

Communication at End of Life

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Objectives

- Learn about common barriers to effective EOL communication strategies
- Discuss key strategies for breaking bad news
- Explore the timing of this communication
- Explore guidelines & tips for improving communication to achieve better end of life care for patients and their families

Poor communication leads to
more suffering, except for pain,
and is the easiest to treat.

Hippocrates, 600 AD

Breaking Bad News

“In general, the most common problems are caused by relatively simple errors....faults in common courtesy, failures in listening, or failures in acknowledging the patient’s goals and needs.” Robert Buckman
Breaking Bad News

Truths

- ◆ What makes sense for the patient today may not be true tomorrow
- ◆ Patients look to physicians to guide them through their decision making
- ◆ Physicians want to do what is best for their patients
- ◆ Physicians and patients both avoid communicating about topics that are uncomfortable

Professional Myths

- ◆ Bringing up death as a possible outcome 'robs' our patients of their hopes & dreams
- ◆ Admitting that we don't know the patient's exact prognosis makes us appear less competent
- ◆ Incorporating available home hospice care services or palliative care as an option is admitting professional failure
- ◆ Discussing possible eventual death labels us as nihilistic and 'negative'

Professional Truths

- ◆ Integrating palliative care and home hospice services are 'value added' components of advanced disease management
- ◆ Prognostication is still an 'art' with more & more science; it is always individualized
- ◆ Patients typically want honest discussion of all the options of their medical care
- ◆ Palliative care integration is offering a very specialized fund of knowledge & skill

Communication 101

- ◆ Traditionally physicians ask, then tell, tell, tell....listen, ask, then tell some more!
- ◆ Dialogue is a sharing interaction
- ◆ Physicians must be courageous to have the special dialogue it takes to become a part of a patient's journey

Communication 101

Understand non verbal communication
Encourage patient to talk AND listen to
what they say

Respond with empathy

Use appropriate humor, silence, self
disclosure, therapeutic touch, reassurance,
support & hope

Effective skills include

- ◆ Repetition
- ◆ Paraphrasing
- ◆ Reflecting
- ◆ Clarifying responses
- ◆ Honest labeling and gentle confrontation
- ◆ Integration of information

Communication Barriers

- Psychological Barriers
 - Patient Fears
 - Physician Fears
 - Family Fears

Communication Barriers

- Cultural Barriers
 - Lack of personal experience with death
 - Unrealistic Expectations; Denial is common
 - Trust issues; informed refusals are ok
 - Cultural beliefs re: disclosure of information /family role in decision making
 - Religious or belief system impact
 - Economic concerns are normal

Physician Lead is critical

- ◆ Patients look to physicians to bring up issues regarding the clinical options
- ◆ Patients and families voice appreciation for exploring all options of care
- ◆ There are opportunities to bring up best case & worst case scenarios in the journey of care (cure, remission, projected disease trajectories and possibly death)

Communication Barriers

- Listening Barriers
 - Assumption & certainty; “Fix it” mentality
 - Limited attention span & time pressure
- Organizational Barriers
 - Lack of support, clinical expertise & motivation to incorporate others
- Language Barriers
 - cultural, ‘medical-ese’, gaps in education

Buckman's protocol

- Prepare by confirming facts & establishing appropriate physical & emotional environment
- Establish what the patient/family knows & wants to know
- Determine how information is to be handled
- Deliver information in sensitive, straightforward manner
Align & Educate
- Respond to emotions of patients, parents, & families
- Establish goals for care and treatment priorities
- Establish an overall plan

"SPIKES" 6 STEP PROTOCOL

- ◆ Setting up the discussion
- ◆ Patient Perception Assessment
- ◆ Invitation to discuss goals & needs
- ◆ Knowledge sharing
- ◆ Empathizing with the Emotions
- ◆ Summarize and Strategize

- ◆ “Although the individual patient is the focus of treatment, the family is the focus of understanding....”

- ◆ Williamson & Noel

Set up the Discussion

- ◆ Do your homework and collect the facts
- ◆ Know options of the disease trajectory
- ◆ Know WHO should be there (family, HCPOA, other physicians involved in the care)
- ◆ Know your community resources
- ◆ Plan the meeting at an appropriate time

Patient Perceptions

.....framing the dialogue

- ◆ What do they already know?
- ◆ What do they want to know?
- ◆ What do they need to know?

Patient Perception Assessment

- ◆ Tell me about your understanding of the most recent tests
- ◆ Tell me what you think is going on with your heart (your cancer, your lungs)
- ◆ Use open ended questions
- ◆ Tell me more....

Invitation

Discussing Goals & Needs

- ◆ What is most important to you right now?
- ◆ What are your hopes for the upcoming days, weeks, months?
- ◆ What do you enjoy doing now?
- ◆ What are you worried about now and in the future?

Invitation.....

Need assessment gets specific

- ◆ What has been hard for you & your family
- ◆ What is your life like at home?
- ◆ How are you feeling? Sad? Anxious?
- ◆ Are you in pain? Any other symptoms bothering you?
- ◆ Would a visiting nurse or aid be helpful?

Reframing Goals.....

“I wish statements..”

