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
“There’s no easy way I can tell you this, so I’m sending you to someone who can.”
"I'm right there in the room, and no one even acknowledges me."
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 Dx, 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?”
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)
Some Problems Are Easily Predictable
“You might be wondering…”

*Or*

“At some point soon you will likely wonder about…”

- Food / fluid intake
- Meds or illness to blame for being weaker / tired / sleepy /dying?
You don’t need one of these to know that as death nears...

- functional decline occurs
- food/fluid intake decr.
- oral medication route lost
- symptoms develop: dyspnea, congestion, delirium
- family will need support & information
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

What if...?

Health Care Team’s Assessment and Expectations
“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?”
Responding To Difficult Questions

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

“He’s one tough cookie. I’ve never seen anyone bounce back from an autopsy before.”
DISCUSSING PROGNOSIS

“How long have I got?”

1. Confirm what is being asked
2. Acknowledge / validate / normalize
3. Check if there’s a reason that this 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”
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A Workshop for New Parents
Experiencing the Transition
to Parenting
“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.
The Perception of the “Sudden Change”

When reserves are depleted, the change seems sudden and unforeseen.

However, the changes *had* been happening.

That was fast!

*Melting ice = diminishing reserves*
Helping Families At The Bedside: Physical Changes

- physical changes of dying can be upsetting to those at the bedside:
  - skin colour – cyanosis, mottling
  - breathing patterns and rate
  - muscles used in breathing

- reflect inescapable physiological changes occurring in the dying process.

- may be comforting for families to distinguish between who their loved one is - the person to whom they are so connected in thought and spirit - versus the physical changes that are happening to their loved one's body.
Helping Families At The Bedside: Time Alone With The Patient

- family may arrive when the patient will no longer recover consciousness; they have missed the chance to say things they had wanted to

- individuals may wish for time alone with the patient, but not feel comfortable asking relatives to leave

- staff may have a role in raising this possibility, and suggesting they explore this as a family
Can They Hear Us?

The question of “can they still hear us?” frequently arises regarding unconscious patients nearing death … of course it’s not possible to know this, however:

- Hearing is a resilient sense, as evidenced by its potential to endure into the early phase of general anesthesia.

- Hearing vs. an awareness of presence of family… restless, minimally alert patients often settle when family are present.

- In our behaviour at the bedside we should assume that some nature of hearing/awareness/connection is maintained… may influence nature of bedside conversations.
Helping Families At The Bedside: Missed The Death

- some family members will miss being present at the time of death

- consider discussing the meaningfulness of their connection in thought & spirit vs physical proximity

- whether they were at the bedside, or had stepped out of the room for a much needed break, or were in fact in a different country, their connection in spirit/heart/soul was not diminished by physical distance.
The Unbearable Choice

• Usually in substituted judgment scenarios
• “Misplaced” burden of decision
• Eg:
  – Person imminently dying from pneumonia complicating CA lung; unresponsive
  – Family may be presented with option of trying to treat... which they are told will prolong suffering... or letting nature take its course, in which case he will soon die
Prolong Suffering

Let Die

DAMNED if you do

DAMNED if you don't

Prolong Suffering

Let Die

C'mon, C'mon - it's one or the other
Helping Family And Other Substitute Decision Makers

- Rather than asking family what they would want done for their loved one, ask what their loved one would want for themselves if they were able to say
- This off-loads family of a very difficult responsibility, by placing the ownership of the decision where it should be... with the patient.
- The family is the messenger of the patient’s wishes, through their intimate knowledge of him/her. They are merely conveying what they feel the patient would say rather than deciding about their care
Example…

“If he could come to the bedside as healthy as he was a month ago, and look at the situation for himself now, what would he tell us to do?”

Or

“If you had in your pocket a note from him telling you that to do under these circumstances, what would it say?”
Helping Family And Other Substitute Decision Makers

- In situations where death will be an inescapable outcome, family may nonetheless feel that their choices about care are life-and-death decisions (treating infections, hydrating, tube feeding, etc.).

- It may be helpful to say something such as:

  “I know that you’re being asked to make some very difficult choices about care, and it must feel that you’re having to make life-and-death decisions. You must remember that this is not a survivable condition, and none of the choices that you make can change that outcome. We are asking for guidance about how we can ensure that we provide the kind of care that he would have wanted at this time.”