

ORIGINAL RESEARCH

Early Palliative Care for Oncology Patients: How APRNs Can Take the Lead

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Abstract

Background: Patients with cancer need expert and multidisciplinary care throughout the trajectory of their illness. Palliative care should be instituted early in the course of their disease. Early palliative care enables patients and their families to control physical, psychological, social, and spiritual symptoms of the disease. In our current health-care system, early palliative care is not being integrated due to a lack of education of providers and nurses, an infrastructure that does not support palliative medicine, and poor communication skills among practitioners. **Methods and Results:** The Palliative Care Quiz for Nursing (PCQN) completed by nurse practitioners at a large Midwest cancer center found that those nurse practitioners had a poor understanding of the basic precepts of palliative care. This is consistent with the current literature. **Conclusion:** Advanced practice nurses should be educated on the principles of palliative care, as they are perfectly situated to advance the integration of early palliative care in the oncology setting.

Patients need expert care throughout their disease trajectory (Kain & Eisenhauer, 2016). It is important to maximize the quality of life (QOL) of patients throughout the course of their disease in order to prevent expensive and often futile treatment that can ultimately cause increased suffering. Palliative care (PC) is defined as care that focuses on the expert assessment and management of pain and other symptoms, assessment and support of

caregiver needs, and coordination of care. It attends to the physical, psychological, social, and spiritual consequences of a serious illness. It is a patient- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of their illness. It is appropriate at all stages of illness, from diagnosis until the end of life (EOL), and it should be initiated while aggressive treatment is still being administered (National Consensus Project, 2018).

The National Comprehensive Cancer Network (NCCN), World Health Organization (WHO), and American Society of Clinical Oncology (ASCO) have expressed support for early PC. They recommend that it begins when a chronic or terminal illness is first diagnosed and continue throughout treatment, comfort care, and throughout the EOL (NCCN, 2018; Tan & McMillan, 2019; WHO, 2018a). The literature demonstrates that early PC consultations improve symptoms, QOL, and even disease outcomes for patients with cancer and their families. When PC is initiated early in the treatment process, patients experience less distress and gain more control over the delivery of their care (Vanbutsele et al., 2015).

Palliative care also reduces unnecessary acute hospital admissions and aggressive treatment at EOL, offsetting increased cost in expanding PC programs (Kain & Eisenhauer, 2016). According to WHO (2018b), cancer is the second leading cause of death globally. The economic impact of cancer is significant and continues to increase. The total annual economic cost of cancer in 2010 was estimated to be approximately \$1.16 trillion USD. This, coupled with the fact that relief from physical, psychosocial, and spiritual problems can be achieved in over 90% of advanced patients with cancer through PC, substantiates the need for PC to be offered to all patients with cancer.

Oncology advanced practice registered nurses (APRN) are often responsible for the care of patients with cancer at all stages of their disease, making it vital for them to be well versed in the principles of PC. In order to assess the PC knowledge and comfort level of oncology nurse practitioners at a large Midwest teaching university, a survey was conducted using the Palliative Care Quiz for Nursing (PCQN) as part of a pilot study. The PCQN underscores areas for improvement and where to focus PC education. Barriers to early PC in oncology patients include a lack of education on PC precepts, inadequate infrastructure for PC delivery, and poor provider communication skills (Kaasa et al., 2018). If PC is to be instituted early in the disease trajectory of patients with cancer, these barriers need to be addressed.

REVIEW OF THE LITERATURE

The literature supports the early implementation of PC. The NCCN has established specific stan-

dards for oncology PC. These include screening all patients with cancer for PC needs, ensuring that providers are properly educated in PC, and incorporating PC into all stages of cancer treatment, from diagnosis to EOL (NCCN, 2018). When PC is offered concurrently with aggressive care, there is improved care for patients with cancer and their families in terms of symptom management, QOL, and overall satisfaction, as well as less psychological distress.

