Original Article

Navigation and Palliative Care*

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Patient navigation represents an opportunity to further the integration of palliative care with standard cancer care. This article defines palliative and hospice care and describes some of the current challenges of integrating palliative care into other forms of care. It also considers outcomes that navigation might be expected to improve for patients receiving palliative care or enrolled in hospice. These outcomes include symptom relief; communication efficacy; transitions of care; and access to palliative care, hospice, and bereavement care for families. Although these outcomes may not have been specifically assessed in patients in cancer navigation programs, they represent important outcomes for patients receiving palliative care and their families. It is recognized that the types of outcomes that are important to track for patients and families receiving palliative care should be consistent with outcomes at other stages of illness. ***Cancer* 2011;117(15 suppl):3585–91.** *© 2011 American Cancer Society.*

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INTRODUCTION

This article defines palliative and hospice care, describes some of the current challenges of integrating palliative care into other forms of care, and considers important outcomes that navigation might be expected to improve for patients receiving formal palliative care or enrolled in hospice. We recognize that the types of outcomes that are important to track for patients receiving palliative care and their families should be consistent with outcomes at other stages of illness. The concept that palliative care must fit seamlessly within overall cancer care is foundational in this argument, even if a patient is not formally seen by a palliative care clinician or enrolled in a hospice. If even introducing the topic of palliative care as an approach is considered taboo for patients, families, and navigators, it will be challenging to implement it when it is most needed, the setting of serious and life-threatening illness. Therefore, a secondary goal of this article is to uncouple palliative care from end-of-life care for navigators and the patients and families whom they serve.

Definitions

Palliative care

Palliative care is focused on the relief of suffering, the treatment of symptoms, and the overall support of patients and families at any stage of illness. Palliative care is applicable to medical illnesses of all types. As an approach, palliative care includes hospice care (defined below), but it also serves a broader population of patients including those receiving disease-modifying therapy and those who have prognoses of >6 months who are generally not served by hospice care. Contemporary definitions of palliative care from the World Health Organization (WHO) and cancer-specific organizations all focus on the multidimensional nature of suffering and the goal of palliative care to improve this throughout the trajectory of illness.

WHO has defined palliative care as: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by

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means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual."[1]

Two major cancer-specific organizations, the American Cancer Society (ACS) and the National Cancer Institute (NCI), have also offered definitions of palliative care. The ACS defines palliative care as: "Care aimed at relieving suffering and improving quality of life is called *palliative care* or *supportive care*. The focus is on the patient and family rather than on the disease. Palliative care treats pain and other symptoms caused by the disease."[2]

The NCI defines it as: "Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment."[3]

All 3 of these definitions emphasize the concept that palliative care is not an alternative to traditional care but is an adjunct to other forms of medical care. Although there might be a point at which a patient is formally referred to a palliative care or hospice program, a focus should be introducing these concepts of improvement of quality of life and prevention of suffering early in the disease process and throughout its trajectory.

Hospice

Hospice is an older term and a program that dates from the 1970s and is focused more exclusively on end-of-life care. Largely defined by the Medicare Hospice Benefit, hospice is the interdisciplinary care of patients and families when a patient has an illness for which the prognosis is expected to be 6 months or less and when the focus of care is on comfort-oriented approaches. Generally, hospice is considered a subset of palliative care, one that is focused on the last stage of life. As an example of the attempts to unify these 2 approaches, the main professional and advocacy organization for hospices that was once called the National Hospice Organization is now called the National Hospice and Palliative Care Organization (NHPCO). NHPCO defines hospice as: "Hospice focuses on caring, not curing, and, in most cases, care is provided in the patient's home. Hospice care also is provided in freestanding hospice centers, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients of any age, religion, race, or illness. Hospice care is covered under Medicare, Medicaid, most private insurance plans, HMOs, and other managed care organizations."[4]

The growth of modern palliative care has resulted in a defined medical specialty; certification programs for nurses, social workers, and others; and multiple textbooks and journals. In parallel, the dissemination of hospice care has also been dramatic: More than 1 million of the approximately 2.4 million patients who die in the United States each year receive hospice care before they die.[5] Of these patients who die in hospice care, 38.3% (or approximately 380,000) have cancer. Based on overall figures of 562,875 patients who died of cancer in 2007[6] (the last year for which data are available), this means that approximately 2 of 3 cancer patients likely receive hospice care at some point during their illness. Although we do not know how many of these patients had navigators during their cancer care, the high number of patients who receive navigation make it extremely likely that there will be patients who have been in a navigation program who make a transition to hospice at some point in their course and/or who receive palliative care. Because palliative care as a field endeavors to treat patients earlier in the course of their illness (beyond a 6-month prognosis), it is likely that the number of patients and families who would both qualify for and benefit from palliative care will be even greater than the number for hospice.

