

## Welcome to the Third Edition of Knowledge Notes!

The Franciscan Northwest Physicians Health Network (FNPHN) is bringing Knowledge Notes to you as a quarterly educational resource. Each edition will provide a variety of short articles on a particular clinical topic. The Summer Edition will focus on aspects of Palliative Care, including Pain Management, How to Discuss Palliative Care, and How to Discuss Palliative Care with a Patient. The Fall Edition will be devoted to Diabetes.

Knowledge Notes is produced by the Franciscan Health System Education Services Department, with guidance from the CCN Clinical Education Ad Hoc Subcommittee, and is intended to support our partner organizations in the delivery of excellent patient care in the post-acute care setting.

While learning is fun, we want to make Knowledge Notes more fun. Every edition will contain a question that is based on that quarter's content. We will offer a \$5 Starbucks card to two people who email in the correct answer. This month, cards will go to the **first** and **third** person with the right answer. So look for that question, and send your answer to [www.knowledgenotes@outlook.com](mailto:www.knowledgenotes@outlook.com)

Over time, the FNPHN website ([www.fnphn.com](http://www.fnphn.com)) will become a convenient repository of information and learning that you and your fellow employees can freely access 24/7/365. We are always looking for feedback about how we are doing, so please give us feedback at [zenafuhrmann@fhshealth.org](mailto:zenafuhrmann@fhshealth.org)

Once again, welcome to the third edition of Knowledge Notes.

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# Knowledge Notes

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# Introduction

**In addition to these Knowledge Notes be aware that Franciscan Hospice and Palliative Care have developed a very informative web site that discusses related aspects. Follow this link to view the site.**

<http://www.chifranciscan.org/Health-Care-Services/Hospice-and-Palliative-Care/>

## Defining Palliative Care

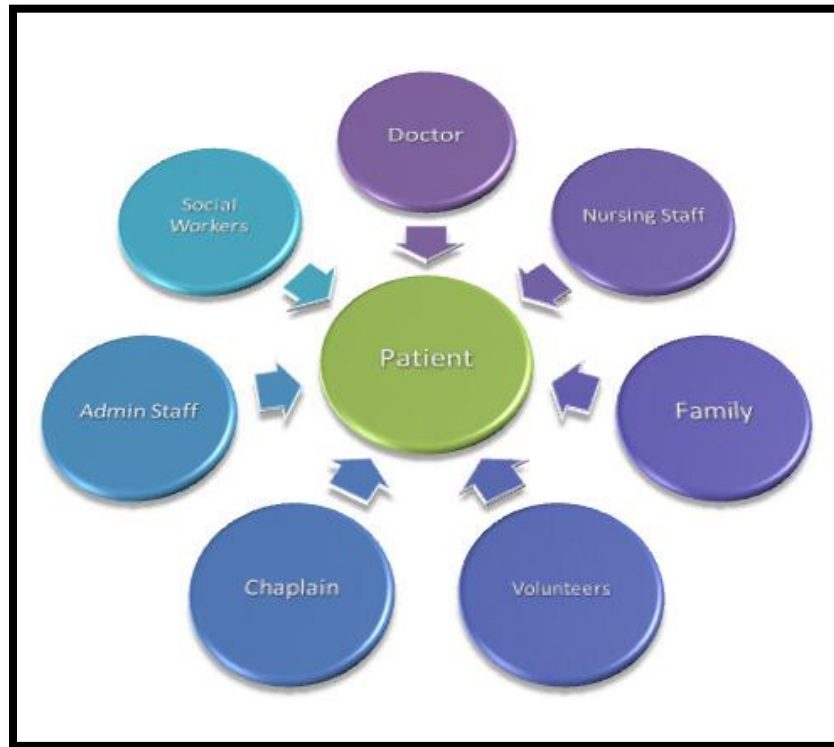
Palliative Care is an interdisciplinary medical specialty that focuses on preventing and relieving unnecessary suffering by supporting the best possible quality of life for patients and their families facing serious and/or life-threatening illness (UpToDate). According to the World Health Organization (WHO) “Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness...” They go on to say that they accomplish this goal, “through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

### Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications”(WHO: World Health Organization)

Palliative care is a multidisciplinary team approach to providing the patient and family with application of their personal values and preferences for managing their care. These goals may

include: psychosocial aspects, spiritual beliefs, emotional support for patient, family, and caregivers, and assistance with the coordination of care that serious illness may impose.



