Palliative care

- Care focused on improving a person’s quality of life
- Palliative care is for persons at the beginning to the end of their journey with an illness
- Anyone working with patients can provide palliative care—by listening and communicating, addressing symptoms, and creating a plan of care reflective of the person’s values
Areas to explore with the patient/loved ones...

- What should I know about you (or your loved one) to help me provide you (or your loved one) with the best care?
- Is there anything I should know about your culture, beliefs, or religious/spiritual practices that would help me take better care of you?
- Who do you live with? How active are you? What do you enjoy doing? What brings you joy?
- How are medical decisions made in your family?
- Who do you consider your support person(s)?
  - We should know who they consider as their “family”—sometimes it will be family members, friends, partners, etc
- Sometimes people want to know all the details about their condition, sometimes they just want to know the big picture, and sometimes they don’t want to know anything and prefer I talk to a loved one. What do you prefer?
Addressing symptoms

- Physical
- Emotional
- Social
- Spiritual
Physical symptoms

- Decrease in functional ability
- Fatigue
- Constipation, diarrhea
- Nausea, vomiting
- Lack of appetite
- Pain
- Shortness of breath
- Insomnia

✓ Increased physical symptom burden can worsen other symptoms such as anxiety, depression, spiritual distress
• Can use the **Edmonton Symptom Assessment System revised version (ESAS-re)** to assess symptom burden for patients with advanced illness

  • Persons rate pain, tiredness (lack of energy), drowsiness (feeling sleepy), nausea, lack of appetite, shortness of breath, depression (feeling sad), anxiety (feeling nervous), wellbeing (how do you feel overall), on a scale of 0 (none)-10 (worst)—with 0 having no pain and 10 having worst possible pain that they feel at the time of taking ESAS-re, for example

  • There is a blank space to include other symptoms on the ESAS-re that patients can also rate on a scale of 0-10, such as insomnia, constipation, and diarrhea
Emotional symptoms

- Depression and anxiety
- Grief
- Poor coping skills
- Distress related to poorly controlled physical symptoms such as pain and nausea

✓ Increased emotional/psychological distress can worsen other symptoms such as pain; depression can increase the risk of suicidal ideation and potentially requests to hasten death
Social symptoms

- Difficulties with access to care
- Unstable housing situation (homeless, etc)
- Lack of ability to pay for essential goods (food)
- Financial burden: paying for medications, caregiver has to stop working to care for patient, transportation costs
- Caregiver burnout
- Changes in partner/family dynamics: is one partner, who was usually in the caregiver role, now taking care of his or her wife/husband/significant other?
• Limited financial resources can affect how the patient is cared for
  • Will the caregiver lose his job if staying at home for another month is best for the patient?
  • Can the person afford her pain medications?

• Change in family roles can increase stress in the family
  • Is the partner willing to care for the other? Will that partner needing help allow the other person to care for him or her?

• Caregiver burnout can affect how the patient is cared for
• Spirituality is not the same as religion
  • Spirituality can be thought of as how a person seeks and expresses meaning or purpose of being
  • Religion is often considered an organized expression of spirituality by belonging to a specific system of faith
  • Some people consider themselves spiritual without identifying with a particular religious faith or denomination and express their spirituality in individual ways that may influence their health care needs
Spiritual symptoms

- Fear of dying
- Fear of abandonment from God
- Viewing disease as a punishment—“Why me?”
- Seeking to understand the meaning of his or her suffering or pain in a religious/spiritual context
- Does religious belief guide the patient on pain management or how aggressive to continue to be in the face of declining health?
  - If so, is this causing distress to the patient?
  - Is this a source of comfort to the patient?
Spiritual symptoms

- Spiritual distress can worsen physical symptoms
  - Can present as a deep pain that is not relieved with opioids
- Spiritual distress can worsen emotional/psychological symptoms such as anxiety
- Spiritual distress can worsen social symptoms if there is unresolved arguments with family members, for example

