

Challenges in End-of-Life Care

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Objectives

- To encourage and empower nursing professionals in successfully navigating hospice planning**
- Increase knowledge regarding hospice->sort out fact vs fiction**
- Challenge common fears held by practitioners**
- Review the effects of age, culture and religious views on hospice/end of life planning**
- Discuss communication techniques to facilitate difficult conversations**

SUPPORTIVE CARE/PALLIATIVE CARE/HOSPICE

SUPPORTIVE CARE

- According to the National Cancer Institute (NCI), supportive care is defined as care given to improve the quality of life of patients who have a serious or life-threatening disease.
- The goal of supportive 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 (NCI, 2017).
- Sometimes supportive care is used interchangeably with palliative care.

HOSPICE

- Hospice is a special type of supportive care in which medical, psychological, and spiritual support are provided to patients and their loved ones when cancer therapies are no longer controlling the disease.
- The goal is to neither hasten nor postpone death but rather to control pain and other symptoms of illness so patients can remain as comfortable as possible near the end of life.
- Hospice focuses on caring, not curing. (NCI, 2017).

DEBUNKING COMMON MYTHS ABOUT HOSPICE

- Hospice is a specific place
- Hospice is only for people with cancer/old people/dying people
- In home hospice care is only available if a family member is available to assist with care
- Hospice care is expensive
- Hospice is for when all hope is gone

Naierman and Turner, J. (americanhospice.org)

PROVIDER BASED BARRIERS TO ACCESS

- Knowledge deficit regarding available resources
- Ignorance regarding what hospice care entails
- Reluctance to refer
- Others

Hawley P. (2017). Barriers to Access to Palliative Care. *Palliative care*, 10, 1178224216688887. <https://doi.org/10.1177/1178224216688887>

RELUCTANCE TO REFER

- Confusion regarding the difference between hospice and palliative care
 - Recognizing the point of a patient's unmet needs is challenging
 - Common “triggers” to refer often occur during transitions in treatment i.e. detection of metastases; or detection of distress in screening tools
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- Feeling of abandoning the patient

Hawley P. (2017). Barriers to Access to Palliative Care. *Palliative care*, 10, 1178224216688887. <https://doi.org/10.1177/1178224216688887>

KEY TAKE AWAYS

- Honest communication with patients regarding their prognosis at the initial visit
- Having a point person at the office who can discuss advanced care planning (i.e. advanced directives)
- Scheduling a specific time to discuss hospice within the first 3 visits
- Offer to discuss the patient's prognosis, coping strategies and goals of care at each transition
- Clinicians can contextualize goals of care that preserve hope and optimism while maintaining appropriate treatment aims

McAteer R. and Wellbery, C. (2013). Palliative care: Benefits, barriers and best practices. American Family Physician. Dec 15; 88 (12): 807-813.

PATIENT/FAMILY BARRIERS TO ACCESS

- Association of hospice with going somewhere to die
- “Magical thinking” associated with discussing death
- Patient’s fear of letting down their health care team
- Patient’s fear of losing a relationship with their loved ones
- Cultural influences on decisions regarding end of life care
- Religious influences on decisions regarding end of life care



CULTURAL DIFFERENCES IN END OF LIFE PLANNING

- Attitudes and approaches to palliative care/hospice planning vary widely among cultures.
- Cohen et al (2010)- Latino vs Cambodian patients: effect of religion, sense of destiny, quality of life regarding end of life decision making.
- Bullock, K (2011)-White vs African American views on advanced care planning and use of hospice benefits.
- Carey et al (2019)- Impact of cultural issues on patients and families.

Bullock K. (2011). The influence of culture on end-of-life decision making. *Journal of Social Work in End-of-Life & Palliative Care*, 7:83-98, 2011.

Carey E, Sadighian M, Koenig B and Sudore R (2019). Cultural aspects of palliative care. Retrieved from: www.UptoDate.com

Cohen MJ, McCannon JB, Edgman-Levitan S, Kormos WA. (2010). Attitudes toward advance care directives in two diverse settings. *J Palliat Med*. 13:1427-32.

