Predictions for exponential growth in the incidence and prevalence of cancer will present a significant challenge to the healthcare system. Most of this care will be provided in the outpatient setting. Although inpatient palliative care programs are well established, this is not the case for outpatient palliative care: only 22% to 59% of outpatient cancer centers report a palliative care program, which are usually small in scope. However, development and growth of outpatient palliative care programs are an essential component to providing excellence in cancer care and will be necessary to address the many new cases of advanced cancer anticipated in the next decades. This article reviews current trends in outpatient palliative care in the oncology setting, with a discussion of selected major studies, methods and challenges in the provision of care, and the impact of nurses in this emerging field.

**KEY WORDS**
advanced practice nursing, cancer care facility, oncologic nursing, oncology, outpatients, palliative care

Palliative care (PC) consultation services have become well established in the inpatient setting, with 92% of National Cancer Institute (NCI)–designated cancer centers reporting inpatient PC services. However, PC programs in the outpatient (OP) setting are much less common, with 59% of NCI cancer centers and 22% of non-NCI cancer centers reporting OP PC programs, and these services are generally small in scope.\(^1\)\(^-\)\(^3\)

The American Society of Clinical Oncology (ASCO) recommends increased integration of PC into the oncology setting in order to achieve high-quality comprehensive cancer care by 2020.\(^4\) Because a significant proportion of cancer care is given in the OP setting, extensive development of OP PC programs is needed to meet the growing demand. In an article titled “Outpatient Clinics Are a New Frontier for Palliative Care,” Meier and Beresford\(^5\) describe this field as an essential link in the continuity of care with inpatient PC services. By providing this link, OP PC in oncology may prevent or shorten hospitalizations, improve quality of life (QOL) and mood, and prolong life.\(^5\)\(^-\)\(^6\)

This article explores the current status of PC in the OP oncology setting in North America, including structure of care, focus of visits, and other service issues. Opportunities and challenges for future development are discussed, as well as the role of the nurse and advanced practice RN (APRN) in the provision of PC in cancer care.

**Contextual Setting**
The American Cancer Society anticipates that the number of persons with newly diagnosed cancer will double to 2.6 million by 2050.\(^7\) Although survival trends are increasing, half of those diagnosed with cancer still succumb to the disease, with a current estimate of 1500 American deaths per day from cancer.\(^7\) A 2004 analysis of Medicare data from 28 777 cancer patients showed that care in the last year of life was becoming increasingly aggressive. Aggressive care was defined as receiving chemotherapy in the last 2 weeks of life, more than one emergency department (ED) visit in the last month of life, admission to the ICU in the last month of life, or late hospice enrollment.\(^8\) Using similar criteria, a 2012 random sample of 390 deaths over 4 years at a community cancer center found little improvement in these benchmarks at end of life.\(^9\) Recently, the Dartmouth Atlas of Health Care analysis of Medicare data again showed both high-intensity care in the last few weeks of life, along with significant variations in resource utilization and spending throughout the US in the last 2 years of life.\(^10\) These concerning findings may be mitigated by the addition of PC services in the OP setting.\(^5\)

**Pivotal Studies**
Published literature describing PC in the OP cancer setting is limited, but several articles are recognized as pivotal to the field.\(^11\)\(^-\)\(^16\)
**Temel et al (2010)**

Most notable is the study of Temel et al⁶ that examined the effect of initiating early PC for patients with newly diagnosed metastatic non–small cell lung cancer (NSCLC). In this nonblinded randomized controlled trial, 151 patients were randomized to receive either standard care (n = 74) or standard care plus PC embedded in the oncology practice (n = 77). The PC team consisted of six palliative medicine physicians and one nurse practitioner that focused on symptom management, psychosocial needs, goals of care, and treatment decisions. The results demonstrated that patients in the early PC arm reported better QOL and fewer depressive symptoms and lived 30% longer than did the control arm (11.6 vs 8.9 months), despite less aggressive end-of-life (EOL) care. Aggressive EOL care was defined as chemotherapy within 14 days of death, no hospice care, or admission to hospice 3 days or less prior to death (33% early PC group vs 54% control group). A secondary analysis found that those who were randomized to receive early PC had half the odds of receiving intravenous chemotherapy in the last 2 months of life and a higher incidence of hospice enrollment for more than 1 week, resulting in improved QOL at EOL.¹⁷ The benefits noted in this groundbreaking study have important repercussions for increased participation of PC in the OP setting.