Early PC may also improve rates of survival. Temel and colleagues (2010) demonstrated improved survival in patients randomized to early PC (11.6 months) when compared with patients receiving standard treatment (8.9 months). This is an important study demonstrating not only improved QOL but also improved overall survival. The Center to Advance Palliative Care (CAPC) stresses that our nation's focus on the treatment rather than the patient and their family is resulting in unnecessary suffering, costly and futile treatments, and repeat hospitalizations and emergency room visits. Consequently, patients and families are overwhelmed and feel a lack of control over the course of their care (CAPC, 2019). This further leads to unnecessary burdens placed on caregivers as they try to cope with the suffering of their loved ones. Presently, holistic symptom management is often not incorporated into aggressive care and, while the literature advocates for early PC for patients with cancer, this has not yet been translated to clinical oncology practice (Kaasa et al., 2018).

The American Society of Clinical Oncology has established guidelines regarding the integration of PC into cancer treatment. They concluded that PC should be offered in both the inpatient and outpatient settings, and that it should be started early in the disease trajectory, concurrent with active treatment (Tan & McMillan, 2019). Although these guidelines are clear, many oncology providers continue to classify PC as an alternative to active treatment. The belief among providers is that introducing PC is stopping aggressive, curative treatment and relinquishing control of the patient's care (Gomes et al., 2015). Moreover, oncology providers continue to believe that hospice and PC are synonymous despite the evidence otherwise. It is evident that nurses lack appropriate education regarding PC (Autor et al., 2013).

Autor and colleagues (2013) also found that 70% of nurses in their survey did not understand that PC could be introduced during active, aggressive treatment. The literature further suggests that nurses' understanding of the philosophy of PC has not kept up with the 125.8% growth of PC programs (CAPC, 2019). Palliative care education can significantly improve nurses' ability to discuss and advocate for early PC for their patients. Education helps nurses feel more comfortable caring for seriously ill patients, engaging in family meetings, and following the precepts of PC (Harden et al., 2017; Mason et al., 2019).

Early PC in oncology is even more difficult because most providers have had little to no training in discussing prognosis and goals of care (Wong, 2017). Nurses feel ill prepared to care for seriously ill patients and, as a result, often avoid difficult conversations because of their lack of preparation (Brooks et al., 2017). Furthermore, time constraints may prevent early integration of PC. Desai and Schneiderman (2019) warn against avoiding difficult conversations and establishing goals of care due to lack of time. Delaying these important conversations results in patients who are treated too long, leading to prolonged suffering for the patient and family. Patients without established goals of care often lose the ability to direct their treatment and make important decisions at the EOL. Delayed conversations also lead to excessive and futile care, and increase cost to families and society. May and colleagues (2017) found that early PC can decrease hospital length of stay, leading to a 63% reduction in costs. Additionally, establishing goals of care can often help avoid unnecessary testing and pharmaceutical use. When time and valuable resources are spent during a period when little can be done, patients and families are often robbed of the choice to spend time as they would like at the EOL (Desai & Schneiderman, 2019).

Another barrier to early, quality PC is the infrastructure of hospitals and health-care centers. Lack of time and resources contributes to the many obstacles that prevent timely PC. There are few, if any, PC beds in the hospital setting. Additionally, it is difficult to spend the time necessary to discuss goals of care and prognosis when providers work in a high staff-to-patient ratio environment and resources are limited (Earp et al., 2018; Gibbs et al., 2015; Kain & Eisenhauer, 2016; Wong, 2017). In

addition, oncology providers have limited access to PC specialists, and the referral process can be difficult. Roles are often not clearly defined, making multidisciplinary delivery of care challenging. Providers often lack the desire to integrate PC into their practice due to time constraints, as well as the fear of losing control of their patient's care (Earp et al., 2018; Gibbs et al., 2015; Gomes et al., 2015; Wong, 2017). Support staff who focus on the psychological, spiritual, and social needs are often viewed as dispensable when budget cuts are necessitated. The end result is unnecessary suffering, futile and costly interventions, untreated symptoms, repeated hospitalizations and ER visits, and caregivers who are overwhelmed with the care of their loved one, as well as the cost of continued treatment (CAPC, 2019; Kaasa et al., 2018).