Challenges

Some of the contemporary challenges in palliative care and hospice for many chronic medical illnesses, including cancer, center on access and transition. These are domains that cancer navigation is expected to affect. Specifically, clinicians, researchers, and advocates have struggled with the following questions:

When do palliative care and hospice begin?

Although the palliative care principles of excellent symptom control and support for patients and families can be applied at any stage of illness, the formal designation of hospice is associated by practice and by regulation with care closer to the end of life: Patients who are in hospice must have an estimated prognosis of 6 months or less.[7] One of the specific challenges of deciding when hospice care begins is the difficulty of accurate prognostication. There are abundant data about physicians' difficulties prognosticating,[8] and there are also data about the varying and at times unpredictable trajectories of chronic medical illness among patients.[9] Each of these factors has been implicated in the phenomenon of late referrals to hospice, leading some to advocate for decoupling the requirement of a 6-month prognosis from the referral process.

Despite multiple efforts, the median length of stay of patients in hospice remains just more than 20 days,[10] a figure that has not changed for more than a decade.[11] This late timing of hospice enrollment might be limited by communication considerations, by physician or patient preferences, by Medicare admissions and reimbursement criteria, or by other factors. Whatever the reasons are for them, these figures argue for continued attention to the integration of palliative and hospice care into routine cancer care. The hospital and clinic are potential settings to help broach this transition among patients and families. For example, it has recently been shown that more frequent hospitalizations and outpatient visits result in higher use of hospice among women with breast cancer.[12] This finding is likely a marker for more serious illness as well as more opportunities for communication between patients and their providers. As an intervention that spans outpatient and inpatient settings, navigation might help to integrate palliative care with routine cancer care.

Multiple investigators have advocated hospital-hospice partnerships with the goal of allowing referrals to hospice and palliative care to occur sooner in a disease progression and to facilitate earlier integration of palliative care with disease-modifying care.[13-16] In this way, one overall goal for palliative care as a field is for there to be a "continuum of palliative care services" that starts at diagnosis and ends after death, spanning all facets of a patient's illness and care setting (home, hospital, community, etc.).[17,18]

Can palliative care occur in concert with disease-modifying therapies?

In the contemporary definitions of palliative care cited above, it can and should occur in combination with disease-modifying therapies. Although there are a diversity of practices among hospices concerning the use of more "aggressive" or disease-modifying therapies (for example, chemotherapy whose intention is to reduce tumor burden and thereby improve pain), the use of palliative care in conjunction with disease-modifying therapies is a hallmark of many hospital-based and outpatient palliative care programs. This approach is often what patients, families, and providers want, and there is beginning to be evidence of its effectiveness. A recent randomized trial of palliative care delivered to patients concurrently with standard care for advanced lung cancer (which often included chemotherapy) showed that patients in the palliative-care arm had improved quality of life, mood, as well as length of life.[19]

Hospice care generally focuses more exclusively on comfort-oriented care. Although the Medicare Hospice benefit does not cover therapies intended to "cure" illness, there are no regulations that exclude other specific therapies, including those that may be disease-modifying as well as beneficial for comfort. However, the perception of hospice as "giving up" or "giving in" and not "fighting" is one that may be prevalent among heath care providers[20] and patients and their families.[21] In addition, there are also data from at least 1 state documenting specific limitations that hospices place on care.[22] Whether these limitations are based on financial constraints or ideological ones is not clear.

Outcomes

What outcomes does palliative care affect? Although studies have now shown that palliative care results in improved symptom control and quality of life[23] and cost savings,[24] a recent systematic review identified some of the subjective outcomes around family satisfaction as being more commonly impacted than symptom or cost outcomes.[25] In the sections that follow, we consider the types of outcomes in palliative care that we believe are especially relevant to navigation. These outcomes are also summarized in Table 1.

Symptoms

Of all the symptoms, pain, dyspnea, and depression have the most data to support their use as an outcome: Inpatient and outpatient palliative care and hospice referral have been shown to impact these symptoms.[23,25] This is also reflected in the recent call by the American College of Physicians for the inclusion of routine screening for not only pain but also dyspnea and depression in palliative care.[26] The most efficient way to screen for pain is to use a numerical scale of 0 to 10 for patients to rate its severity. For dyspnea, a numerical rating scale can also be used to rate its severity.[27,28] There are a variety of measures of depression in palliative care, with the single item "Are you depressed?" achieving high sensitivity and specificity when validated with more thorough assessments.[29] We do not know whether navigation itself impacts any of these 3 symptoms, and this would be a testable hypothesis. Therefore, including these symptoms as outcomes among patients and families in a navigation program will be important.

