

Integrating Palliative Care: Perspectives for Nurses and Doctors

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Objectives

- To define palliative care and hospice care
- To describe an advantage to palliative care services
- To discuss end of life care options
- To practice a conversation about end of life values and choices
- To share your personal impact of having an advance directive conversation

Scope of Problem

Without palliative care, people are:

- Less prepared to deal with death and dying
- Not aware of options and services for “comfort care”
- Not likely to have a supportive team for symptom management
- Sometimes given treatments that are not beneficial at the end of life
- Less likely to have a “good” death

Definition of Palliative Care

- 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.

---World Health Organization (2009)



A Simpler Description

- Palliative care focuses on “caring” for the patient and family, not on “curing” the patient
- Can be valuable for any age and any stage of a serious, life-limiting illness
- Provides symptom relief and support to help patients function as well as possible
- Is used in hospitals, other community settings, or homes

What is Hospice Care?

- End-of-life care that does not hasten or postpone death
- Comfort and support given to both patients and families
- Giving peace, comfort, and dignity to people who are dying
- Pain and other symptom control to keep the person as alert and comfortable as possible

A Typical Hospice Team

- Clergy or other counselors;
- Home health aides
- Hospice physician (or medical director)
- Nurses
- Social workers
- Dieticians
- Trained volunteers
- Speech, physical, and occupational therapists PRN

Palliative Care / Hospice Care?

- Hospice services **include** palliative care
 - Palliative care can begin at **any** point in an illness, not just close to death
 - Hospice care can begin when death is expected within six months
- Both include services for patients with non-malignant diseases
 - For example, CHF (Congestive Heart Failure) or ESRD (End Stage Renal Disease)

Learning Palliative Care

- It is important to learn how to:
 - Effectively manage and treat pain
 - Talk to families and dying patients
 - Have less emphasis on *doing* something, and more on *being* with patients
 - Integrate “human” aspects of care and practice interacting with others



Providing Palliative Care

- Maintain dignity and privacy
 - Discuss spiritual concerns
 - Promote hopefulness and a sense of meaning
 - Respect beliefs and rituals
- Keep families involved
- Establish trust and rapport
- Manage symptoms such as pain and dyspnea
- Doorenbos, A.Z., Juntasopeepun, P., Eaton, L.H. Rue, T., Hong, E. & Coenen, A. (2013). Palliative Care nursing interventions in Thailand. *Journal of Transcultural Nursing*. 24(4). p. 1-14.

Case Study

- Maria was a 77 year old widow who lived at home. She was taking chemotherapy for lung cancer. When she became weaker and less able to function, she was referred to a palliative care program. The doctor and pharmacist provided medication and treatments for her to be more comfortable.
- The nurse assessed her frequently, with symptom management, coordination, and care planning. The social worker helped with financial concerns. Maria felt like she had the support she needed to understand her illness, even as her condition changed.

Case Study

- Maria quit chemotherapy because she wanted a natural life and death. She was able to be in a hospice program where her goal was for comfort. Pain, dyspnea, anxiety, and other symptoms were well-managed.
- The social worker arranged what she needed to be as active as possible with family events. Maria discussed and wrote down her end of life wishes since she no longer wanted CPR. Her daughter, home health aides, and trained volunteers helped daily so she could live safely in her home as long as possible.

Case Study

- Spiritual care was provided to Maria and her family by helping with prayers and rituals that were important to them. Relationships were prioritized and promoted, making the best use of the time remaining.
- Maria reflected on the meaning of life, and had some counseling from the hospice chaplain about things that were distressing to her. She felt more peaceful and ready as the end of her life approached.
- Hospice staff also provided bereavement services for her grieving family after her death.

Discussion

- *Have you seen palliative care used?*
- *What are some benefits of these services (if any)?*
- *How are the palliative care and hospice programs used in your country?*



Importance of Palliative Care

- Most people fear the thought of their own death and medical intrusion in the dying process
 - Death and dying are too rarely discussed
 - Need better communication among patients, their families, and health care providers
 - Care should fit with needs and wishes of patients
- Since nurses and doctors have close contact with patients and families, they can take the lead in better end of life care

Challenges for Physicians

- Limited training
 - Need communication and behavior skills
 - Need to see its value to patients (adding care, not taking it away)
- Need insight into their own feelings
- Patient relationships are often built on hope for cure
- Unrealistic goals
- Significant time constraints