Although PC knowledge and the overall infrastructure necessary to offer PC is lacking, the WHO has stressed that the need for PC will continue to grow as a result of the rising burden of noncommunicable disease and the aging population (WHO, 2018a). Yet, there appears to be a growing shortage of PC specialists, and it is projected to worsen in the coming years (Kamal et al., 2017). The NCCN (2018), WHO (2018a), and ASCO (Tan, & McMillan, 2019) all recommend early PC for patients with cancer, necessitating basic PC skills for all providers. As evident in the literature, the lack of education, inadequate PC infrastructure, and poor communication skills are barriers in oncology that need to be addressed in order to promote early PC.

METHODS/OBJECTIVE

Project Design and Sample

This was a preliminary study to assess the PC knowledge gaps of APRNs at a large Midwest teaching university. Thirty-eight nurse practitioners were invited to participate, and there were 15 respondents.

Instruments

The PCQN was used to evaluate PC knowledge. The quiz has 20 true or false questions. A higher percentage correct correlates with greater knowledge. The questions addressed physical, psychological, spiritual, and social needs of PC and EOL patients. The quiz has been used in multiple studies and was found to be both consistent and reli-

able in demonstrating the presence of nursing knowledge in PC. The PCQN has an internal consistency of 0.78 (Ross et al., 1996).

Data Collection

The PCQN survey was sent electronically via Qualtrics. Institutional review board approval was obtained prior to sending surveys. All responses were confidential without identifying data. The survey was voluntary, and completing the survey implied consent.

RESULTS

While 93% of respondents understood that PC is appropriate for all seriously ill patients, only 38% understood that PC and aggressive treatment can be offered simultaneously. Most of the respondents had a good grasp of symptom management, but there was room for improvement, especially regarding dyspnea, sedation, anxiety, and the use of placebos. Unfortunately, the sur-

vey found that 100% of respondents felt that the extent of disease should determine pain management (Table 1).

Limitations

The sample size was small, and all participants were from one setting. The setting was a cancer center that is part of a major teaching university. All of these factors make it difficult to extrapolate the results to the general population. The purpose of the study was to identify the needs of a particular group of nurse practitioners. Future research should include a larger, more diverse sample.

DISCUSSION

The findings from this small sample are similar to other studies that demonstrated a lack of understanding of the principles of PC among oncology providers (CAPC, 2019, Kaasa et al., 2018; Wong, 2017). The misconception that PC and aggressive treatment cannot be offered together is prevalent

Table 1. Responses to Palliative Care Quiz for Nursing

Question	True	False	Question	True	False
Q1. Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration.	1	14	Q11. Men generally reconcile their grief more quickly than women.	1	10
Q2. Morphine is the standard used to compare the analgesic effect of other opioids.	11	4	Q12. The philosophy of palliative care is compatible with that of aggressive treatment.	5	8
Q3. The extent of the disease determines the method of managing pain.	0	15	Q13. The use of placebos is appropriate in the treatment of some types of pain.	3	9
Q4. Adjuvant therapies are important in managing pain.	14	1	Q14. In high doses, codeine causes more nausea and vomiting than morphine.	13	0
Q5. It is crucial for family members to remain at the bedside until death occurs.	0	15	Q15. Suffering and physical pain are synonymous.	1	14
Q6. During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation.	8	6	Q16. Demerol is not an effective analgesic in the control of chronic pain.	11	1
Q7. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.	1	14	Q17. The accumulation of losses renders burnout inevitable for those who seek work in palliative care.	5	9
Q8. Individuals who are taking opioids should also follow a bowel regimen.	15	0	Q18. Manifestations of chronic pain are different from those of acute pain.	14	1
Q9. The provision of palliative care requires emotional detachment.	0	15	Q19. The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.	1	13
Q10. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.	12	2	Q20. The pain threshold is lowered by anxiety or fatigue.	5	9