- ◆ I wish I could promise you that but I can't guarantee that will happen....
- ◆ I think I understood you to say that what is most important to you is.....
- ◆ From what we have discussed, it may be helpful to have a

Knowledge Sharing

- ◆ Once individualized goals and needs are understood, sharing knowledge regarding how hospice services can help flows easier
- ◆ Be concrete on the many services offered
- ◆ If patient declines, offer an informational session with home hospice services

Knowledge Sharing

- ◆ Giving patient's clear diagnoses
- ◆ Identifying symptoms as diagnoses
- ◆ Explore the impact on their QOL
- ◆ Practical guidance on how to self educate
- ◆ Continue to include caregivers and decision makers in patient's health care

Empathize with Emotions

- ◆ Empathic responses validate and acknowledge patient's emotions
- ◆ Empathic responses encourage further disclosure
- ◆ Prior experiences or preconceived notions will flavor patients responses and may need to be explored

“NURSE” protocol

- ◆ Naming: It sounds like you are..
- ◆ Understanding: I can see how difficult this is for you and your family..
- ◆ Respecting: I can see how hard you have worked to understand..
- ◆ Supporting: I will support your decisions..
- ◆ Exploring: Tell me more about..

Summarize & Strategize

- ◆ Treatment option discussions are the mainstay of advancing disease management
- ◆ This becomes a huge issue when disease modifying therapies are failing and palliation/QOL becomes a focus of care

When is the Right Time?

Would you be surprised if this
patient died in the next 3-6
months?

Timing of Discussion

- ◆ Eligibility for Medicare Hospice Benefit does NOT equate to appropriateness of when end of life care discussions ought to occur

Triggers for discussion

- ◆ When patient's goals of care and values reflect a change in focus of care
- ◆ Change in clinical status
 - ◆ weight loss, anorexia, dysphagia, cognition failure (Bruera, 2004)
 - ◆ declining functional status
 - ◆ complications of disease directed care
 - ◆ increased hospitalizations

Getting on the same page.....

- ◆ Uncertainty regarding prognosis is a fact and ought not deter a discussion
- ◆ Differing goals of consultants can create problems so establishing patient driven goals and needs sets the course
- ◆ It is our duty to give patients and families as much time as possible to prepare

Choice of Words

- ◆ Hospice Home Nursing
- ◆ Comfort Care
- ◆ Supportive Care
- ◆ Palliative Care
- ◆ Dignity Care
- ◆ Continuation of my care assurance.....

Dignity Conserving Focus

- ◆ Living in the Moment
- ◆ Maintaining Normalcy
- ◆ Seeking Spiritual Growth

Dignity Conserving Goals

- ◆ Continuity of Self
 - ◆ Role Preservation
 - ◆ Legacy
 - ◆ Maintenance of Pride
 - ◆ Hopefulness
 - ◆ Autonomy/ Control
 - ◆ Acceptance
 - ◆ Resilience
- ◆ Chochinov, M., CA: Cancer J Clin 2006

Dignity Conserving Bedside Tool

- ◆ Tell me a little about your life history; particularly the parts that you either remember most or think are the most important?
- ◆ When did you feel most alive?
- ◆ Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?

Dignity Conserving Bedside Tool

- ◆ What are the most important roles you have played in life (family roles, vocational roles, community-service roles, etc)? Why were they so important to you, and what do you think you accomplished in those roles?
- ◆ What are your most important accomplishments, what do you feel most proud of?
- ◆ Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?

Dignity Conserving Bedside Tool

- ◆ What are your hopes and dreams for your loved ones?
- ◆ What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, other[s])?
- ◆ Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
- ◆ In creating this permanent record, are there other issues that you would like included?

DCT: Patient and Professional Satisfaction

- ◆ Pre and post-intervention measures after a 30-60 minute bedside session for 100 terminally ill patients in Canada and Australia
 - ◆ 91% reported being satisfied with dignity therapy
 - ◆ 76% reported a heightened sense of dignity
 - ◆ 68% reported an increased sense of purpose
 - ◆ 67% reported a heightened sense of meaning
 - ◆ 47% reported an increased will to live
 - ◆ 81% reported that it had been or would be of help to their family.
- ◆ **CONCLUSION:** This shows promise as a novel therapeutic intervention for suffering and distress at the end of life.
 - ◆ **Journal of Clinical Oncology**
 - ◆ **August 20, 2005**

Special Circumstances

- ◆ Dementia patients
- ◆ Pediatric patients
- ◆ Managing difficult patients & colleagues
- ◆ Managing stressors and preventing burn out

Effective Team Profile Consideration

- Professional competence
- Current knowledge & skill
- Prior work experience
- Consensus building skills
- Willingness to trust, give up personal agendas, patience, openness, flexible
- Personal & professional insight

Effective Team Profiles

- Respect for each team members specialized body of knowledge
- Being an encourager/exhorter
- Open to improved communication skills
- Appropriate use of humor
- Support of continuing quality improvement

Symptoms of Dysfunction

- Closed vs Open structure (cliques)
- Team leader dysfunction (the kingdom)
- Lack of community collaboration
- Self perpetuation in growth
- Scapegoating or Blaming
- Economic motives surpass clinical care goals

Summary

- GOOD COMMUNICATION IS CRITICAL TO YOUR PERSONAL AND PROFESSIONAL SUCCESS.....

Summary

- ◆ Learn the basics of empathic communication (NURSE)
- ◆ 'Time and allign' discussions for end of life planning with expressed patient goals and needs for optimal success (SPIKES)
- ◆ Incorporate the use of palliative care therapies into advanced disease management early on

Final Thought...

◆ Late Fragment

And did you get what you wanted
from this life, even so?

I did.

And what did you want?

To call myself beloved.

To feel myself beloved on the earth