

Primary Palliative Care for Every Nurse Practitioner

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Abstract

The ability to provide primary palliative care is a skill set that nurse practitioners should **acquire, develop, and refine**. The relief of suffering—physical, emotional, and spiritual—leads to improved patient outcomes and higher patient satisfaction. Primary palliative care skills include **thorough and effective symptom assessment and management, initiating and guiding conversations around advance care planning**, and completing medical directives that guide care with life-limiting/life-threatening illness. In this study, multiple online resources are identified to provide easy access to learning opportunities and reference material to build skills.

Introduction

Palliative care is defined by the World Health Organization as "**early** identification and **impeccable** assessment and treatment of pain and other problems, physical, psychosocial and spiritual."^[1] The Center to Advance Palliative Care has a broader definition to include improving quality of life for both the patient and the family.^[2] **Palliative care is not limited to symptom management; it also includes discussion about goals of care and advance care planning**.^[3,4] In this article, primary palliative care skills focus on symptom management and advance care planning to include goals-of-care discussions.

Nurse practitioners (NPs) in all fields care for people with serious or potentially life-threatening illness. With the stated aim of palliative care to prevent and relieve suffering, NPs have an opportunity to offer primary palliative care in all practice settings. Palliative care is provided along with curative and disease-modifying therapies; it should be available at any stage of a serious illness.^[3,5–7] Screening tools exist to help identify patients who need palliative care.^[8] Triggers for primary palliative care include distress in the physical, emotional, or spiritual domains. The **"surprise" question is also a useful screen tool**: Would you be surprised if this patient died in the next year? If the answer is no, then palliative care should be considered.^[9]

Palliative care can be divided into primary, secondary, and tertiary levels. Tertiary palliative care is available at academic medical centers with specialist knowledge and research moving the field forward, caring for the most complex cases. **Secondary palliative care** is provided by clinicians offering consultation and specialist care and also for difficult and complex cases. **Primary palliative care involves using basic palliative care skills and should be practiced by all NPs**.^[10] The purpose of this article is to present the idea that primary palliative care is a part of every NP's practice, and to introduce the skills that comprise primary palliative care. Resources are identified that provide learning opportunities that build skill in primary palliative care.

Symptom Management

Symptom management can be very challenging. In palliative care, when presenting with a symptom complaint, **disease progression must always be considered**. Disease progression needs to be identified to help with the ongoing goals-of-care discussions. The symptom causing the most distress will vary, based on the underlying illness. Often-cited symptoms include pain, breathlessness, fatigue, anorexia, nausea/vomiting, constipation, depression, dry mouth, and sleep disturbance.^[4,11] This article is not intended to teach symptom management but rather to serve as an introduction to the useful tools that can assist with symptom management in primary palliative care. Refractory symptoms may need the consultation of secondary or tertiary palliative care providers.

Fast Facts^[12,13] is a resource to help manage symptoms. This web-based resource allows a search under the symptom name and provides a 1- to 2-page snapshot to help guide assessment and treatment. There is also a mobile application. Popular topics, such as pain, have over 84 Fast Facts on a multitude of topics relating to assessment, management, dose titration, and interventional approaches. In keeping with the palliative care focus on holistic care, there are also Fast Facts on many of the emotional, spiritual, and communication issues that arise in palliative care conversations.

Pain is often reported by palliative care patients. Interventions are focused on the relief of pain, **preventing or managing side effects of analgesics**, and finding the correct balance between the two. The patient's subjective experience of the severity of pain (eg, using the 0–10 scale) and how the

pain is impacting function are key parameters. Maintaining function may be a more important evaluation parameter than simply a number on the pain scale. The basics of pain management are followed, starting with nonpharmacologic interventions, such as heat/ice, physical therapy/occupational therapy/behavioral therapy, and/or medication management, and including nonopioids and adjuvants. If ineffective, then a trial of opioids may be indicated, and consideration for referral for interventional therapies offered by pain management specialists. When prescribing opioids, current guidelines for safe and effective prescribing are available, along with educational opportunities to build skill in this challenging area.^[14,15] Safe opioid prescribing is a critical knowledge area and there are multiple free, online education opportunities that provide continuing medical education credits.^[16] Strong skills in pain management are a core competency for palliative care providers.

An opioid that is used more frequently in palliative care than in routine pain management is methadone. It should not be assumed that methadone only treats addiction. Difficult-to-treat pain may respond to methadone due to the unique properties—both mu agonist and N-methyl-D-aspartate agonist receptor activity. The use of methadone is an advanced palliative care skill. Experienced palliative care NPs are familiar with this medication for pain management and consultation is recommended. An NP who has a license to prescribe Schedule II meds can prescribe methadone for pain. A special license is needed to prescribe methadone to treat opioid addiction.