Challenges for Nurses



Ethical dilemmas

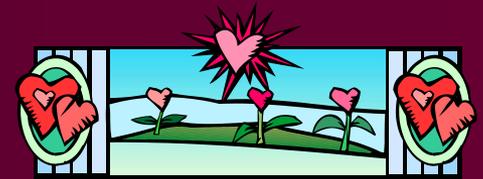
- Waiting on providers to:
 - Make a prognosis
 - Put in orders for care
 - Discuss preferences for end of life and resuscitation before an emergency happens
- Thinking about palliative care as an option even when there is not a cancer diagnosis

Challenges (Continued)

- Needing to decrease confusion about what a DNR (Do Not Resuscitate) order means
 - Knowing how far to go with other invasive treatments
 - Understanding the many levels of comfort care
 - Trying to get patient choices **in writing**
- Needing realistic prognosis and treatment outcomes to set reasonable goals
- Acute care areas may not be open to palliative care

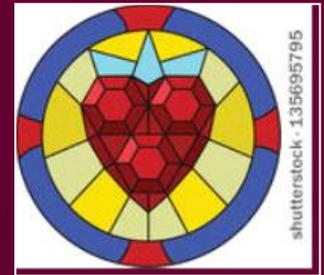
How to “Shift the Picture”

- Increase palliative care training
- Work together with providers
- Take time to talk to patients about their wishes
- Try to discuss end of life decision-making with all your adult patients
- Let them know that they have a choice
- Expect improvement in end-of-life care
- Practice conversations about advance directives



Accept a “New Picture”

- Shift to person-centered and family-centered care
- Avoid a paternalistic approach
- Redirect hope
- Have family conferences and give regular updates to avoid conflicts about patient’s treatment choices
- Focus on improving end of life care in your workplace



Growth of Palliative Care

- As the percentage of aging population increases, so will the need for end-of-life care
- Key goals include integrating palliative care
 - Throughout the course of illness
 - With earlier hospice referrals (rather than just a short time before death)
 - By making it more affordable and accessible
 - Developing social, organizational, and economic policies

Palliative Care in Nicaragua

- Lack of affordability
- Lack of availability
- Limited supplies of some medications in pharmacies
- No palliative care education in medical curriculum according to Pastrana et al. (2013)
- 7 Latin American countries had nurses trained to start pediatric palliative care in their hospitals, with one in Nicaragua according to Rivas (2015)

Palliative Care in Latin America

- Has unequal health care systems
 - Located mostly in large, urban areas
 - With no services in certain countries/communities
- Is taught in many medical schools
- Involves a network of interested groups and individuals who hope for further development
- Has very different availability of opioids between countries with use far below the world average
- Pastrana, T., Eisenclas, J., Ceneno, C. & DeLima, L. Status of palliative care in Latin America. (2013). From www.supportiveandpalliativecare.com

Discussion

- Compare U.S. to Latin America:
 - How is the pain medication availability in your country?
 - How do you manage pain?
 - Who usually talks about end of life preferences or advance directives?



Barriers to End of Life Discussions

- Shyness or discomfort about emotional responses
- Fear of death/dying
- Lacking information or being confused about advance directives
- Denial, or not understanding the situation
- Believing that the conversation could or should wait
- Not taking the time
- Feeling a lack of skill for the discussion

Skills for End of Life Discussions

- Discuss bad news sensitively and respectfully
- Provide information, as much or as little as the patient wishes
- Allow them to express their emotions
- Try not to rush them
- Clarify concerns and problems
- Set realistic goals
- Help the patient and family find options that reflect their values

What are Advance Directives?



- Appointing a person to make medical decisions for you if you are not able to make your own decisions (Power of Attorney for Health Care)
- Sharing preferences and what you hope for in life and death
- Giving instructions for end of life health care

Qualities to Look for in a Medical Decision-Maker

- Appoint someone you trust who is willing and able to be your health care agent and who:
 - Knows you well
 - Is able to listen to you share thoughts and wishes
 - Is able to understand your goals and preferences
 - Is willing to honor your wishes
 - Functions well in emotional situations
- Information from personal communication with Danielle Rathke, Gundersen Health Advance Care Planning Coordinator 5-8-17

Start the Conversation

- “Have you ever thought about or written down choices about your future medical treatment?”
- “Who do you want to make tough medical decisions for you, if you are not able to?”
- Watch videos about choosing a medical decision-maker (Choose English or Spanish on website):
<https://prepare.prepareforyourcare.org/page/1-3-3vd>
- <https://prepare.prepareforyourcare.org/page/4-4-1vc>

Discuss End of Life Wishes

- Ask, “*What does having a good life mean to you?*” (Find out what their goals and values are)
- “*What is important to you?*” (Ask “*Anything else?*” more than once.)
- “*What do you hope for at the end of your life?*”
- Discuss options to meet those preferences, goals and values
- Promote sharing the conversation with family
- Information from personal communication with Danielle Rathke, Gundersen Health Advance Care Planning Coordinator 5-8-17