Source: Curtx Systems

## Criteria for Palliative Care Assessment

Several key indicators have been identified that can be used as triggers for the need of a Palliative Care Assessment when patients are admitted to the hospital. “Primary” criteria are used as minimal indicators for hospitals to screen patients at risk of palliative care needs that may be unmet. More specific indicators are the “Secondary” criteria that provide a higher probability that there are unmet palliative care needs. See indicators below for each criteria category (Weissman, 2011).

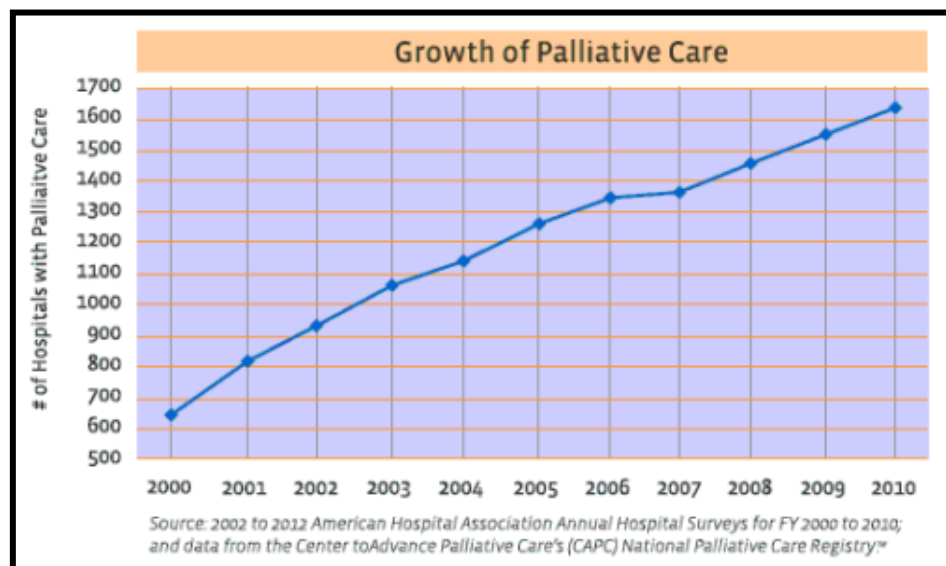
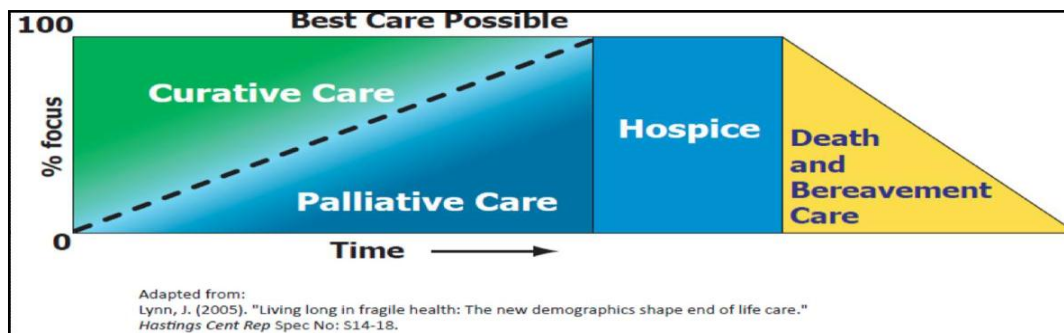
### Primary criteria:

- Frequent admissions – more than one admission for the same admitting diagnosis within the past several months
- Decline in function, feeding intolerance, or unintended decline in weight (e.g., failure to thrive)

