Strategies to Assist in Optimal Timing for Hospice Referral

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OBJECTIVES

- Review the continuum of palliative care and hospice
- Understand barriers to, and the importance of, timely referral to hospice
- Recognize when and how to begin end of life discussions with patients and families
- Review communication strategies for end of life and goals of care discussions

Institute of Medicine Report

DYING IN AMERICA:

Improving Quality and Honoring Individual Preferences Near the End of Life

"A substantial body of evidence shows that broad improvements to end-of-life care are within reach."

2014

IOM Report – Delivery of Person-Centered, Family Oriented Care

- People nearing end of life often experience multiple apparently preventable hospitalizations
- Demand on families is increasing
- Palliative care is associated with higher quality of life and, on average, longer life*
- Widespread adoption of timely palliative care nonetheless appears slow

IOM Report – Clinician-Patient Communication and ACP

- Most patients unable to make their own decisions about care at end of life, and will receive care in hospital from physicians who do not know them, therefore ACP is essential

- Most choose care focused on relief of pain and suffering; ACP and medical orders are needed because the default mode in hospitals is acute care

- Frequent conversations about end of life care values, goals and preferences are necessary to avoid unwanted treatment. However, most people – particularly younger, poorer, minority, and less-educated individuals, do not have these conversations. Clinicians need to initiate these conversations about end of life care choices and work to ensure that patient and family decision making is based on adequate information and understanding.

IOM Report – ACP cont’d

- All individuals should have opportunity to participate
- Clinicians initiate high quality conversations about ACP, integrate those into plans and communicate those with other clinicians
- Clinicians to revisit advance care planning discussions with their patients because individuals’ preferences and circumstances may change over time

IOM Report – ACP cont’d

- Incentives, quality standards, and system support are needed to improve clinician communication skills and more frequent and productive clinician-patient conversations

IOM Report – Professional Education and Development

- Problem remains: deficits in equipping physicians with sufficient communication skills

IOM Report – Policies and Payment Systems

- Incentives under fee-for service Medicare result in more use of services, more transitions and late referral to hospice
- Payment silos contribute to care fragmentation, hinder coordination across providers and encourage inappropriate utilization
- Changes are needed to incentivize comprehensive palliative care

WHO Definition

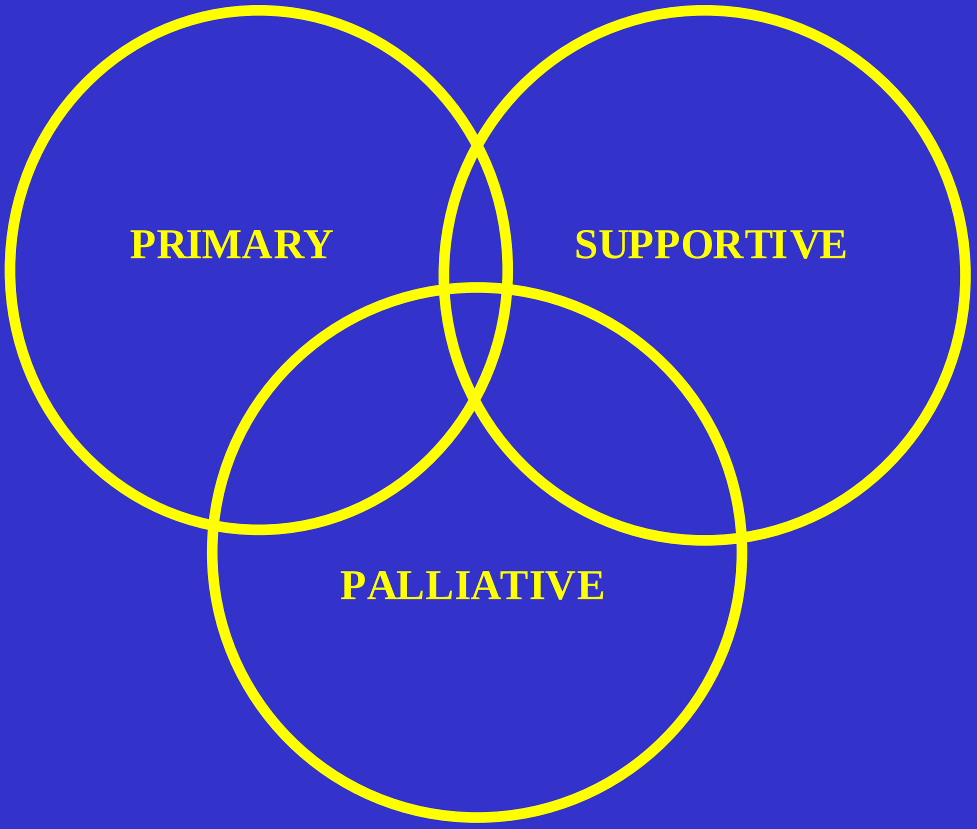
"*Active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families*."