RELIGIOUS DIFFERENCES IN END OF LIFE PLANNING

- **Roman Catholicism:**
 - Church makes a distinction between ordinary and extraordinary care
 - Euthanasia is not permitted-nor is “euthanasia by omission”
 - Gray area on patient decision to accept or deny other therapies
- **Judaism:**
 - Suicide, assisted suicide and euthanasia are not permitted
 - Withdrawal of care is usually not allowed
 - Comfort care is accepted
 - No requirement for a Jewish patient to accept any treatment not viewed as curative
- **Islam:**
 - Life is sacred but finite in duration
 - Suicide, assisted suicide and euthanasia are prohibited
 - Do not resuscitate (DNR) orders are only allowed in certain situations
 - Living wills and advanced directives are not recognized in Islamic law
- **Hindu**
 - Pain and suffering are normal parts of life-part of karma
 - Concepts of Acceptance and Detachment

Steinberg, S (2011). Cultural and religious aspects of palliative care. *Int J Crit Illn Inj Sci.* 1(2): 154-56.

AGE AND END OF LIFE PLANNING

- Coping with Cancer (CwC) NIH funded project wanted to identify age related differences in treatment preferences
 - 3 age groups: younger (20-44); middle (45-64); older ≥ 65
 - Middle and older aged patients were less likely to desire and less likely to receive life prolonging treatment
 - Younger patients wanting life prolonging treatment were more likely to receive compared to middle/older age patients wanting treatment
 - Younger patients *not* wanting life prolonging treatment were *less* likely to receive treatment related to their preference compared to middle/older aged patients

Parr, J. D., Zhang, B., Nilsson, M. E., Wright, A., Balboni, T., Duthie, E., Paulk, E., & Prigerson, H. G. (2010). The influence of age on the likelihood of receiving end-of-life care consistent with patient treatment preferences. *Journal of palliative medicine*, 13(6), 719–726. <https://doi.org/10.1089/jpm.2009.0337>

KEY TAKE AWAYS

- Culture, religious beliefs and age all influence a patient's perception about palliative care, end-of-life planning and hospice benefit use
- Trust is a must
- Realize there is an entire system at play
- Open communication is key
- Minimize cultural and linguistic understanding
- Create a shame free environment
- Avoid questions that may lead to an “us or them” dynamic



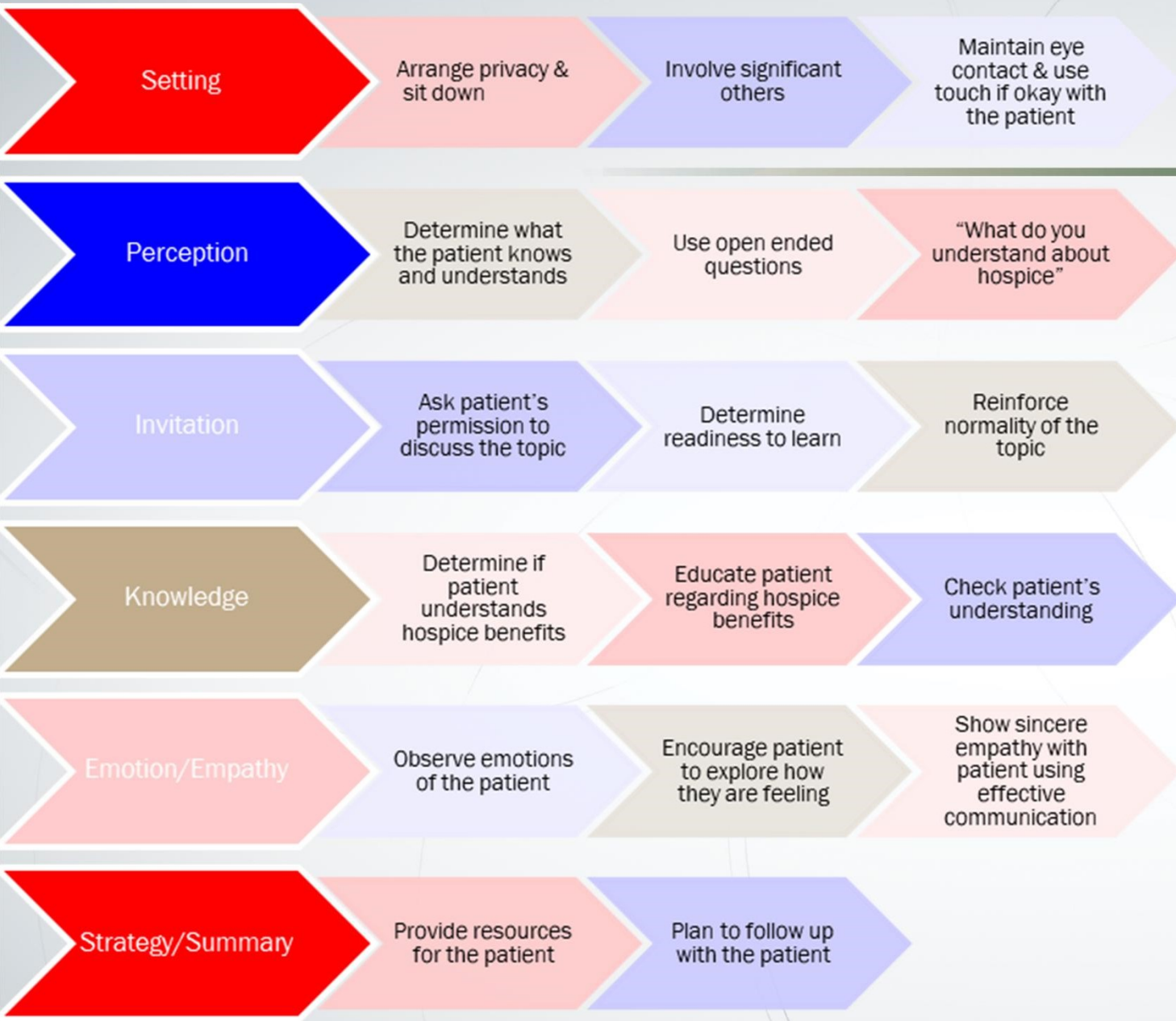
Carey E, Sadighian M, Koenig B and Sudore R (2019). Cultural aspects of palliative care. Retrieved from: www.UptoDate.com