Note. Bold indicates correct answer.

in most health-care providers, as well as patients and their families, and is a major barrier to early initiation of PC (Autor et al., 2013; Gibbs et al., 2015; Gomes et al., 2015; Kain & Eisenhauer, 2016; Wong, 2017). Providers, patients, and family members need education regarding the benefits of PC. While providers specially trained in PC should be available to patients with cancer, all oncology providers need to be competent in offering basic PC to assure that early PC is provided to every patient. The survey completed in this study demonstrated a lack of knowledge regarding the importance of early PC during the early stages of cancer. It also highlighted a need for more education in the areas of symptom management, psychological and social assessment, and care. The majority of respondents do not completely understand the precepts of PC and are not prepared to offer basic PC services to their oncology patients.

The PCQN is a validated tool that is easy to administer. It can be used to identify knowledge deficits and common misconceptions held by advanced practitioners regarding PC. Educational material specific to the needs of providers can be developed using the results of the survey. Practitioners can also use this tool to stimulate discussion and promote PC principles among their colleagues (Ross et al., 1996).

APRNs are perfectly situated to help facilitate this initiative. Nurses often develop strong relationships with their patients and families. Their day-to-day care increases their awareness of family dynamics, patient values, and EOL wishes (Kirby et al., 2014). Because of the role they play in their patients' care and lives, as well as the fact that holistic and compassionate care is at the core of nursing practice, nurses should take a lead role in palliative and EOL care. APRNs should be competent in providing basic PC to their patients. Specifically, oncology APRNs should have specialized skills in this area. These should include knowledge regarding pain and symptom management, communication, advance care planning, and shared decision-making. They should be able to provide psychosocial and emotional support while also attending to their patients' cultural and spiritual needs (Dahlin, 2015). Oncology APRNs also need to understand the importance of caregiver support (Kaasa et al., 2018).

While all APRNs in oncology do not need to be specialists in PC, they do need to possess the skills necessary to provide basic PC to all of their patients while making appropriate and timely referrals to a specialist when needed. In order to facilitate this, standardized care pathways can help APRNs attend to the holistic needs of their patients. Furthermore, education in PC should be required of all new employees. The End-of-Life Nursing Education Consortium (2019) has graduate-level modules in PC for nurses. These modules can be incorporated into the orientation process. Continued use of the modules and lunchtime lectures can be offered throughout the year. Palliative care content should be included in yearly mandatory updates, alongside basic cardiac life support, fire, and safety certifications. Additionally, nursing school curriculums should guarantee that PC is interwoven throughout the programs, ensuring that all graduating nurse practitioners have a firm understanding of the precepts of PC.

While addressing knowledge and comfort with PC precepts is important, a culture that centers on treatment at the expense of patient-centered care will continue to prevent early PC initiatives. Our nation's focus is on treating disease with an emphasis on cure, while the holistic needs of the patient and the family are secondary. In order to improve the infrastructure of oncology care, the assessment and referral process to PC needs to be easy, valued, and mandatory. A systematic symptom assessment and standardized care pathway need to be established and utilized in the oncology setting. Flaherty and colleagues (2018) developed a 10-question Palliative Assessment Screening Tool (PAST), which was used by staff nurses during the admission or transfer assessment of patients. The tool was purposely composed of a limited number of questions so that it would be fast and easy to complete. In practice, if any of the questions are answered yes, the nurse will request an interprofessional review of that patient's chart. They found that this tool helped nurses identify PC needs earlier and begin timely completion of advance directives. The PAST was developed into an electronic tool that was embedded into the organization's documentation system, making it easy to access and complete.