Delivery of Palliative Care and Hospice

- Primary team alone
- Primary and Palliative Care teams together, collaborative care
- Transfer to specialty Palliative Care
- Transfer to Hospice Care

Integrated Palliative Care

SM Weinstein MD, FAAHPM



Palliative Care Goals

- Essential goal is to reduce (prevent and relieve) suffering = better quality of life

  … *quaternary prevention* …

- Improve patient’s functional status
- Improve family functioning

SM Weinstein MD FAAHPM

Advance Care Planning

- Goals discussion
- Advance directives – in hospital orders
- Advance directives – out of hospital

Hospice

- A benefit
- Part of H&PM with special emphasis on end of life care

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Hospice Outcomes

- Safe and comfortable death for patient
- Support family bereavement
- *"God may have a plan for you, but he doesn't have a plot (SMW 1/14) …"*

Policy Statements and Guidelines Promote *Integrated Palliative Care*

- National Consensus Project for Quality Palliative Care

  Patient and family needs assessed throughout the continuum, routinely integrate PC into care, often requires expertise of multidisciplinary group

Policy Statements and Guidelines Promote *Integrated Palliative Care*

- WHO

  PC enhances quality of life and may also positively influence the course of illness

- 1990 – begin at time of diagnosis

Policy Statements and Guidelines Promote *Integrated Palliative Care*

- ASCO – achieve the vision of comprehensive cancer care by 2020

VA – HOSPICE and PALLIATIVE CARE

The VA defines Hospice and Palliative Care as a continuum of comfort-oriented and supportive services provided across settings, including hospitals, extended care facilities, outpatient clinics and the private residence

VA PROMISE SURVEY

PROCESS OF CARE	Average increase in the percent of families reporting “Excellent” care
•Palliative care consultation	18%
•Care in a dedicated hospice unit	14%
•Documented discussion about the Veteran’s goals for care with a family member	19%
•Chaplain visit with a family member	9%
•Chaplain visit with a Veteran	8%
•Bereavement contact	7%
• Do Not Resuscitate order	25%

Palliative Care Evidence

- Growing evidence that palliative care improves clinical outcomes and quality of life
- Growing evidence that family satisfaction with end of life care improves when palliative care is provided prior to a patient’s death
- Earlier palliative care may reduce health care resource utilization and costs

Why are hospice referrals delayed?

- Professional barriers
- Patient barriers
- Family barriers
- System barriers

Challenges and Issues

- Physicians/providers commit to practice medicine honestly and to “first do no harm”
- However, we often withhold information when communicating with seriously ill patients about their diagnosis, treatment options, and prognosis
- Failure to communicate “the truth” may be purposeful, done with the good intention of protecting the patient from harm, or it may be unintended
- *Does it matter*?

THE MISMATCH

- Doctors often ignore or misunderstand what patients want in terms of treatment, and this "preference misdiagnosis" can be harmful to patients
- In one study, authors reported doctors cannot recommend the right treatment without fully understanding a patient's preferences, yet evidence suggests there are often large gaps between what patients want and what doctors think they want
- Such 'preference misdiagnosis' can lead to costly, unwanted treatments

BMJ.2012Nov8;345:e6572.doi:10.1136/bmj.e572.
Stop the silent misdiagnosis: patients' preferences matter.
Mulley AG, Trimble C, Elwyn G.