➢ It is important to identify if the person is having spiritual distress and involve the chaplain if needed
Spiritual assessments

• “Do you consider yourself a spiritual person?”
• “Do you struggle with the loss of meaning and joy in your life?”
• “Do you currently have what you would describe as religious or spiritual struggles?”
• HOPE
  H: Sources of hope, meaning, comfort, strength, peace, love and connection
  O: Organized religion
  P: Personal spirituality and practices
  E: Effects on medical care and end-of-life issues
Responding to emotions

**NURSE**

- **Naming**
  - This must be frustrating/overwhelming/scary...
- **Understanding:**
  - You are right. This isn’t fair.
  - I can see how important ___ is to you.
- **Respecting:**
  - You have done everything we have asked of you.
  - You are such a great advocate for your dad.
- **Supporting:**
  - We will be with you every step of the way.
  - We are here to help you in any way we can.
- **Exploring:**
  - Tell me more about what ___ [fighting, a miracle, etc] might look like for you (or for you dad)
  - Tell me more about what worries you.

**Use “I wish” statement**

- I wish things were different.
- I wish [we had better treatments for your cancer].
Communication aides

- Ask-tell-ask
- SPIKES: communicating serious news
- REMAP: communicating to achieve a shared decision
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<tr>
<th>Ask</th>
<th>Tell</th>
<th>Ask</th>
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<td><strong>Ask: Assess patient (family) understanding</strong>&lt;br&gt;• “What have the doctors told you about your medical condition?”&lt;br&gt;• “What do you think about....?”&lt;br&gt;• Avoid: “What is your understanding of what the doctors have told you?”</td>
<td><strong>Tell: Provide information in small amounts</strong>&lt;br&gt;• Make sure you know what information the patient/family wants to know &amp; who should be present during the conversation BEFORE the conversation</td>
<td><strong>Ask: check understanding</strong>&lt;br&gt;• Can you tell me about the [two options] we spoke about?&lt;br&gt;• What questions do you have about what we discussed?</td>
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• Premeeting: what do you know about what is important to the patient?
  • In previous encounters, have you asked “What should I know about you (or about mom, etc) to help me provide you (or your mom) with the best care?”
  • Do you know who should be at the visit (patient, which loved ones) and what type of information the patient/loved ones want to know about?

• Setting: prepare for the meeting
  • Make sure there is enough seating, minimize distractions

• Perception: assessing how the patient/loved ones view the medical situation
  • “Can you tell me what have the doctors told you (and your family) about your medical condition so far?”

• Invitation: is the patient/loved one ready to receive the information?
  • “Would it be okay if we talked about [the results of your scan]?”

• Giving knowledge and information to the patient/loved ones
  • Give small amounts of information at a time; use straight-forward language (minimize medical terms)

• Addressing emotions with empathic statements
  • NURSE and I wish statements

• Strategy and summary: discuss next steps and a follow up plan
REMAP:
Reframe
Expect Emotions
and Empathize
Map the future
Align with values
Propose a plan

• Reframe: clarify what the patient (loved ones) know and then reframe the details of the patient’s health status into a bigger picture rather than starting with too many details
  • “You have been through a lot during this hospitalization. I am worried that by continuing [a certain treatment], it is causing you more harm than good.”

• Expect Emotion
  • NURSE and “I wish...” statements

• Map out values: explore what is important to the patient/loved ones, hopes and worries
  • “In order to figure out the best plan for you, is it okay if we talk about what is most important to you at this point?”
  • “You have said spending time with your children is important to you, what else?”
  • “When you think about your future, what worries you?”

• Align with values: reflect back to patient/loved ones what is most important
  • “From what you have been telling me, it sounds like time with your family is most important to you right now.”
  • “From what you are telling me, it sounds like your [dad] values....”

• Propose a plan that aligns with the values discussed
References


