Communication at the End of Life

Ian Anderson Continuing Education Program
in End-of-Life Care

Communication at EOL

- Crucial to convey:
  1. Seriousness of illness
  2. Expected course
  3. Treatment options, risks and benefits
  4. Empathy, Support and Caring

- Help in decision-making/advance care planning
- Aid in alleviating pain and distress

Objectives

- Demonstrate skill in communicating with seriously ill patients and families
- Be able to break bad news & respond to the needs of patients and families
- Clearly and honestly address the concerns of patients and families
- Know the consequences of the language used to impart information
- Demonstrate skill in communicating to facilitate decision-making

Objectives (2)

- Demonstrate communicating in such a way that hope is not destroyed yet avoid providing false hope
- Demonstrate empathy and caring both verbally and non-verbally
- Demonstrate sensitivity to culture and religious beliefs
- Demonstrate skill in communicating in special situations: 1) over the phone, 2) with other professionals, 3) with family members from away

Effective Communication

- Skill which can be learned
- Convey information
- Build trust
- Convey empathy and caring
- Decision-making
- Improve quality of care

Goals of Communication at EOL

- Convey respect & understanding for the patient as a person
- Convey information about illness, likely course and treatment options
- Convey empathy and support
- Convey appropriate hope
- Develop a treatment plan in context of person's value history
- Arrange F/U and ongoing caring and support

Barriers due to Patients & Families

- Misunderstandings
- Biases
- Lack of knowledge of death
- Re-alignment of family roles
- Lack of support, coping mechanisms ⇨ crisis
- Physical & emotional depletion
- Strong emotions
- Differences in values, beliefs and culture

Barriers due to Healthcare Providers

- Depth of relationship with patient
- Fears of uncertainty in diagnosis/prognosis
- Personal & professional experiences with illness & death
- Fatigue, psychological & emotional stress
- Fears of own mortality
- Lack of education
- Fear of emotions (own & others)
- Personal beliefs, values
- Bias
- Fears of being messenger
- Iatrogenic complications
- Unrealistic expectations of success
- Inconsistent approach: “mixed messages”

Barriers due to Healthcare System

- Time constraints/Size of practice
- Lack of previous relationship
- Lack of privacy in hospital/clinic/hospice
- Interruptions

Communication at the EOL-Preparation

- Review chart and test results
- Discuss with other team members:
  1. Purpose
  2. Information that needs to be conveyed
  3. Team's perception of the patient's/family's knowledge, understanding, emotional state
- Decide who will be present
- Ask patient if they want information to be conveyed to family/surrogate instead
- Fix a time/aim to avoid interruptions

A 9-Step Approach to Communication at EOL

1. Start the meeting
2. Agree on purpose
3. What does patient/family/SDM know?
4. What information is necessary for decision-making?
5. Share the information/respond to emotions

A 9-Step Approach to Communication at EOL

6. Discover goals/hopes/expectations/fears: "Values History"
7. Address their needs
8. Develop a plan
9. Follow up

Start the Meeting

- Quiet, private place
- Avoid hallways, doorways, communal waiting rooms
- Sit
- Introduce team and explain roles
- Ask family to introduce themselves and explain relationship to patient

Builds relationship with patient & family

Purpose

- To update (from your point of view or theirs)
- To break bad news
- To discuss a decision point
- To provide emotional and psychological support

What do they know?

- Most have thoughts or beliefs about illness
- Allows you to assess:
  1. Language used
  2. Level of understanding
  3. Misconceptions/misinformation
  4. Time of last update/information retained/understood
  5. Emotional state/coping abilities

Asking what they know…

- Conveys that you value what they think and feel
- Strengthens relationship
- Summarize what was said ⇒ confirms listening and understanding
- Check patient's/family's understanding to this point

How much information is needed?

- Diagnosis, likely course, prognosis
- Treatment alternatives, risks, benefits
- Effect on quality of life, goals, values, beliefs, expectations, fears
- Pain and symptom palliation
- Expected and anticipated decisions
- Dying process, location of death, available health care support

Sharing the Information

- Simple and clear
- Language of fluency, appropriate to level of understanding
- Wait for reactions
- Listen to concerns, fears, hopes & expectations
- Be attuned to emotions AND address them
- Show empathy and compassion
- Summarize
- Are there questions, concerns?