Challenges and Issues

- Autonomy has gradually become the key concept in the doctor-patient relationship, yet “truth telling” is far from the norm

Autonomy and Informed Choice

- The clinical ethical principles of autonomy and informed choice require that patients have the information necessary to make medical decisions on their own behalf
- In reality, the process of care is dynamic with multiple people involved as a patient experiences a serious illness over time

Barriers to Communication

- Avoidance/Ambivalence – professional
- Avoidance/Ambivalence – patient/family

- Physical
- Language
- Literacy
- Health literacy
- Cognitive deficits
- Psychological barriers
- Family dynamics

Communication

- Caring for seriously ill patients and families is a process that usually requires many communications over time as the patient’s condition changes

- What do we mean by the truth?

- The patient/family has “truth” to communicate that is equally important to the “truth” we need to communicate

Patient and Family Truths

- Values
- Preferences
- Goals
- Meaning
- Caregivers’ perspectives

Truth Telling

- The patient/family need information regarding disease, prognosis and treatment options to make informed choices

- Providers are required to have communication skills and cultural competency – *this is a tall order!*

Truth Telling

- Sometimes called “breaking bad news”
- SPIKES protocol
- Have conversations in the context of a therapeutic relationship, repeatedly over time

If when is NOW, then HOW?

- Acknowledge the importance of patient/family involvement in creating a treatment alliance and plan
- Identify a communication framework for discussing end of life care with patients and families
- Need “truth telling” communication skills for these difficult discussions
- There has been shown to be an improvement in patient satisfaction and patient/family grieving process with the use of a “truth telling” communication approach

SPIKES

- 1 *s*etting up the interview
- 2 assessing the patient's *p*erception
- 3 obtaining the patient's *i*nvitation

SPIKES

- 4 giving *k*nowledge and information
- 5 addressing patient's *e*motions and empathic responses
- 6 *s*trategy and summarizing

Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: Application to the patient with cancer. Oncologist. 2000;5:302–11.

Truth Telling -> Conversation

Having conversations in the context of a therapeutic relationship:

… the patient is comfortable …

- Simple statement of expectations and time
- LISTEN – keep your ears on
- Values, preferences, goals
- Disease course, prognosis, treatment
- Resources
- Advance care planning, directives
- Conclude – what was achieved, what’s next

Communication Issues – Who are the Participants?

- Does the patient have the capacity to make medical decisions?

YES – with family members
YES – but no family members

TEMPORARILY INCAPACITATED – wait

NO – with a designated surrogate
NO – with no designated surrogate
    -> may have to obtain a guardian

Communication Issues – What

- What discussions need to occur, ie content:

  - disease status
  - prognosis
  - treatment options
  - advance care planning = DNR/DNI, other future treatments, caregiver issues, disposition

Communication Issues – What

DEATH

- “How much time do I have?”
- “What is going to happen to me as I’m dying?”
- “How will I die?”
- “What is going to happen to me after death?”

- “How will s/he die?”
- “What can we expect to see and do in the agonal phase”? ***
- “What do we do after s/he dies?”

Communication Issues – When, How Much, Getting to Goals

- Providers must first assess the patient/family readiness for information, and their ability to understand and assimilate highly complex clinical information

- Providers must elicit the patient’s values and preferences, and also must know what resources are available – all goes in the crucible of reality so that appropriate goals can be formulated

Challenges and Issues

- Providers often avoid end of life discussions
- Providers and patients are ambivalent and may wait for signals to initiate conversation

Curr Opin Support Palliat Care. 2012 Sep;6(3):355-64. doi: 10.1097/SPC.0b013e328356ab72.

Challenges in end-of-life communication.

Galushko M, Romotzky V, Voltz R.