**Bakitas et al (2009)**

An important nurse-led study of PC in the OP cancer setting is the Project ENABLE II (Educate, Nurture, Advise, Before Life Ends).¹³ Three hundred twenty-two subjects with recently diagnosed advanced cancer were randomized to receive usual care or the PC intervention. Led by two APNs, the intervention involved four structured psychoeducational sessions followed by monthly telephone calls. The educational sessions focused on patient activation, self-management, and empowerment for self-advocacy with training in communication with the oncologist. Results showed improved scores for QOL and mood in the intervention group compared with the usual group, but failed to show differences in symptom intensity scores compared with the control arm, which may have been due to relatively low symptom burdens in the groups.¹⁸ In addition, no differences were found in hospital or ICU days or ED visits. However, this study showed the impact of the APRN in education and empowerment of the cancer patient and the benefit of PC toward improved mood and QOL.

**Prince-Paul et al (2010)**

In a pilot study, an APRN was integrated into a community oncology setting to provide PC consultative services to adult patients with advanced cancer.¹⁴ Patients received either usual care (n = 52) or PC in addition to usual care (n = 49) and were then followed up for 5 months. The APRN worked in a collaborative fashion, with oncologists providing pain and symptom control, education on medication adverse effects, psychosocial-spiritual support, and discussions related to EOL preparation. Patients in the PC arm experienced significantly lower mortality rate at 4 months and were 84% less likely to be hospitalized. More than 77% of the subjects were receiving chemotherapy during the study period. The authors emphasize that PC services can be effectively provided to patients receiving chemotherapy by using a collaborative model between oncology and PC. By combining these specialties, more comprehensive and individualized care can be provided, with the benefit of better symptom control and smoother transition toward EOL care.

**Muir et al (2010)**

Set in a private OP oncology practice, the Comprehensive Advanced Care PC team was embedded in the cancer clinic. This study focused on quality care outcomes, provider satisfaction, volume of consultations, and the time saved by the oncologist by the PC service.¹⁵ Palliative care consultation was associated with a 21% reduction in symptom burden and improved oncologist satisfaction. In addition, PC consults saved the practice an estimated 162 hours in the second year or an average of 170 minutes of oncologist time for each new referral seen by the PC service. The authors noted that embedding PC in the oncology team resulted in earlier PC referrals and enhanced the overall effectiveness of the care more favorably than would individual services alone.

These studies illuminate key findings of the essential contribution of PC toward improving QOL and mood without shortening life span.⁶,¹³,¹⁴ In addition, data support patients’ willingness to talk about advanced disease issues and desire to make appropriate preparations for their eventual death.¹²

**Provision of PC in the Outpatient Cancer Setting**

A wide variety of models exist for OP PC programs. However, they are generally small, with 500 patient visits annually.⁵ They are typically affiliated with cancer centers, often in close proximity to the oncology clinic. Clinic availability ranges from one-half day per week up to 5 full days weekly.⁵ Although clinical practice guidelines for PC exist,¹⁹ there is no evidence to support what OP infrastructure is best for the patients with advanced illness and their families.¹¹,²⁰,²¹ Several questions related to the most optimal delivery of PC in the OP setting remain.

**How Are Patient Referrals Determined?**

Inpatient PC programs are increasingly utilizing referral criteria algorithms as a means of identifying patients most in need of a specialty-level consultation.²² In this approach, a consideration for PC consultation is initiated based on variables such as disease (metastatic cancer), patient (severe
pain), or family (difficulty coping). However, few OP PC centers have adopted this process. Algorithms for automatic PC referrals will likely become utilized more frequently as demand grows for a finite number of OP PC services. Indeed, ASCO issued a Provisional Clinical Opinion recommending that patients with metastatic NSCLC be offered concurrent PC along with standard oncologic care at initial diagnosis based on the study findings of Temel et al. Other examples of criteria for triggering a PC referral in the OP setting are shown in Table 1.

Rabow et al surveyed 12 leading OP PC centers in the US. These centers primarily saw cancer patients. Most of the referrals (76%) were initiated by the oncologist, with 23% from the inpatient PC service. Proximity to the oncology clinic resulted in a significantly higher referral rate, with an 85% increase in referrals after moving to an integrated practice. Glare et al evaluated the feasibility of a PC screening tool in a gastrointestinal oncology clinic using National Comprehensive Cancer Network (NCCN) PC guidelines. A one-page tool was developed, with points assigned for performance status; the presence of metastatic disease, complications, or serious comorbid diseases; and PC problems including symptoms, distress, psychosocial concerns, or complex decision making. During a 3-week period, the clinic nurse screened 119 with cancer. Depending on the specific criteria used on the screening tool, 7% to 17% of patients would be eligible for a PC consultation using the NCCN guidelines. The authors concluded that prepopulating the instrument from the electronic health record and refining the tool to five items would capture all of those needing PC referral. Use of this PC screening tool was recommended at the initial visit, after hospitalization or other change in medical status, and every 6 months.

