Best Practices for End-of-Life (EOL) Communication

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“What treatment in an emergency is administered by ear?”

“Words of comfort.”

From Cutting for Stone by Abraham Verghese, © 2009
Learning Objectives

• Understand the fundamentals.
• Apply these elements in hypothetical situations.
• Integrate elements into your practice.
• Reflect on what you bring to EOL care.
• Develop a greater appreciation for the benefits.
• Open to the possibility of continuing to develop your skills.
  (Fink, 2003)

Presentation Overview

• Background
• Stages of communication with best practices
  • Introductory
  • Working
  • Terminal
• Preparing for EOL with Advanced Care Directives
Background

- Benefits of good EOL communication
- Barriers to good EOL communication
- Qualities of good end-of-life communication
- Basic and advanced essential behaviors

Benefits of good EOL communication

Benefits to patients and families:
- Feel less abandoned, eases bereavement (Back et al., 2009).
- Become better informed and able to choose more appropriate treatments (Wright et al., 2008 and El-Jawahri et al., 2009).
- Choice of less futile treatments may reduce health care costs (Zhang et al., 2009).
Benefits of good EOL communication

Benefits to health care workers:
- Personal growth, confronting one’s own death, self knowledge, personal faith, experiencing transcendence, developing realistic expectations (Stiles, 1990).
- Compassion satisfaction (Coetzee & Klopper, 2010).

Barriers to good EOL communication

- Discomfort with facing mortality.
- Time constraints and workload.
- Contradictory messages about patient prognosis from different members of the health care team.
- Lack of prior relationship and experience with patient and family.
  (Liaschenko, O’Connor & Peden-McAlpine, 2009; and Steinhauser, 2001)
Qualities of good EOL communication

- Patients have defined it as being available (Stiles, 1990).
- Nurses have defined as helping with “The Big Picture” (Liaschenko, O’Connor & Peden-McAlpine, 2009).

Basic and Advanced essential behaviors (Perrin, 2010, p. 175.)

**Basic**
- Interpreting “bad” news
- Listening to clients’ concerns about EOL care
- Acting as an advocate for patient in EOL care
- Being with the patient and family during the dying process when death is expected

**Advanced**
- Conveying “bad” news
- Initiating discussions of EOL treatment options
- Dealing with families after a sudden, unexpected death
- Presenting organ donation options
Stages of EOL communication

Stages are “parallel to the dying trajectory.”

- Introductory
- Working
- Terminal

(Perrin, 2010)

Introductory (Perrin, 2010)

- Get to know the patient and family.
- Balance level of disclosure according to patient’s wishes.
- Take note of cultural considerations.
  http://ethnomed.org/
EOL Communication Toolbox

Cultural Assessment question:
“Some patients want to know everything about their condition, others prefer that we talk to their families. How would you like to get information?”
(Kagawa-Singer and Blackhall, 2001)

Case Study

Delia is a 90-year-old woman with osteoporosis and mild heart failure. She is in the hospital with an infection and complications following hip replacement surgery after falling in her home. She has completed an advanced care directive and has chosen allow natural death in the case of cardiac arrest. What questions would you ask in getting to know Delia?
Working

Explore the patient’s perspective, goals of treatment, and feelings about death and dying (Perrin, 2010).

Communicate as an ally with the patient (Stajduhar et al., 2010).

Use empathetic communication (Gauthier, 2008).

“I wish” statements may be helpful (Platt, 2001).

Case Study

You have gotten to know rather well. She was a homemaker and active as a volunteer. She is close to her daughter who has power-of-attorney for her. Delia has lived independently up until this point, going out to lunch with friends regularly and keeping up her reputation as a “clothes horse.” Delia understands that her hip incision is not healing and IV antibiotics have not wiped out the infection in her hip. When she is conscious, it is hard for her to grasp where she is and what is happening. She misses her husband who died in World War II. When talking with her daughter she says, “If this isn’t going to get any better, you don’t let them do anything that makes it last longer, okay?” What would your priorities be now in talking with Delia and her daughter?
SPIKES mnemonic protocol

SPIKES provides better outcomes when delivering bad news.
Protocol is based on a physician’s own experiences as well as his review of literature (Buckman, 2001).
Other studies have confirmed its usefulness (Miner, 2011).