Avoid

- Talking down to patients and families
- Jargon
- “Why” questions: justification, promotes defensiveness
- Language you would use with a colleague
- Euphemisms
- Do NOT say: “I know what you are going through”

  “I know what you feel”

  “I know how hard this is”

Prognosis

- Expect to be asked
- May ask in order to make decisions and/or to confirm seriousness
- Explain in generalities: days to weeks, weeks to months, months to years

from Buckman R., *How to Break Bad News: A Guide for Health care Professionals*, Johns Hopkins University Press Baltimore 1992).

- May lead to EOL decision-making discussions

Non-Verbal Communication

- Facial expressions
- Gaze
- Head movement
- Posture
- Interpersonal distance
- Touch
- Voice

Adapted from Hall JA, Affective and Non-Verbal Aspects of the Medical Visit, The Medical Interview, Lipkin M Jr, Putnam SM, Lazare A eds., Springer 1994 p. 499

Common Emotional Response to Patient/Family Emotions Things to Avoid

- Diversion
- Withdrawal
- Jargon
- Provision of false hopes of cure or greater likelihood of benefit
- Inappropriate destruction of hope

Better Responses – Things to do

- Don’t be afraid of silence
- Don’t abandon
- Don’t make promises
- Don’t give false reassurances
- Recognize the power of non-verbal communication
- Develop a plan with patient and family
- Explore goals, hopes, expectations and fears

Patients'/Families' Responses When Faced with Unexpected or Bad News

- Shock
- Grief
- Fear
- Guilt
- Anxiety
- Anger
- Bargaining
- Over-dependency
- Shielding
- Disbelief
- Denial
- Displacement
- Depression

From Buckman R., *How to Break Bad News: A Guide for Healthcare Professionals*, Johns Hopkins University Press Baltimore 1992

Take a Values History

- Decisions need to be made in context of goals, values, beliefs, expectations and fears

- Need to discover goals to:

1. see patient as person
2. provide emotional and psychological support
3. develop a Rx plan respecting dignity of person
4. recognize person as different from the provider

Address their Needs

Depends on purpose:

1. Bad news: explore & respond to immediate needs for empathy & support

2. Decision-Making: explore understanding, remaining questions, need for more time, empathy/comfort with decision

3. Convey support: pain/symptom control, coping abilities

Develop a Plan

1. **Bad News:** When will more information be available? Who will need to be consulted? When you will next meet?
2. **Decision-Making:** What decisions are anticipated? Time frame? How will they affect goals?
3. **Support:** What are we going to do? How can we help improve coping abilities and quality of life? How can we diminish fears?

Arrange for Follow Up

- Invite them to share un-addressed concerns
- Normalize their experience
- Acknowledge the likelihood of misunderstandings in emotionally charged circumstances
- Provide contact information and time of next meeting

Mistakes

Can be retrieved:

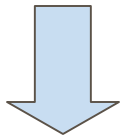
1. by sharing your emotions
2. by apologizing
3. by backing up and explaining medical jargon

Talking with Families of Capable Patients

- Done only with patient's consent and knowledge
- Serious illness may mean patient and family = unit of care
- Supporting family may help family support loved one
- May help them express love and caring
- Need time to express emotions
- Be prepared to arrange for additional support

When Families are Separated by Distance — Common Problems

- News conveyed over the phone and/or by other family members
- Misunderstanding and miscommunication common
- Anxiety, guilt, disbelief, denial, anger common



- Sense of urgency/Seen as “demanding”

When Families are Separated by Distance — An Approach

With a capable patient's consent & knowledge

- Be prepared to give bottom line first and explanations later
- Start at the beginning and be flexible
- Crucial to ask them what they know
- Acknowledge the difficulties of living away
- Recognize and deal with emotions

Communication Over the Phone

- Introduce yourself & ask who you are speaking to
- Keep it clear and simple
- Invite them to hospital/office for more details
- Listen for emotions (tone of voice)
- Difficult silences: Shock? Understanding? Asleep?
- Be empathetic
- Address practical concerns: Driving? Others to call? Anyone there to support?

When Language is a Barrier

- Arrange for a translator
- Ideally not a family member
- Role is to translate NOT expand
- Confidentiality
- Warn translator about nature of news/purpose of meeting in advance
- Give information in small chunks and check understanding

Professional as Patient or as Family Member

- Increased educational needs
- Illness may affect ability to think and cope
- If treated as a colleague may not receive needed empathy and support
- Acknowledge expertise and give support
- May not have in-depth knowledge of current illness and Rx