Who Provides the Care?
An interdisciplinary team is the most common approach to the delivery of PC in the OP oncology setting. In a survey of 71 NCI facilities and 71 non-NCI facilities, Hui et al reported the composition of most PC teams includes physicians (80%), physician assistants (71%), social workers (55%), nurses (47%), and other health professionals (<50%). This survey included data from both inpatient and OP PC, but did not differentiate between them. In a survey of 351 California acute-care hospitals, 27 (8%) reported the provision of OP PC services. At 20 reporting sites, the OP staff was divided to RN (0.9 full-time equivalent [FTE]), APRN (0.7 FTE), social work (0.8 FTE), and physician (0.3 FTE). The survey of 11 leading OP PC programs by Rabow et al report similar findings, staffed by the following disciplines: RN (1.6 FTE), APRN (0.9 FTE), social work (0.7 FTE), and physician (0.6 FTE). Other team members may include nutrition, chaplaincy, rehabilitation medicine, pharmacy, psychiatric nurse counselor, physical therapist, occupational therapist, speech therapist, and wound care nurse. Bookbinder et al reported that inclusion of a social worker in their study resulted in 100% completion of advance directives and was essential for providing psychosocial support and improving access to social services.

What Is the Structure of Care Given?
There is a great deal of heterogeneity in the delivery of OP PC services. However, three primary models exist: consultation, collaborative care, and primary PC.

In the consultation model, patients are evaluated, and recommendations are provided for management of the problems identified during the visit. Suggestions to the medication regimen are offered, but the PC team does not write prescriptions. The PC team may or may not offer ongoing follow-up visits for patients. Unfortunately, Rabow et al found that the consultation PC model resulted in a low percentage of their recommendations being followed. Their model utilized a social worker, who assessed the patient and consulted with the PC physician about the case. Recommendations were developed and forwarded to the

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**TABLE 1 Sample Criteria for Palliative Care (PC) Consultation in the Outpatient Cancer Center**

<table>
<thead>
<tr>
<th>(1) Diagnosis specific</th>
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<tbody>
<tr>
<td>a) The “surprise question” (“Would you be surprised if this patient died within 1 year?” If not, PC consultation is indicated.)</td>
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<tr>
<td>b) Presence of advanced or metastatic malignancy or findings consistent with advanced disease, such as malignant pleural effusion</td>
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<tr>
<td>c) Diagnosis of a highly fatal malignancy, such as pancreas or esophageal cancer</td>
</tr>
<tr>
<td>d) Refractory hematological malignancies (eg, elderly patients with acute myeloid leukemia)</td>
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<tr>
<td>e) Undergoing high-risk stem cell transplant</td>
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<table>
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<th>(2) Patient specific</th>
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<tbody>
<tr>
<td>a) Uncontrolled symptoms (severe pain, nausea)</td>
</tr>
<tr>
<td>b) Poor performance status (Eastern Cooperative Oncology Group score of 3 or 4; Palliative Performance Scale score ≤50)</td>
</tr>
<tr>
<td>c) Frequent hospitalizations</td>
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<table>
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<tr>
<th>(3) Patient/family/caregiver specific</th>
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</thead>
<tbody>
<tr>
<td>a) High levels of emotional, spiritual, or psychological distress</td>
</tr>
<tr>
<td>b) Difficulty coping</td>
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<tr>
<td>c) Request PC services</td>
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</table>
primary care provider in a letter from the PC physician. Data indicated that PC suggestions for medication changes to improve pain and depression were rarely instituted. The authors’ conclusions suggested incorporating PC services earlier and using a more direct approach for management of PC issues, including managing PC-related prescriptions.

The collaborative care model is the most popular. Also known as the integrated, embedded, or concurrent PC model, the PC team takes the lead in managing certain aspects of care, such as symptom management, whereas the oncologist focuses on disease-modifying therapy. Regular communication with the oncology team is essential to provide coordination of care, give consistent messages to patients, and avoid redundancy. Several authors report that this approach leads to the best outcomes. However, these models are not uniform, and services vary widely by site.

