Communication In Palliative Care

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Objectives

• Review fundamental components of effective communication with patients and their families

• Discuss potential barriers to effective communication in palliative care

• Consider an approaches/framework to challenging communication issues

• Consider challenging communication scenarios, and the impact on families
Setting The Stage

- In person
- Sitting down
- Minimize distractions
- Family / friend possibly present
Silence Is Not Golden

- Don’t assume that the absence of question reflects an absence of concerns.

- Upon becoming aware of a life-limiting diagnosis, it would be very unusual not to wonder:
  - “How long do I have?”
  - “How will I die”

- Waiting for such questions to be posed may result in missed opportunities to address concerns; consider exploring preemptively.
Be Clear

“The single biggest problem in communication is the illusion that it has taken place.”
George Bernard Shaw

Make sure you’re both talking about the same thing

There’s a tendency to use euphemisms and vague terms in dealing with difficult matters… this can lead to confusion… e.g.:

• “How long have I got?”
• “Am I going to get better?”
Titrate information with “measured honesty”

“Feedback Loop”

Check Response: Observed & Expressed

The response of the patient determines the nature & pace of the sharing of information
How does this family work?
When Families Wish To Filter Or Block Information

• Don’t simply respond with “It’s their right to know” and dive in.
• Rarely an emergent need to share information
• Explore reasons / concerns – the “micro-culture” of the family
• Perhaps negotiate an “in their time, in their manner” resolution
• Ultimately, may need to check with patient:

“Some people want to know everything they can about their illness, such as results, prognosis, what to expect. Others don’t want to know very much at all, perhaps having their family more involved. How involved would you like to be regarding information and decisions about your illness?”
Connecting

- A foundational component of effective communication is to connect / engage with that person… i.e. try to understand what their experience might be
  - If you were in their position, how might you react or behave?
  - What might you be hoping for? Concerned about?
- This does not mean you try to take on that person's suffering as your own
- Must remain mindful of what you need to take ownership of (symptom control, effective communication and support), vs. what you cannot (the sadness, the unfairness, the very fact that this person is dying)
Difficult Conversations
Introducing the Topic

- One of the biggest barriers to difficult conversations is how to start them.

- Health care professionals may avoid such conversations, not wanting to frighten the patient/family or lead them to think there is an ominous problem that they are not being open about.

- Discussions around goals of care can be introduced as an important and normal component of any relationship between patients and their health care team.
“I’d like to talk to you about how things are going with your condition, and about some of the treatments that we’re doing or might be available. It would be very helpful for us to know your understanding of how things are with your health, and to know what is important to you in your care... what your hopes and expectations are, and what you are concerned about. Can we talk about that now?”

(assuming the answer is “yes”)

“Many people who are living with an illness such as yours have thought about what they would want done if [fill in the scenario] were to happen, and how they would want their health care team to approach that. Have you thought about this for yourself?”
Patient/Family Understanding and Expectations

Health Care Team’s Assessment and Expectations

What if...?
“I know it’s been a difficult time recently, with a lot happening. I realize you’re hoping that what’s being done will turn this around, and things will start to improve... we’re hoping for the same thing, and doing everything we can to make that happen.

Many people in such situations find that although they are hoping for a good outcome, at times their mind wanders to some scary ‘what-if’ thoughts, such as what if the treatments don’t have the effect that we hoped?

Is this something you’ve experienced? Can we talk about that now?”
1. **Acknowledge/Validate and Normalize**
   
   “That’s a very good question, and one that we should talk about. Many people in these circumstances wonder about that...”

2. **Is there a reason this has come up?**
   
   “I’m wondering if something has come up that prompted you to ask this?”

3. **Gently explore their thoughts/understanding**
   
   - “Sometimes when people ask questions such as this, they have an idea in their mind about what the answer might be. Is that the case for you?”
   - “It would help me to have a feel for what your understanding is of your condition, and what you might expect”

4. **Respond, if possible and appropriate**
   
   - If you feel unable to provide a satisfactory reply, then be honest about that and indicate how you will help them explore that
Discussing Prognosis
DISCUSSING PROGNOSIS

“How long have I got?”

1. Confirm what is being asked (be clear about question)
2. Acknowledge / validate / normalize
3. Check if there’s a reason that this is has come up at this time
4. Explore “frame of reference” (understanding of illness, what they are aware of being told)
5. Tell them that it would be helpful to you in answering the question if they could describe how the last month or so has been for them
6. How would they answer that question themselves?
7. Answer the question
“First, you need to know that we’re not very good at judging how much time someone might have... however we can provide an estimate.

