Responding to common concerns at end of life

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Content

- Discuss common concerns at end of life and potential approaches to care
- Reflect on the experience and the perspective of the family
- Define and understand some of the elements in effective communication


Disclaimer

« I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel»

Maya Angelou

Context

- the end of a family member's life, reactivates that family's history and invokes vulnerability.... often in a strong emotional context
- the family is part of the patient's care circle best advocate (expert on the pt)

Importance of this subject

- Less than 10% of people die suddenly, more than 90% die after a period of illness and gradual deterioration.
- Care at EOL has profound effect on all involved; pt, family, friends, caregivers (including professional)

Challenges for us

- Family reactions (unpredictable!!)
- Conflicting points of view
- Our own emotional demands
- Knowledge and confidence

Communication is key!

Cultural perspective

We are not familiar with dying

- We react instinctively, and often poorly, when death approaches….largely because we don’t learn about death
- We don’t see it and we rarely talk about it

- While we know that death happens, we don’t quite believe that it will happen to us (at least not in the foreseeable future anyway)

- As we are increasingly insulated from death, we have also been bombarded by suggestions that we are to some extent protected from it

The irony

- Is that death has become unfamiliar territory just when there is so much more that we need to know about it

- Advances in medicine have complicated death

- *So it is with little knowledge, a blind faith in medicine and a strong sense of personal control over life that we enter the doctor's office and in the realm of terminal illness, begin making decisions about how we or our loved ones will die*

examples....

- “are you just going to let him starve to death?”
- “I would never let my dog suffer like that!”
- “if my mother knows she is dying, she will let herself go and die sooner”

Family perspective

- Personal limits
  - *Exhaustion, loss of control, facing mortality*
- Relationship with patient
  - *Role reversal, advanced care planning/ burden of decision making*
- Ambivalence, doubt, ?guilt

Key features in communication

SPIKES

A roadmap for breaking bad news

- **Setting** –prepare for the meeting
- **Perception** –assess the patient's understanding of the clinical situation
- **Invitation** – ask permission to engage in conversation about a sensitive topic – this demonstrates respect
- **Knowledge** –the information the team wishes to convey
- **Empathy –** helping the patient see through the fog of his/her emotions and responding with empathy
- **Strategy/ Summary** –summarize what was discussed

P - Perception

Explore "Frame of Reference"

- Understanding of illness
- Expectations / hopes / goals
- Concerns / worries / fears
- Cultural / Spiritual factors that may influence
- Individual's approach to illness / dying

I - Invitation

Seek permission

- « Many people experiencing such circumstances wonder about / are concerned about …[*fill in blank*]. »
- « Would you like to talk about that? »
- « Are you comfortable discussing these issues? »

K - Knowledge

- **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

Preemptive discussions

- “You might be wondering…”

Or

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

  Food / fluid intake

  Meds or how illness will progress…

Skillful titration of information

- Listen and watch for clues…
- The response of the person determines the nature and the pace of the sharing of information
- « feed-back loop »

E - Empathy

Acknowledge - Validate - Normalize

- This is a biggie!
- People can spend an entire lifetime without hearing others talk about dying… their worries, fears

S - Summary

- Clarifications; further questions?
- letting others know (additional supports)
- plans for follow-up; « where to go from here »

Common questions at end of life

- « Why are you letting my mother starve to death? »

- **What about ……?**
  - *an IV*
  - *a feeding tube*
  - *a transfusion*
  - *antibiotics*
  - *Resuscitation, ….*

Your mother is not eating because she is dying…she is not dying because she's not eating

« This is going on too long…is there nothing you can do? »

- UNHELPFUL RESPONSE:

  « I can’t do that, it’s against the law! »

  -While accurate, this shuts down further dialogue, such as exploration of the reason for these sentiments

  « I can see this is really hard on you, tell me about what is worrying you… »

« My father loved life! I do not want him to be palliative»

« My mother is strong, she has been able to get through pneumonias before. I think she is going to get better! »

Family asks you not to tell their loved one their diagnosis (or not to use certain words, like “cancer”, “terminal”, “dying”)

Filtering of 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" a resolution*
- *Ultimately, will need to check with patient*

Closing remarks…

- Do not underestimate your presence and just listening (with curiosity)
- Empathy and self-awareness go hand in hand
- Empathy is understanding “their” definition of a good death is not yours

- Use your experience to initiate a discussion

« in my years of working, I have learned that people often worry about ….. »

- Check perspectives all the time and remember « there is always a story »
- People search for meaning (and may need help seeing it)

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Maya Angelou

THANK YOU

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