Dyspnea is another frequently encountered symptom that has an impact on quality of life and is present in many serious conditions.^[17] A stepwise approach to manage dyspnea with nonpharmacologic intervention to include physical therapy, activity modification, and/or rehabilitation may be indicated. Opioids and anxiolytics may also be indicated. With progressive dyspnea, oxygen support may progress from nasal cannula to intubation. Primary palliative care interventions include explanation of therapies, options, and risk/benefit with current and potential oxygen delivery methods.

Anorexia and weight loss is often very distressing to the patient and family. Anorexia is often seen with progressive, life-limiting illness. In this state, the body is not able to effectively use the calories consumed and muscle wasting continues despite adequate calories.^[18] With preemptive counseling, NPs can discuss the misperception that eating more will improve or restore health. Counseling families on this reality and preparing them for anorexia and weight/muscle loss is a primary palliative care skill.

It is unfortunate that any patient has to suffer with constipation as there are so many effective therapies available. One of the issues leading to constipation is that clinicians do not ask and patients do not report. Many medications are constipating, especially opioids. Progressive disease decreases activity and appetite, both contributing to constipation. It is essential to evaluate the etiology because the treatment will depend upon the cause. If the constipation is severe, it is important to determine whether there is an impaction. Starting bowel stimulants against an impaction will greatly increase pain. If not impacted, starting with a softener/stimulant combination and adding agents, such as osmotics, as needed, can avoid the use of an enema or suppository. Prevention and early intervention are key primary palliative care skills.

Equally as important as the distressing physical symptoms are issues related to spiritual or emotional distress. Asking a patient if religion or spirituality is important and if they feel supported starts the spiritual assessment. Formal tools exist, such as the FICA (Faith, Importance, Community, Address in Care) and the HOPE (sources of Hope, the role of Organized religions, Personal spirituality and practices, Effects on medical care and end-of-life decisions).^[19] Primary palliative care involves asking the patient if they have specific religious or spiritual beliefs that can be incorporated into the plan of care, if they are supported in a faith community, and whether they need connection and support. Spiritual advisors should be referred to when these needs exceed the NP's skills.

Advance Care Planning

In a perfect palliative care world, advance directives for care at end of life would be documented, medical powers of attorney would be named, and these documents would be shared with all health care providers. The reality is that this does not happen, and many hospitalizations are for a crisis when decisions need to be made and there has not been an open and honest discussion of the illness trajectory. Primary palliative care skills consist of advance care planning to include naming medical decision-makers and identifying health care wishes. These health care wishes should support the patient's goals of care. If possible, the discussion should start in the outpatient setting,

when patients and family are able to be presented with information and have time for thoughtful discussions and documentation.^[3] The goals of care are unique to the individual; for instance, what is **important at this time in life or in the future**, **what gives life meaning**, and what the intended legacy involves. **Goals may change over time, so the conversation is ongoing**. Direct language (eg, let's have a conversation about your health care wishes, now and in the future) can serve as a starting point.

NPs enter into these discussions **without an agenda for what are the "correct" decisions**. The desired outcome is to have the patient understand the issues and make informed choices based on their goals and their definition of quality of life. **NPs need to be prepared to discuss disease trajectory, realistic interventions, and prognosis**. Palliative care advocates that advance care planning be **documented and revisited** with subsequent changes in health status.^[3] With progressive illness, there may be a steady and slow decline, there may be times of crisis followed by stability, or an acute event may occur that leads to death. Health care that includes seemingly magical medications and ever-innovative surgeries or devices can lead some patients and families to think that, regardless of the issue, there is a way to restore health and function. The reality is that there will come a time when death approaches.

Facilitating productive conversations is a skill that can be learned and improved with practice. There are online resources to build expertise, both with written material and with video demonstrations. VitalTalk^[20] has videos and 1-page bullet-form information sheets that are excellent resources for both novice and experienced palliative care clinicians. **Included on the VitalTalk website are examples of phrases to use during many types of palliative care conversations**. In addition to phrases, there are guidelines to structuring these conversations.^[3,4,17,21] Important steps include **having the correct people present for the conversation** in an environment conducive to a private discussion; inquiring about the understanding of the current illness or condition and expected trajectory; identifying the patient's expectations, goals, and values; and elements of quality of life. During the discussions, there is an opportunity to clarify and educate, to work together to define next steps, and to build consensus toward the treatment plans. This is an ideal time for the NP to ask about preferences for life-sustaining therapy, discuss patient wishes, and counsel on expected outcomes. Tools for structuring these conversations include the SPIKES protocol ().^[9,11] A 10-minute video explanation of using this video is available online, search under the key word spikes.^[22] There are many other videos demonstrating this protocol and variations that can be found by searching the key words "breaking bad news."