Discuss Care Preferences

- *“What types of medical treatments would you like to be used or not used?”*
- Consider breathing tubes, feeding tubes, invasive treatments, and CPR (cardiopulmonary resuscitation)
- *“Would you or would you not want your life to be prolonged if the risks and burdens of treatment are more than the expected benefits of treatment?”*
- *“What situations might cause you to change your mind?”* Discuss if terminal illness, age, disability, pain, or being in a coma would make a difference

Talk About Your Choices

- Watch a video from the patient's perspective:
- <https://prepare.prepareforyourcare.org/page/2-4-2va>
- *Discussion: Do patients respond to the end of life conversations in the way that you expected?*
- Watch a video from the doctor's perspective:
- <https://prepare.prepareforyourcare.org/page/2-2-1va>
- *How do these examples compare to end of life decision-making in your country?*

Write Down Your Choices

- Tell your family about your preferences and who you chose as your medical decision-maker (or Power of Attorney for Healthcare)
- Have it in writing, so they can remember what you chose
- Make changes by rewriting the document and/or by talking to your medical decision-maker
- Even if the forms are not available, your medical decision-maker can still speak for you

Practice Having the Conversation

- Pairs of students use Advance Directive Conversation Guide. Role play: Nurse and patient discuss and fill out an advance directive form in Spanish

http://www.caringcommunity.org/wordpress/wp-content/uploads/2012/04/ADForm_and_Instr_Span-SHD-05.pdf

- Or in English

<http://www.caringcommunity.org/wordpress/wp-content/uploads/2012/04/AD-Form-and-Instr-2015.pdf>

Changing Advance Directives

- Discussion: *Would the following situations affect your end of life choices? Why or why not?*
 - Terminal illness (which can't be cured and is expected to result in death in a short time)
 - Advanced age (such as over 90 years old)
 - Being in a coma (and not expected to recover)
 - Advanced heart disease or heart failure
 - Having a serious disabling and/or painful condition

Discussion

- *Discussion: How did you feel when you started the conversation?*
- *How did you feel after you finished writing your advance directive?*
- *Do you see any benefit to this process?*
- *Why or why not?*



Conclusion:



- End of life discussions are very important to understand the patient's perspectives
- You can promote palliative care as a valuable option to improve the quality of life for your patients
- Initiate communication with patients, nurses, and doctors
- Use advance directives to communicate care choices
- You are uniquely positioned to have effective and compassionate end of life conversations

Resources

- Advance Health Directive Form (English or Spanish) (2015). Retrieved from <http://www.caringcommunity.org/wordpress/wp-content/uploads/2012/04/AD-Form-and-Instr-2015.pdf>
- Multimedia information about Advance Directive conversations (English and Spanish) at www.prepareforyourcare.org
- National Council for Palliative Care. (2009). Retrieved from <https://www.nhs.uk/Planners/end-of-life-care/Documents/Planning-for-your-future-care.pdf>

References:

- Arnold, R. (2003). Challenges of integrating palliative care into postgraduate training. *Journal of Palliative Medicine*. 6, 801-807.
- Doorenbos, A.Z., Juntasopeepun, P., Eaton, L.H. Rue, T., Hong, E. & Coenen, A. (2013). Palliative Care nursing interventions in Thailand. *Journal of Transcultural Nursing*. 24(4). p. 1-14.
- Gilligan, T. (2003). When do we stop talking about curative care? *Journal of Palliative Medicine*. 6, 657-660.
- Haylock, P. J. (2003). TNEEL: A new approach to education in end-of-life care. *American Journal of Nursing*. 103(8), 99-100.

- Norton, S. A. & Bowers, B. J. (2001). Working toward consensus: Providers' strategies to shift patients from curative to palliative treatment choices. *Research in Nursing and Health*. 24, 258-269.
- Pastrana, T., Eisenclas, J., Ceneno, C. & DeLima, L. Status of palliative care in Latin America. (2013). From www.supportiveandpalliativecare.com
- Reb, A. (2003). Palliative and end-of-life care: Policy analysis. *Oncology Nursing Society*. 30(1), 35-50.
- Rivas, S. (2015). Education program in pediatric palliative care nursing: Culturally relevant with methodology training the trainer. *Pediatric Blood & Cancer*. 62:S390,
- World Health Organization. (2009). WHO definition of palliative care. Retrieved from <http://www.who.int/cancer/palliative/definition/en/>