“Doing this job badly will never be forgiven. Doing it well will never be forgotten.”

Robert Buckman, MD, PhD
SPIKES mnemonic

S: Create an appropriate physical and emotional SETTING
P: Assess the patient’s PERCEPTION of their situation
I: Seek an INVITATION from the patient to deliver information
K: Provide KNOWLEDGE using clear language
E: EXPLORE EMOTIONS and respond in an EMPATHATIC manner
S: Partner with the patient to create a SUMMARY and STRATEGY

SPIKES mnemonic

SETTING
• Don’t initiate unless you have adequate time.
• Find a private space.
• Sit, or try to be at eye level.
• Remove physical barriers.
• Minimize distracting noise.
• Introduce or reintroduce yourself.
• Provide tissues.
SPIKES mnemonic

PERCEPTION
- Ask the patient about how they understand their situation.
- Note any disconnection.
- Tailor your what you say accordingly.

SPIKES mnemonic

INVITATION
- Ask the patient if they want all of the information you have to share.
- Suggested phrase: “Shall I go on and give you all of the details on the most recent tests and what we recommend?”
- Respect the right of the patient to decline.
SPIKES mnemonic

KNOWLEDGE
- Explain information gradually.
- Use the same level of language as the patient.
- Take breaks to respond to reactions and confirm comprehension.
- Respond to any denial with empathy.
- Allow for periods of silence.

SPIKES mnemonic

EXPLORE EMOTIONS and use EMPATHATIC manner
Respond to the patient’s responses with empathy:
1. Name the emotion the patient is experiencing.
2. Name what is causing the emotion.
3. Show that you can connect the cause to the emotion.
SPIKES mnemonic

SUMMARY and STRATEGY
- Clarify the patient’s understanding of the situation.
- Work with the patient to create a strategy.
- Listen to the patient’s response to the strategy.

Case Study

Darren is a 44-year-old man who has been diagnosed with advanced pancreatic cancer that has metastasized to his liver. He is being hospitalized to control his severe abdominal pain. He has authorized release of information about his condition to family members. His mother comes to visit but he is in too much pain to talk at length. He asks you to tell her that he has pancreatic cancer. How would you use the SPIKES mnemonic to deliver this information to Darren’s mother?
**EOL Communication Toolbox**

Helping to clarify treatment options:
“I noticed the physician/advanced practice nurse was talking with you, what did s/he say?”
“Many people have questions about what this means for them, what questions do you have?” (Perrin, 2010).

**Other Best Practices During Working Stage**

Never say “There is nothing more we can do.”

Instead: identify goals for palliative care. (Murphy and Price, 1995).
EOL Communication Toolbox

Emotional assessment:
Rather than saying “How are you feeling?” ask “How are you feeling deep inside yourself?”
“What is most important to you right now?” (Perrin, 2010).

EOL Communication Toolbox

Spiritual assessment:
“What brings meaning and comfort to you?”
“How are you doing with all of this, with the big questions?”
“What role, if any, does spirituality or religion play in your life?” (Puchalski & Ferrell, 2010)
Other Best Practices During Working Stage

- Facilitate family meetings and family conferences with members of the medical care team (Scheunemann et al., 2011).
- Provide information on treatment options and EOL care to help patients with decision-making (El-Jawahri et al., 2009).

Terminal

Terminal Stage involves

- Helping the patient gain a sense of completion.
- Helping the patient and family say goodbye to each other.
- Explaining the changes observed in the dying process.