Table. SPIKES protocol for structuring conversations

Steps in SPIKES	Operationalize the Steps
Setting up the interview	Private, minimize/no interruptions, having the correct people in the room, having the test results and medical information needed.
Perception—assessing the patient/family's understanding	For example: "Tell me what you understand about your [name the health issue]." Listen to their explanation, identify gaps or misperceptions .
Invitation to share information	For example: "I have results, would you like me to share them now?" "If not now, under what circumstances do you want the information or is there someone else you would like me to talk to?"
Knowledge sharing	Present the information, answer questions, use language/pictures/teaching tools to maximize understanding.
Emotion—responding to the emotion	Be prepared to sit in silence if there needs to be time to process the information. Be prepared for emotions such as tears, anger, acceptance.
Summarizing the discussion	Review to insure understanding and next steps.

NPs need to recognize the "sentinel hospitalization," a transition point in the patient's disease where there is a need to reassess prognosis, treatment options, patient and family understanding, and goals of care.^[23] In addition to physical changes, the social and emotional stress of serious illness may become more apparent and a cause of suffering. If palliative care has not been part of the treatment plan, recognizing the need during the hospitalization or at a follow-up clinic visit may prevent unwanted and burdensome treatments. Failure to prognosticate accurately can lead to poor patient outcomes.^[4] An online reference tool, ePrognosis,^[24] uses factors such as current location, functional status, comorbidities, and lab data to calculate the risk of dying for a group with a similar clinical picture. Limitations of this tool include that it is designed for older adults who do not have a dominant terminal illness. ePrognosis is presented as a rough guide about mortality and not a definitive means of prognostication. Within the ePrognosis site is a link to the Palliative Performance Scale. This tool was developed for palliative care to help prognosticate for patients with advanced cancer and other life-threatening non-cancer diagnoses. Inputting data into the tool yields an estimate of median survival days. This tool can be found by starting at the ePrognosis site, opening the calculator tab, and then opening the hospice tab.

Preparing advanced directives (ADs) has been identified as important in the literature. Treatment preferences, a sense of dignity, and having family support are themes that emerge as essential.^[25] However, there are discrepancies in how patients, families, and health care providers define "a good death." To complete ADs, the patient must have the capacity to understand their medical issues and make reasoned choices. ADs facilitate patients' consideration of their mortality and document medical interventions desired at end of life. Equally important, ADs provide surrogate decision-makers with the patient's voice if (and often when) they reach a point at which they can no longer verbalize their wishes. A lack of preparedness on the part of the surrogate or medical power of attorney increases the risk of conflict and impasse between the medical team and the patient/family team.^[26] In talking with patients and families, NPs may uncover the perception that, if completed, ADs equate with reduced care. Clarify the situation when ADs become useful, namely end of life with a terminal illness or nonreversible medical condition. Counsel patients that ADs should be reviewed regularly, consider annually, and with any significant health care change. The National Hospice and Palliative Care Organization (NHPCO) has a website to assist with documenting ADs, with links to state-specific AD documents.^[27]

The POLST (Physician Orders for Life-Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment) are medical orders for care at end of life. The orders to be written detail what the patient wishes with regard to cardiopulmonary resuscitation if in cardiac arrest. If not in cardiac arrest, wishes for comfort measures versus limited interventions versus full interventions are specified. As with the completion of ADs, the conversation is key to preparing written orders that accurately reflect the patient wishes. Additional information can be found at the POLST website, which provides a link to the program for each state.^[28] The POLST/MOLST coordinator in your state can identify whether NPs can sign the form, how to obtain the forms, and where the relevant training takes place.

When completing ADs, the discussion of artificial nutrition and feeding tube placement may need to be expanded. Symptom management and education for anorexia may have occurred and subsequently need to be reviewed or expanded. The emotional side of "not feeding" and "starvation" need to be discussed with the clinical information on realistic outcomes to expect in this individual situation. What can be done to manage the symptoms should always be indicated.^[18]

In many progressive disease states, kidney failure becomes part of the medical picture and the discussion of starting dialysis becomes pertinent. Both short- and long-term goals need to be explored with informed opinion if dialysis can help accomplish these goals. If there is indecision, having the patient and family visit a dialysis center may be useful to guide informed decision-making.

Transitioning to Hospice Care

With life-limiting illness, there comes a point when death will occur. Ideally, prior to this point, a conversation about hospice care has occurred. Hospice care is a subset of palliative care specific for end-of-life care. Both specialties focus on excellent symptom management and advance care planning based on patient goals. Palliative care focuses on goals of care along the illness continuum, and hospice focuses on life closure and bereavement support. Kelley and Morrison provided a table detailing the similarities and differences in palliative care and hospice.^[11] The NHPCO^[27] is a

resource for helping to understand hospice care. A basic screening question for hospice that can be used in primary palliative care involves prognosis. If the disease continues along the expected course and death is anticipated within 6 months, then a hospice referral should be discussed or initiated.