Table 1. Relevant Outcomes Concerning Navigation in Palliative Care

Domain	Outcome
Symptoms	
Pain	Numerical Rating Scale (NRS): 0-10
Dyspnea	NRS
Depression	Single item: Are you depressed?
Communication	
Goals of care	Goals of care documented Assessment of whether care received matched goals of care Qualitative exploration of whether goals of care discussed
Advance care planning	No. of patients who engage in advance care planning discussions No. of patients who have a documented advance directive Care received consistent with advance directive
Transitions of care	Adaptation of Care Transitions Measure
Bereavement	Impact of Events Scale
Access	No. of referrals to hospice Timing of referrals to hospice No. of referrals to outpatient palliative care program

A role for a patient navigator around symptom outcomes could be to initiate screening and refer to the patient's nurse or physician if the screening reached a certain threshold.

Communication: goals of care and advance care planning

Excellent communication is central to the overall practice of navigation and to palliative care. There are data to support the hypothesis that good communication between physician and patient can help in navigating the transition to palliative care and hospice.[30] Authors have also developed communication strategies for discussing palliative care with patients.[31]

Goals of care.

The discussion of palliative care requires that clinicians discuss goals of care: a patient's values and preferences for care, which might be for life-prolonging care or symptom-oriented care or both.[32] Despite the finding that discussing "goals of care" is assumed to be associated with more serious illness, discussion of goals of care can come at any stage of illness. In fact, one possibility is if it is more routinely integrated into discussions early in the course of illness, it might be easier to discuss when an illness becomes more advanced. For patients with early-stage cancers, the goal of cure may be paramount; for those with metastatic disease, the goal of comfort-oriented therapy may be paramount. One hypothesis is that a navigator who is equipped to discuss communication and goals of care might be able to affect the success (or failure) of the use of palliative care services or a transition to hospice. A second hypothesis is that navigators who are equipped and empowered to discuss goals of care with patients may encourage them to have subsequent discussions with their health care professionals.

Although there are not specific measures of the quality of communication around goals of care, it is considered a fundamental feature of good palliative care and good patient care at any stage of illness. One possibility is to include a qualitative inquiry around how goals of care were discussed between patients and their navigators as well as patients and their health care professionals. Potential outcomes for goals of care could include whether goals of care were discussed, whether they were documented, and whether care received matched stated goals.

A role for patient navigators around goals of care would be to be part of this conversation with patients and families as well as to encourage them to discuss goals of care with their nurse or physician.

Advance care planning.

A second aspect of communication that is relevant for navigation and palliative care is advance care planning. Advance care planning is the formulation, discussion, and documentation of preferences for care in the event that a patient can no longer speak for himself or herself.[33] Advance care planning frequently includes such issues as do-not-resuscitate preferences, but in its full form it is meant to be broader and include multiple aspects of patient preferences for settings and types of care. The conventional means for documenting advance care planning include the naming of a person to represent the patient's wishes (termed a health care proxy) or completion of a document indicating specific preferences (termed a living will). Although there have been some commentaries questioning the construct of advance care planning as reductionistic and overly simplistic,[34] there are also data to show that advance care planning makes a difference for patients in terms of the interventions they receive in the setting of serious illness.[23,35] Many hospices and palliative care programs also monitor advance directive use and include it as a quality measure. Outcomes in this area include presence or absence of an advance directive; satisfaction with the advance care planning process; and whether care received is consistent with the advance directive. Like the topic of goals of care, navigators could be taught to engage in conversations regarding advance care planning with patients and families. This could help address one of the oft-cited barriers for physicians: time.

Transitions of care

Transitions of care, primarily between the hospital and home and long-term care settings, is a known area of risk for miscommunication and adverse events.[36,37] A Care Transitions Measure to characterize the success of transitions between settings of care has been developed and validated in multiple settings by Coleman et al.[38] The transition from active therapy to active therapy and palliative care (receiving these approaches simultaneously such as in an outpatient palliative care program) or palliative care without active therapy (such as in a hospice program) are examples of transitions of setting and care providers that may occur in the course of illness for patients with cancer. Applying and adapting the Care Transitions Measure to these transitions is an example of an outcome in palliative care that cancer navigation might impact. This measure might be able to be applied at multiple points along the navigation spectrum because patients will likely make multiple transitions of care in the course of their illness. Patient navigation is fundamentally about transitions of care: Including the use of hospice care as a discrete outcome will be consistent with other types of transitions that navigation might be expected to impact.