Despite complex logistical and communication issues, this model is feasible and results in oncologist satisfaction. In the primary PC model, the PC service takes over all aspects of care, with the APRN, physician assistant, or physician functioning as the patient’s primary care provider. Care includes diagnosis, management, and prescriptions for an array of health issues, including the life-limiting disease. This model is not well described in the oncology setting, but may be favored by patients who wish to decline antineoplastic therapy yet are not eligible for, or are not interested in, hospice enrollment. Care may be provided in the cancer center, a separate OP clinic, or in the home.

What Is the Focus and Length of the PC Visit?

Descriptions of the focus and length of PC visits vary in the literature depending on the referring oncologist, the oncology clinic setting, and the PC providers available to see the patient. In addition, the focus of a clinical research encounter will differ depending on the purpose of the investigation. Von Roenn and Temel describe five domains of care to focus PC visits: physical symptoms, spiritual care, assistance with practical needs, EOL care, and support for decision making.

In a companion article to the study of Temel et al, Jacobsen et al described specific components of visits with metastatic NSCLC patients receiving early OP PC. Documentation was analyzed for interactions by seven PC clinicians in visits with 67 patients. The median total time spent with patients at the initial consultation visit was 55 minutes (range, 20-120 minutes). The individual components of the visit were analyzed and showed that the greatest time was spent in symptom management at the initial visit: symptom management (median time, 20 minutes; range, 0-75 minutes), patient and family coping (median time, 15 minutes; range, 0-78 minutes), and patient education and illness understanding (median time, 10 minutes; range, 0-35 minutes). Notably, lower QOL scores, as measured by Functional Assessment of Cancer Therapy–General (FACT-G) scale, predicted longer visits.

In another study, initial appointments were scheduled for 90 minutes, for a combined nurse practitioner and social worker visit. Similarly, a Canadian study found that initial visits took 90 to 120 minutes for a combined nurse-physician visit. These reports confirm that the provision of a PC encounter takes time, especially when multiple distressing issues are present. Not addressed in these reports is the amount of time needed to facilitate coordination of care with the oncology team. Concurrent practices should make communication with the oncologist easier, but each visit may require a 5- to 15-minute previsit and postvisit discussion, depending on complexity of the issues.

What Assessment Measures Are Used in Clinical Practice?

Common measures used in the OP PC setting are listed in Table 2. The National Palliative Care Research Center references many of these tools on their Web site. Formal assessment tools should be considered, even in the clinical nonresearch setting, as use of a systematic assessment tool results in a 10-fold increase in reported symptoms, compared with open-ended questioning.

Challenges Related to Service Viability and Integration

Although it is clear that PC offers significant benefits in the OP oncology setting, important barriers continue to exist. In a survey of 89 cancer center executives, the two major barriers identified when instituting PC included poor reimbursement and limited institutional resources. Reimbursement for services is a key concern for the viability of OP PC programs and will be further discussed below. Additional challenges related to OP PC service viability are identified in Table 3.

Funding Issues

By its nature, providing PC services is a time-intensive endeavor and involves significant personnel costs. Funding sources in the OP PC setting are reported as billing of third-party payers (49%), institutional support (45%), and philanthropy (6%). In 1996, a V-code modifier for PC, V66.7, was created. However, this is an unreimbursed secondary code, rather than a primary diagnosis-related group billing code.

Use of an APRN appears to provide cost savings due to lower salaries compared with physicians. However, Bookbinder et al found that APRN billing revenue alone was not sustainable in the long term, especially as APRNs are reimbursed by the Centers for Medicare & Medicaid Services at 85% of the physician-billing rate. In addition, there was an inability to bill for extensive use of telephonic support for management of symptoms and distress, as these are not “allowable charges.”

Thus, it appears problematic to expect OP PC to be a self-sustaining program based on third-party reimbursement.
alone; facility or philanthropic support is required for ongoing fiscal success. Indeed, PC services could potentially lead to increased costs for an institution, which may or may not be recovered through decreased frequency of ED visits or hospitalization in a standard fee-for-service environment.25 However, in the managed care setting, OP PC services may be found to be more fiscally advantageous. The Center to Advance Palliative Care Web site offers detailed information on billing tools and financing of PC programs, especially in the inpatient setting.16 Seeking external community resources may be a method to grow and sustain the PC program but requires time and expertise for success.

