workers, therapists, and volunteers. Based on individual assessments, PC providers will engage interdisciplinary teams. Such teams strive to meet the emotional, psychological, and spiritual needs of patients and their loved ones. By consulting PC, experienced NPs may embrace collaboration with the various members of PC interdisciplinary teams.

When consulted early in the course of chronic illnesses, PC NPs may care for patients and families throughout illness continuums. Such additional professional relationships reduce feelings of abandonment and fragmentation, as well as increase coordinated interventions and services. When appropriate and desired, earlier referrals to hospice may also be initiated (Kuebler, 2003).

Conclusion

At this moment, family members are making EOL decisions nationwide. Because more than 90% of critical care deaths occur because of decisions to withdraw or withhold care (as cited by Wiegand, 2008), American families face the ramifications of their decisions. Families often hope for miracles and improved outcomes; they need time to process the eventuality of their loved ones' chronic and possible terminal conditions. Often, families feel as if they are on a roller coaster given the constant information they receive during the courses of their loved ones' serious illnesses. When appropriate, families need to feel they are ready to consider withdrawal of life-sustaining care (Wiegand, 2008). By consulting PC at the beginning of their loved ones' life-limiting and chronic illnesses, difficult decisions may have been avoided or eased through advance care planning and goals of care conversations.

At this moment, NPs are experiencing practice limitations that negatively impact their patients. Although NPs are authorized Medicare B providers, community NPs are unable to order home care and/or hospice for their patients because of regulatory issues and language associated with Medicare Part A. Presently, Medicare Part A language specifies that physicians (but not NPs) may order home care and/or hospice. Consequently, Medicare patients must see both their NP and a physician colleague to obtain such services. This illogical requirement results in extra costs and inconveniences. Specifically, 14.3% of surveyed NPs who participated in the 2009 American Academy of NP Membership Survey believed that ordering hospice care was difficult (Goolsby, 2009). With support from its members, the American Academy of NPs has been and will continue to press lawmakers to change the language and interpretation to allow NPs to order home care and/or hospice (<http://www.aanp.org/NR/rdonlyres/D6A7DD88-0E75-42D7-9F84-20726A4E68C5/0/FactSheetMedicare-OrderingHomeHealthCare610.pdf>).

At this moment, institutions and individual providers are also deciding how to incorporate the compelling evidence from the 2010 Temel et al. study. Overall, many providers believe that the future for PC is promising. Byock (2009) predicts that "One can imagine future oncology teams that have absorbed components of palliative care, rehabilitative, and survivor services within a seamless, longitudinal patient- and family-centered care process" (p. 171). By initiating a PC consult for patients diagnosed with life-limiting and chronic medical conditions early in their disease courses, NPs will ultimately improve patient-centered care.

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