Bereavement

Simple interventions that hospital-based palliative care can provide have been shown to improve bereavement outcomes of patients who died in intensive care units (ICUs).[39] Lautrette et al demonstrated that a basic communication strategy consisting of family meetings and a brochure for families about dying and grief was able to improve family outcomes of anxiety and depression and post-traumatic stress disorder (PTSD) in the bereavement period. Hospices by Medicare regulation are required to have bereavement services for the year after the death of the patient. The impact of hospice on bereavement outcomes has been difficult to document, with some studies showing minimal impact[40] and others reporting mixed results.[41] One potential reason for the limited impact of hospice may be the short length of stay that patients in hospices currently have: There may not be the time to develop a relationship with a patient and family that has the potential to influence their bereavement. If a brief intervention such as that reported for ICU patients can impact bereavement among family members, one can hypothesize that a more sustained communication intervention between navigators and patients might have an even greater effect. Therefore, a measure of bereavement and family coping such as the Impact of Events Scale, which was used in the study of bereaved family members of patients in the ICU, could be used as an outcome of bereavement. It is a 15-item scale that has been validated in multiple studies and settings.[42] Although the role of the navigator would not be to continue navigation into the bereavement period, a testable hypothesis is whether the provision of navigation can impact a family's experience of bereavement. This outcome is an important one because of the possibility that excellent navigation during a patient's illness has the potential to impact bereavement among his or her family members after death.

Access

Palliative care and hospice have tried to reach diverse populations of patients and families, but they have at times had difficulties in doing so. In 2009, the last year for which data are available, 5.3% of hospice patients were Hispanic and 8.7% were African American.[10] These numbers represent lower numbers than the representation of these groups in the overall US population. Hypotheses for the reasons for this lower representation range from historical inequities of care to cultural, linguistic, and communication barriers.[43] We do not know the demographic make-up of patients who receive palliative care because it is not a specific Medicare benefit. In its attention to access at other stages of illness, navigation could be hypothesized to impact access among these populations of patients and families to hospice services as well as other services earlier in the course of illness. Fischer et al have developed and implemented a model for palliative care navigation among Latino patients in Colorado.[44] Among the outcomes that they measured were number of hospice referrals and timing of hospice referrals among underrepresented groups. These would be appropriate outcomes overall for tracking the use of hospice among patients and families in a navigation program. The role of the navigator would not be to automatically steer patients toward hospice but rather to discuss this option with them and their families

DISCUSSION

In its most ideal form, palliative care is well integrated into all types of cancer care in which a navigator guides a patient: from access, to diagnosis, to initial care, to follow-up care, and to referral to palliative care and/or hospice. This last point may come earlier in the course of a patient's experience in the case of the subset of patients who have metastatic disease at diagnosis or may come years or decades after presentation in the case of patients with early-stage cancers. For some patients, it may be that hospice or a formal referral to palliative care are never broached. However, it is important to consider these outcomes for navigation and palliative care for at least 2 reasons: 1) patients at any stage of illness have multiple symptoms, and 2) patients at any stage of illness have goals of care that may be broad (to "beat this cancer") or may be specific ("to make sure I can get my medicines"). Different aspects of palliative care may demand integration into cancer care in different ways. For example, because the prevalence of symptoms is so high in patients at many stages of cancer, a palliative approach that includes symptom control will be an integrated part of their care, even if discussions of end-of-life planning are not. On the other hand, there will be many patients, both those far from the end of life and those closer, who will want to discuss and plan for that time. Having specific outcomes and specific training for navigators in these areas (knowledge of what palliative care is; knowledge of symptoms and how to screen for them; skills in discussing goals of care or advance care planning; knowledge of how to access hospice or palliative care resources) is therefore crucial. It is also probable that many of the same types of outcomes that are important at other stages of navigation will be important for patients and families who are undergoing or considering palliative care.

The final argument for why an acknowledgment of palliative care earlier than the last month of a patient's life is important is because palliative care is most successful when it is appropriately integrated from diagnosis on and not considered a secondary form of care. Temel et al's study of outpatient palliative care for patients with metastatic lung cancer has convincingly shown this to be the case.[19] Although initial discussions of palliative care for patients in active treatment might focus on symptom management, advance care planning, and decision making, later discussions as an illness has progressed may focus more specifically on comfort measures, hospice, and support for patients' families. If navigators, patients, and families have a sense of these domains early in the course of an illness, they can be more seamlessly integrated later in care. Therefore, the outcomes that we have proposed concern symptom management, communication, transitions, access, and family bereavement. We are mindful that in addition to the training they currently receive regarding navigation skills, navigators may require specific training in palliative care to help patients and their families at these later stages of illness.

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