Quick and easy assessment tools are necessary in order for providers to be able to complete them with their present workload. According to Earp and colleagues (2018), oncology clinicians claim that the lack of opportunity is the greatest impediment to delivering early, systematic, oncology-integrated PC to more patients. They identified their own lack of time (attributable to high staff-to-patient ratios and competing work priorities), as well as a lack of proper facilities and access to specialized PC staff or services, as deterrents to early PC. The three most frequently cited barriers were all opportunity influenced.

The literature highlights the need to allow providers time and support to assess and address the PC needs of their patients. To do so, we need to shift from illness-focused care to care that values the patient, their goals of care, and their QOL. Interventions to address opportunity-related barriers include enablement, environmental restructuring, and restriction. Enablement includes making sure all providers understand their roles and responsibilities regarding PC. Examples of environmental interventions that make referrals quick and easy include ensuring there are easy-to-administer assessment tools, symptom management pathways, and electronic health record prompts. Guaranteeing easy access to specialized PC in both the inpatient and outpatient settings would also fall under environmental interventions. Implementing PC guidelines can help increase the desired behaviors while subsequently restricting the opportunity to engage in behaviors that are undesirable.

Multidisciplinary teams are a key aspect of PC and need to be adequately funded (Kaasa et al., 2018). Oncology APRNs should have easy access to an interprofessional team so that they can

offer holistic assessment and care to all their patients. The infrastructure needs to embrace PC and invest in educating and training specialists to support APRNs when PC needs become more complex (Kain & Eisenhauer, 2016). This needs to occur at both the national and local level. Oncology APRNs need to take an active role in advocating for changes that support early PC for their patients (Table 2).

IMPLICATIONS FOR PRACTICE

Early PC involves excellent symptom management and attention to the holistic needs of the patient and their family. This is something every oncology APRN should feel comfortable providing and taking the lead on to ensure early PC for all of their patients. This can be done through education and use of validated tools such as PCQN and PAST. The End-of-Life Nursing Education Consortium (2019) offers train-the-trainer programs that are often free of charge. APRNs who complete these courses can take the lead in educating their colleagues. Surveys such as the PCQN can be used at any institution to identify knowledge deficits and misconceptions regarding PC and direct educational content. Tools are necessary to improve and simplify the assessment and referral process. Tools such as PAST and electronic medical record prompts can be used to identify PC needs early, thus leading to earlier interventions. Ultimately, a change in culture from an illness focus to a patient-centered focus will help improve funding for and direct nursing education in PC. The literature supports the benefits, both financial and in patient outcomes, and APRNs can present this information to administrators, offering concrete steps on how to make PC an integral part of oncology care.

Table 2. Strategies for Integrating Early Palliative Care

Education	Infrastructure	Culture
Required palliative care education for all new employees (ELNEC)	Make assessment and referrals easy, valued, and mandatory	Incorporate palliative care into nursing school curriculums
Lunchtime lectures	Provide adequate funding for multidisciplinary teams	Shift from illness-focused care to patient-focused care
Mandatories	Create standardized care pathways	Invest in education and training at the national and local levels
Ensure all providers have basic palliative care skills	Utilize electronic health record prompts	

Note. ELNEC = End-of-Life Nursing Education Consortium.

CONCLUSION

Early PC services for patients with advanced cancer needs to begin in the outpatient setting. For this to occur, particularly given the sparsity of PC providers, we should expect that all oncology providers understand the principles of PC and are comfortable in providing basic PC. All providers should feel comfortable initiating discussions regarding prognosis and goals of care. Although this specific survey was completed by a small sample, the results are consistent with the literature and clearly demonstrate the need for oncology APRNs to take a lead in making early PC available to all oncology patients. An important role of all nurses is patient advocacy, and making sure early PC is possible is an important way to ensure that all patients with cancer receive the holistic and compassionate care they deserve. ●

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