We can usually speak in terms of ranges, such as months-to-years, or weeks-to-months. From what I understand of your condition, and I believe you’re aware of, it won’t be years. This brings the time frame into the weeks-to-months range.

From what we’ve seen in the way things are changing, I’m feeling that it might be as short as a couple of weeks, or perhaps up to a month or two”
Talking About Dying
“Many people think about what they might experience as things change, and they become closer to dying. Have you thought about this regarding yourself? Do you want me to talk about what changes are likely to happen?”
First, let’s talk about what you should not expect.

You should not expect:

– pain that can’t be controlled.
– breathing troubles that can’t be controlled.
– “going crazy” or “losing your mind”
If any of those problems come up, I will make sure that you’re comfortable and calm, even if it means that with the medications that we use you’ll be sleeping most of the time, or possibly all of the time.

Do you understand that? Is that approach OK with you?
You’ll find that your energy will be less, as you’ve likely noticed in the last while.

You’ll want to spend more of the day resting, and there will be a point where you’ll be resting (sleeping) most or all of the day.
Gradually your body systems will shut down, and at the end your heart will stop while you are sleeping.

No dramatic crisis of pain, breathing, agitation, or confusion will occur - we won’t let that happen.
Understanding Families: Transitions Framework

• Helps individuals, families, and caregivers understand, anticipate and address the changing emotional, spiritual, social, or family needs that often arise from diagnosis to death

• It makes these needs normal and expected rather than something that surprises or upsets us

• It encourages the health care team to see the strengths and coping within families, rather than only their struggles and problems

• It improves assessment of psychosocial issues and ensures timely, relevant, congruent intervention

Cairns, Thompson, Wainwright (2003)
The Path Not Chosen

- A new awareness
- Family dissonance
- Isolation
- Uncertain time
- The faces of hope
Challenging Situations

• **Anger:** recognizing sources of anger: threat/loss; multiple losses; guilt; anticipatory grief; fear

• **Persistent anger:** injustice in relationship to society
  - initial grievance/distress not heard
  - lifelong pattern: “wounded”

• **Open conflict:** Often rarely acknowledged, poorly understood emotions
  - Listen beyond words spoken
  - De-escalate think deeply about other person’s position; *hear the story*
  - emotional shift in one party leads to an emotional shift in another
Resistant People

- “small acts of living”
- In response to painful events in their lives, people develop patterns that protect them from the impact of the pain
- Views withdrawal, argumentativeness, suspiciousness as a habituated response to pain
- Approach with curiosity vs. counter resistance

Wade (1997)
Model of Effective Communication

• Observe what is happening in the exchange or what is happening internally

• Acknowledge our feelings associated with the situation

• Acknowledge our need or wish that is unmet or compromised in this situation and gives rise to our emotion. Or, check out the other person’s feelings and needs

• Request or invite the other person to consider another way of dealing with the situation—one more likely to get results that we both want—or offer something that the other seems to be asking of us

M.Rosenberg (1999)
Working with Families with “Seriously Disrupted Relational Abilities”

- Recognize the warning signs: intense unrelenting conflict; hostility; lack of commitment to one another; rifts; history of severe mental illness or disorder

- Be prepared to deal with high level of conflict/instability: regular communication; modest expectations; agree on leadership/roles in family meeting; security plan; include all factions if in agreement with ground rules

- Increase structure of family meetings: clear ground rules; equal participation; firm limits on arguments; direct communication; avoid “taking sides”; very important to debrief

King and Quill (2006)
Relational and Communicative Competence

“Effective communication takes place when practitioners can move fluidly between their position as experts and their position as curious and respectful human beings. Such relationships must be shaped by mutuality and reciprocity”

Browning (2003)
What Families Need

• Acknowledgement
• Understanding
• Communication
• Teamwork
• Healthy Caregivers
Exquisite Empathy

• Highly Present
• Sensitively attuned
• Well-boundaried
• Heartfelt empathic engagement
• Invigorated rather than depleted by intimate connections

Kearney et.al.(2009)
Wounded Healers

- The Hero
- The Martyr
- The Parent
- The Expert
- The Priest

Joan Halifax, Being with Dying (2008)
Palliative Care Mantra

“FEEL DEEPLY
ACT WISELY”

Elisabeth Causton