COMMUNICATION TOOL: SPIKES



- Designed to help deliver bad news to patients-can be modified to discuss difficult conversations.

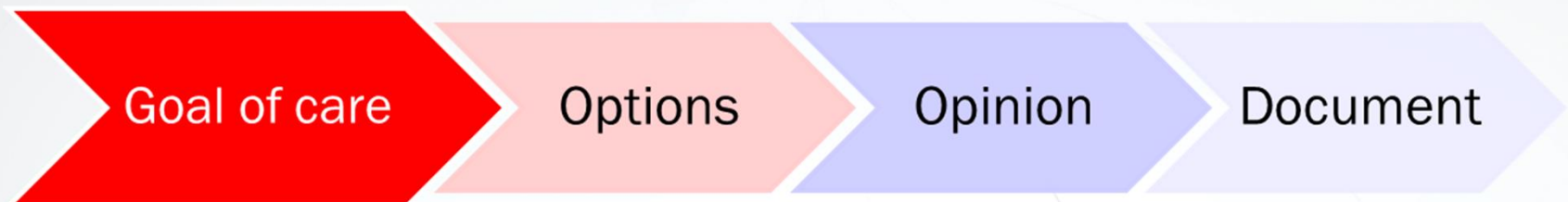
Baile et al. (2000). SPIKES-A six-step protocol for delivering bad news. Application to the patient with cancer. *Oncologist*



**Every good
conversation
starts with
good listening.**

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COMMUNICATION TOOL: GOOD



“It is **GOOD** to incorporate patient and family preferences into decision making”.



Goal of Care

Assess patient's values and wishes

What is the patient's overall goal

Identify specific goals



Options

Discuss all available options

Discuss pros and cons

Honor values



Opinion

Provide your professional opinion

State facts and provide data

Explain rationale



Document

Provide resources to patient

Make necessary referrals

Document in your treatment notes

STRATEGIES FOR APPROACHING COMMON ISSUES IN END OF LIFE PLANNING

Strategies	Suggested Phrases/Tools
<ul style="list-style-type: none"> Asking about the patient as a person (using open ended questions) 	<p><i>“What do I need to know about you as a person to give you the best care possible?”</i></p> <p><i>“What else do you want me to know about you and your friends/family that will help me take good care of you?”</i></p>
<ul style="list-style-type: none"> Ask questions that will help you learn more about the patient’s life, family, cultural background, and spiritual beliefs 	<p><i>“Are there things that I should know about your family background, religious beliefs, or community that would help me take better care of you?”</i></p> <p><i>“How important is religion or spirituality in your life?”</i></p> <p><i>“Can you tell me anything about your customs or spiritual beliefs that might affect your health care?”</i></p> <p><i>“Some patients have spiritual or religious beliefs that prevent them from having certain tests or treatments, do you have any specific concerns?”</i></p>

Thank You