Challenges and Issues

- Patients and caregivers agree that truth telling should be a 'dosed and gradual' process

Patient Educ Couns. 2008 Apr;71(1):52-6. Epub 2008 Jan 3.

Truth-telling at the end of life: a pilot study on the perspective of patients and professional caregivers.

Deschepper R, Bernheim JL, Vander Stichele R, Van den Block L, Michiels E, Van Der Kelen G, Mortier F, Deliens L.

- Patients often have poor understanding of their medical conditions

Surrogates and Truth Telling

- 93% (166 of 179) want the truth
- Facilitates family in their medical decision making, support for one another, and their overall planning
- Surrogates believed that avoiding discussions about prognosis was not an acceptable way to maintain families' hope
- Suggested there is a relationship between early disclosure about a patient's prognosis and families' initiation of preparatory processes that may mitigate adverse bereavement outcomes

Latifat Apatira et al *Ann Intern Med*.
2008 December 16; 149(12): 861–868.

SURROGATES PERSPECTIVE

- Overall, surrogates felt that avoiding discussions about prognosis is NOT an unacceptable way to maintain hope. The main explanatory theme was that timely discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of a patient's death. Other themes that emerged included surrogates' belief that an accurate understanding of a patient's prognosis allows them to better support the patient and each other, a moral aversion to the idea of false hope, the perception that physicians have an obligation to discuss prognosis, and the notion that some surrogates look to physicians primarily for truth and seek hope elsewhere. A few surrogates (6 of 179) felt that physicians should withhold prognostic information because of a belief that discussing death could be emotionally damaging to the family or could negatively affect the patient's health.

SURROGATES PERSPECTIVE

- Emotional preparation is a process that requires time to unfold
- Knowing about a poor prognosis also meant that family members would have the chance to say final words
- IT IS OUR OBLIGATION TO BRING AWARENESS OF IMPENDING DEATH TO FACILITATE HEALING AT END OF LIFE

HOPE

- Hope is never false
- Hoping for the best while preparing for the worst
- Hoping (praying) for a miracle and accepting medical information
- Planning for uncertainty

HOPE

- A recent study showed that 57% of Americans believe that divine intervention could save a person when physicians believe treatment is futile. Twenty percent of physicians also endorsed this belief.

Jacobs LM, Burns K, Bennett Jacobs B. Trauma death: views of the public and trauma professionals on death and dying from injuries. Arch Surg 2008;143:730–5

Hope and Truth Telling

- Truth-telling in healthcare practice can be regarded as a universal communicative virtue; however, there are different views on what consequence it has for giving or diminishing hope.

  The aim of this article is to explore the relationship between the concepts of truth-telling and hope from a relational ethics approach in the context of healthcare practice. Healthcare staff protect themselves and others to preserve hope in the care of seriously sick patients and in end-of-life care. This is done by balancing truth-telling guided by different conditions such as the cultural norms of patients, family and staff. Our main conclusion is that the balancing of truth-telling needs to be decided in a mutual understanding in the caring relationship, but hope must always be inspired. Instead of focusing on autonomy as the only guiding principle, we would like to propose that relational ethics can serve as a meaningful perspective in balancing truth telling.

Nurs Ethics. 2012 Jan;19(1):21-9. Epub 2011 Dec 2.
Balancing truth-telling in the preservation of hope: a relational ethics approach.
Pergert P, Lützén K.

Not Telling the Truth

- Cultural disparities in attitudes towards truth-telling persist; however, these differences should not be used as excuses not to respect the rights and individual preferences of cancer patients by making assumptions based on their age, sex, type of cancer, language and/or cultural background.

Eur J Cancer Care (Engl). 2010 Sep;19(5):589-93. Epub 2009 Dec 3.
Not telling the truth: circumstances leading to concealment of diagnosis and prognosis from cancer patients.
Shahidi J.