- The “surprise question”: You would not be surprised if the patient died within the next 12 month period or before adulthood.
- Complex care interventions required – e.g., functional dependency; advanced home care for ventilator support, antibiotic administration, feedings other than oral
- Admission that is initiated because of difficult-to-control psychological or physical symptoms (e.g., moderate-to-severe symptom intensity for greater than 24-48 hours)

### Secondary criteria:

- Admission from long-term care facility or medical foster home
- Elderly patient, cognitively impaired, with hip fracture
- Metastatic or locally advanced incurable cancer
- Chronic in home oxygen use
- Out-of-hospital cardiac arrest
- Current or past hospice program participant
- Inadequate social support (e.g., family stress, chronic mental illness)
- No history of completing an advanced care planning discussion/document



Great emphasis is given throughout the written information on palliative care definitions and philosophy that palliative care is by its very nature a multidisciplinary/interdisciplinary approach to the care of the patient and family through incorporation of the full range of physicians, nursing staff, social workers, nutritionists, chaplaincy members, counselors, and rehabilitation specialties. Yet not only does it include these established members of the team, but it extends to include ancillary services of physical therapy, speech therapy, occupational therapy, and age specific experts.

Question #1: All patients admitted to the hospital or Nursing Home should have a Palliative Care Assessment done regardless of the reason for admission. True or False

## Pain

### Pain Management

Palliative care aims to relieve suffering in all stages of disease and is not limited to end of life care. According to UpToDate, "Pain is among the most prevalent of symptoms. When pain is unrelieved, it can be a source of great distress. This distress not only can affect the patient but also may extend to family caregivers, who may experience guilt, anger directed at medical personnel, or regret that persists long into the future. The care of patients with unrelieved pain also may adversely affect professional caregivers, potentially increasing the risk of burnout."

Pain management during this process all the necessary interventions for primary care providers and all the clinician should have proper acquired indispensable skills in pain management. Establishing goals of care within a patient's values systems; consists of communication between the patient and all those involved in his or her care.

Considerations while managing pain:

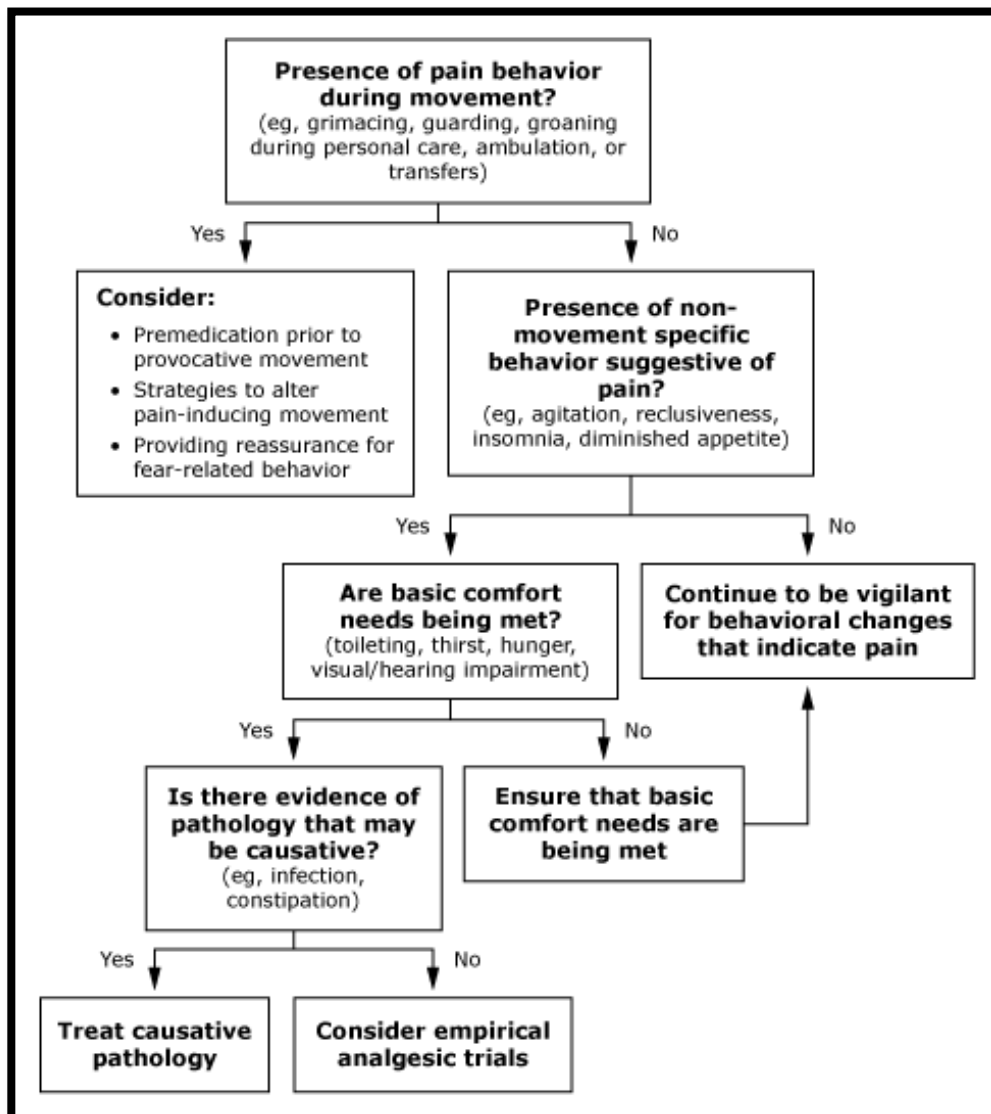
- Goals
- Values
- Beliefs
- Knowledge
- Fears
- Hopes
- Psychosocial
- Spiritual
- Practical support both to patients and their family

