Health Literacy and Palliative Care: The Family Caregiver Perspective

Carol Levine
Director, Families and Health Care Project
United Hospital Fund
IOM Roundtable, July 9, 2015
Health Literacy Is Hard To Achieve

- Obtaining, processing, and understanding basic health information and services is a high standard for patients and family caregivers.
- Health care environment is constantly changing and becoming more complex.
- Need to understand insurance, bureaucratic language, and institutional arrangements, not just medical terminology.
- Understanding “services” may be harder than understanding “basic health information.”
What a Caregiver Expects from the Health Care System
What a Caregiver Actually Experiences
Why is Palliative Care So Hard to Understand?

• Hard to spell
• Hard to pronounce
• Confusion between hospice and palliative care
• Even professionals don’t share same definition
  • Palliative care doctors—specialized medical care
  • Home care nurses—ordinary care for sick people
  • Long-term care staff—keeping resident quite and comfortable
Before Learning New Information, Have to Unlearn Misinformation

- “Palliative care is for dying people”
- “Palliative care is offered just to save the government money”
- “Palliative care means giving up hope”
- “Pain drugs lead to addiction”
- “You have to be in a hospital to get palliative care”
- “Insurance won’t cover palliative care at home”
- “Palliative care means the doctor is abandoning the patient and family”
Special Challenges for Family Caregivers

- Intense emotional component
- Making health care decisions with or for another person
- Conflict or different levels of understanding within family
- Not part of health care team—feeling excluded
- Concern about affordability
- Concern about being able to provide complex care at home
Family Caregivers Want Information

• United Hospital Fund’s Family Caregiver Guide to Hospice and Palliative Care
  • www.nextstepincare.org/Caregiver_Home/Hospice
  • Most frequently downloaded guide in English and Spanish
  • Also available in Chinese and Russian; all free
  • Popularity suggests that family caregivers are not getting information from health care providers
  • Chart compares hospice and palliative care
Hospice and palliative care: A comparison

<table>
<thead>
<tr>
<th>Goals</th>
<th>Palliative Care</th>
<th>Hospice Care</th>
</tr>
</thead>
<tbody>
<tr>
<td>To assess and treat the patient’s pain and other physical, psychosocial, and spiritual problems.</td>
<td>To keep the patient comfortable, as free as possible from pain and symptoms, and allow him or her to maintain a good quality of life for the time remaining. Hospice accepts death as an inevitable outcome for a patient with a terminal (end-stage) illness. In hospice, both the patient and family are the focus of care.</td>
<td></td>
</tr>
<tr>
<td>Patients</td>
<td>Palliative care accepts patients who have complicated or advanced medical disease. There is no time limit in terms of life expectancy – patients may or may not be dying. Patients can get treatments intended to cure. They also can participate in research studies.</td>
<td>Hospice only accepts patients who are near the “end of life” (meaning they have a terminal illness) and are likely to die within 6 months if the disease runs its normal course.</td>
</tr>
<tr>
<td>Where care occurs</td>
<td>Palliative care is usually given in hospitals. Sometimes it takes place at nursing homes or assisted living facilities. Palliative care at home is possible but not readily available.</td>
<td>Most hospice care happens at home, although it can also be given in other settings as well, such as the hospital, nursing home, or assisted living facility.</td>
</tr>
<tr>
<td>Who provides the care</td>
<td>Palliative care is a medical subspecialty. This means that doctors and nurses who practice palliative care have extra training about ways to manage symptoms. They work with a team of other professionals.</td>
<td>Hospice care is a team approach, led by doctors and nurses with special training. Specialists may provide spiritual, psychosocial and other care. Hospice care may require a lot of time and effort from the family.</td>
</tr>
<tr>
<td>Paying for services</td>
<td>There is no special insurance benefit for palliative care. The patient’s health insurance generally covers palliative care services.</td>
<td>Hospice is a Medicare (federally funded) program. Many state Medicaid plans and private health insurance plans pay for hospice. A patient who chooses the Medicare hospice benefit agrees to give up treatments meant to cure disease. This is in return for other types of support and supplies.</td>
</tr>
</tbody>
</table>
Caregiver Assessment as a guide to Discussion

• Acknowledge that there is a lot to learn about palliative care and how it will affect patient and family
• Learn about the caregiving situation; who does what for the patient?
• What are the caregiver’s other responsibilities and limitations?
• Probe worries and concerns
• Be available to answer additional questions
Enhancing Family Caregivers’ Health Literacy about Palliative Care

- Start discussions early, not while in crisis
- Use simple definition of palliative care
- Remember to dispel myths
- Emphasize the benefits
- Involve family caregiver(s) at every stage
- Listen to concerns
- Offer support and training for family caregiver(s)
- Answer questions and repeat information as often as needed
The Four Habits Approach to Effective Communication

1. Invest in the beginning—develop trust
2. Elicit the patient’s and family caregiver’s perspective—listen
3. Demonstrate empathy—words and body language
4. Invest in the end—summarize and review next steps

Source:
Thank you

Carol Levine
clevine@uhfny.org
212-494-0755

United Hospital Fund’s Next Step in Care website
www.nextstepincare.org