(Perrin, 2010)
EOL Communication Toolbox

Taking care of “unfinished business” may be as important as pain relief and symptom management (Tulsky, 2000). “If you were to die soon, what would be left undone?” (Quill, 2000). “Is there an event that would add great meaning to your life? What can we do to have that take place?” (Perrin, 2010, p. 177.)

Case Study

Darren has opted to forego chemotherapy for his pancreatic cancer and is in the hospital for a palliative surgery that may help to reduce the pain he experiences as he dies. There is no way of knowing how long he will live, but statistics show that it is not likely to be for more than 12 months. Darren has two school-age daughters, and has been a source of emotional and financial support for his extended family. He will need to close his tax accounting practice. What are aspects of his care that he may want to discuss with his health care providers?
Terminal

Encourage expressions of love and forgiveness (Byock, 2004).
Explain the changes observed in the dying process (Lewis et al., 2011).
Accept symbolic language used by the dying person (Callanan, 1994).

EOL Communication Toolbox

Explaining changes observed in the dying process to families:
“When a person is very close to dying, their breathing and appearance may change but it doesn’t mean that they are in pain. Would it be helpful for me to explain these changes so you might know what to expect?” (Perrin, 2010).
Terminal

After death
• Prepare the body so that the family can have time alone so say goodbye (Matzo & Hill, 2010).
• Provide an environment that is appropriate for individual families and cultures (Mazanec & Panke, 2010).
• Remember to reach out to the family with a phone call or card after the patient dies (Back et al., 2009).

Advance Care Directives

Advance Care Directives (ACDs) have potential to improve EOL care.

ACDs alone don’t ensure that wishes are carried out (Covinsky et al., 2000).
Advance Care Directives

Best Practices for discussing ACDs in different situations:
• As part of routine visit.
• As part of a hospitalization.
• With the diagnosis of a chronic illness.

Advance Care Directives

As part of routine visit:

Offering ACD counseling to patients may increase their satisfaction with visit to provider (Tierney et al., 2001).
EOL Communication Toolbox

Inviting a patient to discuss ACDs:
“Ms. Smith, I’d like to talk with you about advance care planning. I think it’s important to discuss with all of my patients. It’s so important that I have discussed this topic with my own physician. Are you familiar with advance care planning?”

“Mr. Jones, you are really proactive and good at taking care of your health and preparing for the future. Have you ever considered what type of medical care you would want if you ever became too sick to speak for yourself? Creating an advance care directive and discussing it with your family can ensure that you are cared for the way you want, even if you are unable to speak for yourself. (Emanuel et al., 1995).

Case Study

Velma is a 74-year-old African-American woman with COPD. She is visiting her health care provider with her daughter for her annual influenza vaccination and to refill prescriptions. How might you ask if Velma would like to discuss setting up an Advanced Care Directive?
Advance Care Directives

As part of a hospitalization:

The vast majority of patients are willing to discuss their preferences for CPR and mechanical ventilation if asked (Nicolasora et al., 2006).

Advance Care Directives

With the diagnosis of a chronic illness:

EOL discussions may help patients to make the most appropriate choices for their care (Wright et al., 2008).
Initiatives to encourage EOL discussions in our greater community:

www.honoringchoices.org
Offers online resources for generating EOL discussions among family members.

Start Talking Early and Plan (STEP) program encourages EOL decision discussions between patients and their health care proxies. (Gutheil & Heyman, 2005)

Advance Care Directives

Ask and listen for cultural considerations about EOL care.

- Individual autonomy is not valued in all cultures. (Kagawa-Singer & Blackhall, 2001)
- Culture and access to healthcare affect choices in EOL care (Hanchate et al, 2009)
Advance Care Directives

Patient preferences change over time.

- Keep the discussion going after completion of an ACD.
- Keep on asking and listening.

(Covinsky et al., 2000).

References


References


References


References


Tulsky, J. A. (2000). Factors considered important at the end of life by patients, family, physicians, and other care providers. *JAMA (Chicago, Ill.)*, 284(19), 2476-2482.