Communication – The Palliative Care Team

- The interdisciplinary palliative care team members share responsibility for communicating with the patient and family, as well as with other professionals

- Each team member contributes importantly to “truth telling” and supporting the patient/family in medical decision making and advance care planning

Teaching Communication Skills to Patients and Families

- Patients/families also need communication training
- A comprehensive literature review of studies describing communication interventions for patients receiving end-of-life care was undertaken. Ten electronic databases were searched. Inclusion criteria were all English language studies relating to patient-professional communication interventions for patients with life-limiting conditions receiving end-of-life care.
- **RESULTS:**

  Of the 755 articles initially identified, 16 met the inclusion criteria. Three core themes emerged from the synthesis of the literature using education to enhance professional communication skills, using communication to improve patient understanding, and using communication skills to facilitate advance care planning.
- **CONCLUSION:**

  Although limited, evidence relating to the development and evaluation of communication interventions for patients with life-limiting illnesses would suggest that a successful intervention should include combined components of training, patient discussion, and education.

J Pain Symptom Manage. 2012 Jul 21. [Epub ahead of print]

Enhancing Patient-Professional Communication About End-of-Life Issues in Life-Limiting Conditions: A Critical Review of the Literature.

Barnes S, Gardiner C, Gott M, Payne S, Chady B, Small N, Seamark D, Halpin D.

TIPS FOR PATIENTS AND FAMILIES

- “How to talk to your doctor”

- Taking an active role in your health care can help you get the best care possible from your doctor. One way to do this is to improve your relationship with your doctor.

Offers tips to help patient and the doctor improve patient’s health care together.

American Family Physicians

Teaching Physicians

- Experiential learning methods with video feedback
- Well received
- Role models
- Practice makes perfect

Palliat Med. 2012 Jun 18. [Epub ahead of print]

Evaluation of a novel individualized communication-skills training intervention to improve doctors' confidence and skills in end-of-life communication.

Clayton JM, Butow PM, Waters A, Laidsaar-Powell RC, O'Brien A, Boyle F, Back AL, Arnold RM, Tulsky JA, Tattersall MH.

Self-Awareness

- The population of older adults in the United States is growing in size and diversity, presenting challenges to health care providers and patients in the context of health care decision making (DM), including obtaining informed consent for treatment, advance care planning, and deliberations about end-of-life care options. Although existing literature addresses providers' need to attend to patients' cultural values and beliefs on these issues, less attention has been paid to how the corresponding values and beliefs of providers color the care they deliver and their assessments of older adults' DM capacity.

  The provider's challenge is to understand her own unacknowledged anxieties, prejudices, and fears around such charged issues as truth telling, individual agency, capacity, death and dying, and the value of life itself and address their impact on the delivery of care. A social constructivist perspective and the clinical concept of cultural countertransference are proposed as aides in achieving this awareness and improving care.

Gerontologist. 2012 Dec;52(6):739-47. doi: 10.1093/geront/gns008. Epub 2012 Mar 8.
Turning the lens inward: cultural competence and providers' values in health care decision making.
Chettih M.

THE ART ♥

- Health professionals need to initiate end-of-life communication in a sensitive way. Specific demands for health professionals in end-of-life communication are to differentiate ones own emotions and life events from those of patients and to deal with both adequately.

Curr Opin Support Palliat Care. 2012 Sep;6(3):355-64.
doi: 10.1097/SPC.0b013e328356ab72.
Challenges in end-of-life communication.
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CONCLUSIONS

- Communication skills and a general operating framework are necessary for providers to follow when engaging in end of life discussions with patients and families

- The interdisciplinary palliative care team members support one another and other healthcare professionals in this very important, often challenging, and profoundly rewarding work

IOM Report –
Public Education and Engagement

- Calls for broad education, encourages ACP and informed choice based on individual needs and values
- Time to normalize conversations about death and dying!

-> Health care delivery organizations, public health & other government agencies, payers, civic leaders, consumer groups, faith-based organizations, employers, health care professional societies and their members should work collaboratively in the effort to educate and engage the public, share successful strategies and promising practices

DISCUSSION