## Additional Things:

This YouTube video shows the meeting between the patient and the pain management specialist <https://www.youtube.com/watch?v=Q5UOUU4Auko>, the video was designed as a course workshop to help professionals to recognize the need for palliative care services for a patient at every step in the cancer experience.

Under-treated pain places patients at risk for a myriad of complications including depression, weight loss, delirium, functional decline and skin breakdown.

Patients with persistent pain are often frail and elderly. They frequently have cognitive deficits and impaired communication that make obtaining an adequate history challenging. For these same reasons it can also be difficult monitoring the response to pain medications. See the following algorithm which may be helpful in assessing pain in patients with severe cognitive impairment.



Source - UpToDate: Weiner, D, Herr, K, Rudy, T, eds. *Persistent Pain in Older Adults: An Interdisciplinary Guide for Treatment*, 2002; p. 34. Copyright ©2002 Debra Weiner, MD.

# Dealing with Anger

## Awareness

Anger is an emotion and is not uncommon in palliative care. On busy acute care wards, staff often tend to avoid interactions that may lead to expression of anger. However, in providing holistic palliative care, anger emotion should be treated as something that requires exploration, expression and understanding. It can lead to blockade in communication and adversely affect patient care and staff morale and team spirit. Anger may induce violence, be it physical or verbal. Understanding patient as well as our own emotional response, with high self-awareness, laid the foundation for dealing with such difficult situations.

Dealing with anger is common in palliative care. Anger was recognized as one of the essential stages in grieving as described by Kubler-Ross. It is important to acknowledge the anger and demonstrate that you have grasped what the client is angry about. It is also important not to 'dismiss' the anger as part of an adjustment process. Always take the source of the anger seriously (e.g. waiting room delays, or other expectations not being met), even if the response seems out of proportion (Dr. Bryan CW Li). If anger persists, one can try to get the patient to see that, no matter how justified the anger is it is beginning to affect him or her. **If he or she needs help, then simple anger management techniques can be taught:**

- Relaxation Training
- Distraction Activities
- Limiting Rumination

Question #2: It is unusual for a palliative patient to exhibit anger. True or False