Future Research and Trends
Outpatient PC is indeed “the new frontier.”5 Study results in the last few years have shown a significant role for OP PC in the oncology setting. In order to provide better care to those with a diagnosis of advanced cancer and to optimize resource utilization, PC involvement needs to be moved

<table>
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<tr>
<th>TABLE 2 Common Instruments Used to Gather Data in Outpatient Palliative Care13,14,31</th>
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<td>(1) Functional Scales</td>
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<td>(a) ECOG Performance Status33</td>
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<tr>
<td>(b) Karnofsky Performance Scale34</td>
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<td>(c) Palliative Performance Scale35</td>
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<tr>
<td>(d) Scales used primarily in research include the FACT-G36 and the FACIT-Pal38 and FACIT-Pal-Palliative, such as the FACT-L31 and FACIT-Pal-Palliative.</td>
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<tr>
<td>(2) Global symptom scales</td>
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<td>(a) Edmonton Symptom Assessment Scale39</td>
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<td>(b) Memorial Symptom Assessment Scale–Short Form40</td>
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<td>(3) Pain scales</td>
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<td>(a) BPI and BPI Short Form41</td>
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<td>(b) McGill Pain Questionnaire short-form and long-form42</td>
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<td>(a) Distress Thermometer43</td>
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<td>(b) Patient Health Questionnaire44</td>
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<td>(c) Profile of Mood States45</td>
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<td>(a) FICA47</td>
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<td>(b) FACIT-Spiritual Well-being48</td>
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<td>(6) Quality of life</td>
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<tr>
<td>(a) McGill Quality of Life Scale49</td>
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<tr>
<td>(b) Quality of Life at the End of Life–Cancer50</td>
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</table>

“upstream.” The National Consensus Project for Quality Palliative Care recommends referral to PC at the time of a life-threatening diagnosis. What may seem to be “early” PC referrals, may in fact be “just right”: oncologists tend to overestimate prognosis by a factor of three or more. Earlier PC intervention can reduce “overaggressive” and inappropriate treatment in very advanced cancers, improve QOL, and allow for more dignified and peaceful final days. As the field continues to grow and develop, several research questions will emerge that may have the capacity to influence clinical practice and guide quality care. These are highlighted in Table 4.

### Emerging Trends in Refining the Role of the APRN and Nurse in PC

Several studies have demonstrated the emerging role of the APRN in OP PC setting. Staffing data indicate that nurses and APRNs together provide the majority of OP PC services. Nurses receive extensive education in communication skills and psychosocial-spiritual assessment. In fact, Dahlin et al suggest that patients may feel more relaxed and informal with a palliative nurse, compared with a palliative physician, which may result in an improved ability to voice deeply held concerns.

Advanced practice RNS are especially well suited to this setting, as their educational background combines the holistic approach of nursing with medicine’s systems model. The ASCO anticipates a workforce shortage of oncologists and other health professions by 2020 that will create a substantial challenge to ensuring access for all patients with cancer. The APRN role thus emerges as a strategic option for providing PC in the OP cancer setting.

### Interprofessional Education and Training

The Institute of Medicine (IOM) has called for improving palliative and EOL care for patients with cancer. This must be accomplished through an integrated, skilled, and interprofessional work force. Most recently, the IOM report, The Future of Nursing: Leading Change, Advancing Health, released four key messages that aim to address the objectives set forth in the 2010 Accountable Care Act. They include the following: (1) nurses should practice to the full extent of their education and training; (2) nurses should achieve higher levels of education and training through an improved education system that promotes seamless academic progression; (3) nurses should be full partners, with physicians and other health professionals, in redesigning healthcare in the US; and (4) effective workforce planning and policy making require better data collection and information infrastructure. These recommendations reflect the key role nurses play in the delivery of PC services. Development and promotion of palliative nurse leaders are needed as this field expands in response to the anticipated increase in new cancer cases over the next decades. The interdisciplinary approach to care utilized in palliative services will be enhanced by opportunities to comingle with other medical disciplines during training. Such opportunities will increase both the understanding and respect for what each discipline can offer in the delivery of high-quality cancer care.

### CONCLUSION

The vital role of OP PC in the provision of comprehensive cancer care is increasingly acknowledged. Yet, questions remain regarding the best model for care delivery, how to secure stable funding sources, and how to encourage acceptance of PC participation by the patient, caregiver, and...
oncologist. With the majority of cancer care given in the OP setting, there is a critical need for growth of OP PC programs. Additionally, the rapid development of inpatient PC services nationwide will inevitably result in a more OP consults as patients are discharged home and followed in the OP clinic. Research has shown that PC and oncology are no longer mutually exclusive domains; instead, a collaborative model can provide optimal care and save oncologists’ time. Palliative care nurses and APRNs are strategically situated to provide a significant proportion of OP PC services. Ongoing education in management of advanced illness is essential for nurses and other healthcare providers to meet the anticipated future growth in the total number of cancer cases.

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