Hospice is appropriate when further medical therapies may not modify the course of the terminal illness, or the patient does not wish to pursue any further disease-modifying therapies. Hospice admission is not based only on prognosis; the patient's goals for care must be such that they can be supported by hospice. If in doubt, a hospice information visit should be arranged so that the patient/family can discuss with the hospice team whether admission is appropriate at the time. The goals of hospice are symptom management and prevention of suffering, preparing for death in the setting of the patient's choice, and providing the supports needed to ensure comfort and life closure according to the patient's wishes. Hospice clinicians support the patient and family through this final phase of life, while allowing the primary NP to stay involved if they wish to maintain a consultant role. Currently, NPs cannot sign the certification for hospice care, as an MD's signature is required. Primary palliative care clinicians are encouraged to establish a relationship with the hospice providers in their community so that informational visits or enrollment can occur when needed.

Discussing Code Status

Within the ADs is a discussion/documentation on code status/resuscitation status. This is a conversation about patient goals and quality of life. Patients may have had code status discussions at different times along the illness continuum. It is important to explore the patient's goals of care and help them determine whether the options for resuscitation will help achieve their goals.

Cardiopulmonary resuscitation may be familiar to people from television programs, but the layperson's understanding may not be based in reality. Patients and families may have heard some terms, but it cannot be assumed that there is a good understanding of what the interventions mean and can realistically accomplish. NPs may need to discuss with treating specialists whether there is available disease-modifying therapy and what the prognosis is based on the specialist's expert opinion and knowledge of the patient. If the specialist has already had the relevant discussion, then reinforcing important points can highlight a consistent message and prevent confusion around a very sensitive topic.

When discussing code status, patient and family medical literacy should be considered. The NP should provide education on risk/benefits and expected outcomes of the interventions specific to the current medical issues. Time should be allotted for questions and review. If the discussion has occurred in a crisis, and if there has not been AD or POLST/MOLST documentation, time may be needed to process the information before a decision can be made.

When discussing code status, palliative care needs of comfort and quality of life are always part of the plan of care. Suffering from any symptom (physical, emotional, or spiritual) is an emergency and needs to be treated as such. The conversation should be reframed on what will occur with a focus on comfort and support, not what is withheld.

Document the conversation for a code status or POLST/MOLST form. Include who was present for the conversation, what was discussed, decisions made, forms completed, any questions or concerns, and any follow-up needed. Include copies of any completed forms in the medical record. Provide patient/family copies of documents completed. If there is conflict, secondary or tertiary palliative care may be needed to reach consensus. If there is concern about the patient's capacity or the decision-makers involved, or if there is conflict, then consulting ethics, legal, or risk management experts is recommended.

Refer When Needed

Consultative palliative care should be used in complex cases. Difficult-to-manage symptoms, complex family dynamics, and challenging care decisions around life-sustaining therapies are examples of triggers for secondary or tertiary palliative care.^[6]

Unfortunately, access to palliative care is still limited in some parts of the country. Issues like hospital size, location, and ownership are identified barriers to program development and implementation.^[7] With limited access comes the imperative for all providers to become skilled as first-line palliative care providers. In addition to the resources provided in this article, the End-of-Life Nursing Education Consortium course for advance practice nurses is offered throughout the year in

efforts to continue to build skill.^[32] The Hospice and Palliative Nurses Association is the professional organization for nurses working in this area.^[33] To help identify advance practice clinicians that have documented expertise in palliative care/hospice, both the Hospice and Palliative Nurses Association and the NHPCO offer resources available online.

Conclusion

More research is needed to document the outcomes of primary palliative care. Multiple studies have documented the benefits of secondary and tertiary care, but similar work needs done for primary palliative care. Studies are needed to determine whether ADs are being completed and followed. Also needed are studies that reflect the impact of primary palliative care on quality of life all along the illness continuum. Successful educational interventions to prepare NPs to be primary, secondary, or tertiary palliative care providers need to be identified with time and cost data. The need for palliative care is growing and the number of qualified providers is still small.

Primary palliative care supports the patients and families at every stage of a life-limiting or life-threatening illness. Assessing for and relieving suffering is the goal, and this is accomplished with comprehensive symptom management and ongoing conversations about goals of care and quality of life. NPs treat and advise patients and families who need palliative care and have needs that change over the illness trajectory. As NPs incorporate primary palliative care into their practice, they can be reimbursed for the time and effort invested in this aspect of holistic patient care.