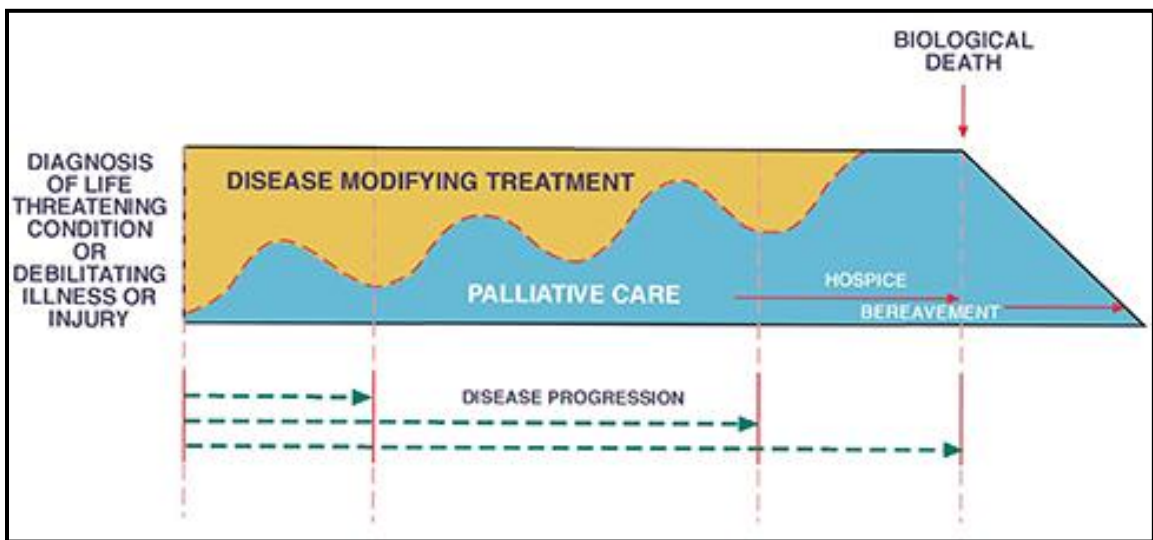
## Additional Things:

- This YouTube video: <https://www.youtube.com/watch?v=hnvKBiVu-hQ>, discusses the lessons and experiences from the perspective of a Palliative Care Nurse.



## What you can expect to happen during this time:

- **Behavior:** out of control, yelling, apologetic, excuses
- **Coping stance:** blaming, placating
- **Feeling:** angry, hurt, scared
- **Feeling about feeling:** guilt, resentment, shame embarrassment
- **Perception:** unreasonable, wrong, unfair, self-victim, world-unsafe
- **Exception:** should accept me, others to respect me, listen to me
- **Yearnings:** to be respected and validated
- **Self:** low self esteem, out of touch with inner self



Source: Ascension Health Palliative Care Model

## Acknowledgment

**Engage rather than withdraw from the patient.** The natural tendency for clinicians is to cut short the office or hospital visit, find ways to avoid contact with the angry patient or family member, or to try to mask his/her own anger in order to continue to interact with the patient.

Robert Houston MD has written a very helpful article listing 10 rules for engaging the dying patient. Some of his rules which are pertinent to this discussion are:

- Engage the patient, but do not enmesh with and do the emotional work for the patient.
- Maintain adult-adult communication rather than fostering the patient's dependency.
- Do not personalize the patient's anger.
- Adopt a patient-centered worldview by ascertaining his/her values, priorities, hopes.
- Normalize anger so that the patient can move through this stage.

## **Additional Things:**

- This YouTube video: [https://www.youtube.com/watch?v=HRgsv\\_xj3Ug](https://www.youtube.com/watch?v=HRgsv_xj3Ug) , explores the emotional and physical support given by nurses to patients during their time of palliative care.

# **How to Discuss Palliative Care**

## **Steps to take**

There is increasing awareness of the need for effective communication in health care, particularly with people who face a frightening diagnosis and an uncertain future for themselves or someone close to them.

## **Be Aware**

Being aware of the emotional responses of ourselves as well as others allowed us, as healthcare workers, to cope with challenging situations involving difficult communication. In dealing with highly expressed emotions, this is especially important.

## **Communication challenges when dealing with patients who have incurable and/or life threatening disease:**

- Breaking bad news
- Denial
- Collusion
- Difficult questions
- Emotional reactions

## Examples of How to Address Communication Challenges:

Step	Participant Behavior Code	Example of Dialogue Coded Positively
Assess perception	Assesses the patient's perception of the situation	"Tell me what your understanding is at this point."
Discuss big picture	Elicits the patient's values or goals	"What is most important to you now?"
Ask about worries	Asks about worries, fears, or concerns	"Do you have any particular concerns?"
Respond to emotional content of difficult questions	Responds to the question "How much time do I have?" including an empathic response Responds to the question "Isn't there anything more you can do?" including an empathic response	"Is there anything in the future you are thinking about specifically?" "There are many things we can do to help."
Propose care plan	Not assessed	
Checks for understanding	Checks that the patient has understood the conversation	"Tell me what you are taking away from our talk."

Step	Participant Behavior Code	Example of Dialogue Coded Positively
Setting	Not assessed	
Perception	Assesses the patient's perception of the situation	"Have you been told anything about your test by anyone else?"
Invitation	Requests the patient's permission to proceed	"Are you ready to talk about the CT results now?"
Knowledge	Uses the word <i>cancer</i> when giving the bad news	"The CT shows that the cancer has returned."
Emotion	Waits at least 10 s after giving bad news	Silence for 10 s while the patient is still too upset to talk
Makes an empathic statement as the first response to the patient after bad news	"It looks like this is not what you expected."	
Asks for the patient's emotional reaction explicitly at some point after the bad news	"How are you doing with all this?"	
Summary	Summarizes the follow-up plan	"So the next step will be for us to meet tomorrow to talk about the chemo in more detail."

Source: <http://archinte.jamanetwork.com/article.aspx?articleid=76964>

## Additional Things:

If you are interested in practical guidance on how to address palliative care to patients and families, please go to the following website:

[http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff\\_059.htm](http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_059.htm), the End-of-Life Palliative Education

Resource Centre (EPERC) Fast Facts provide concise guidance on how to:

- Deliver bad news
- Run a family conference
- Respond to strong patient emotions
- Respond to the angry patient
- Help maintain hope

- Make referrals to palliative care
- Talk to patients' young children
- Use an interpreter effectively
- Evaluate and respond to requests for hastening death
- Discuss with families what to expect when the patient dies.
- Emotional issues, and questions about life and existence



Source: [elearning.educationforhealth.org](http://elearning.educationforhealth.org)

# DEFINITIONS

The definition of palliative care has evolved over time. From the opening of St. Joseph's Hospice for the Dying in 1905 and St. Christopher's Hospice in 1967 until the 1980s, palliative care was largely delivered through hospice programs. Until recently, palliative care was seen as care provided for people who were not receiving active treatment for cancer, and were in fact dying of their disease. It is now recognized that the principles of palliative care are applicable earlier in the course of any serious illness and that palliative care can and should be provided alongside disease modifying treatment. According to the World Health Organization (WHO) position statement, "this change in thinking emerged from a new understanding that problems at the end of life have their origins at an earlier time in the trajectory of disease" (5).

The following definitions reflect the modern concept of palliative care:

- The WHO defines palliative care as: "An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual" (6).
- The Centers for Medicare and Medicaid Services (CMS) have endorsed the following definition: "Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice" (7).
- The Center to Advance Palliative Care defines palliative care as: "Specialized medical care for people with serious illnesses...focused on providing patients with relief from the symptoms, pain and stress of a serious illness — whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any

age and at any stage a serious illness and can be provided along with curative treatment” (8).

Hospice, as defined by the Medicare hospice benefit, is a health care delivery system under which support and services are provided to a patient with a terminal illness where the focus is on comfort rather than curing an illness (9). Thus, hospice can be considered a program that delivers palliative care to patients at the end of life, while palliative care can be appropriately offered to patients at any time along the trajectory of any type of serious illness, even concurrent with restorative, life-prolonging therapies (10). Hospice is a model of palliative care that is offered to patients at the end of life when curative or life-prolonging therapy is no longer indicated. While all care that is delivered by hospices can be considered palliative care, not all palliative care is delivered in hospices.

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