



## Difficult Conversations related to End-of-Life Care



### Why

- Legislation
- Patient Self-Determination Act
- Palliative Care Information Act
- Family Health Care Decisions Act



## Why (continued)

- Informed Consent
- Late referrals for end of life care
- Ethical Issues –
  - Autonomy
- Opportunity to complete end of life tasks
- Practical Matters



## Types of Conversations

- Between initial diagnosis and death
- Unfavorable prognoses
- Treatment Failure
- Advance care planning
- Shift to Palliative/Hospice focus



## What is Important

- Clear communication
- Effective Symptom Management
- Preserving of Autonomy and Control
- Avoiding prolongation of dying
- Minimizing burden to the family
- Strengthening relationships with loved ones
- Attention to issues of spirituality
- Attention to the site of death (Larson and Tobin)



## Patient/Family Barriers

- Stigma
- Embarrassment
- Fears of death and dying
- Cultural prohibitions
- Family's desire to restrict information



## Barriers to understanding

- Anxiety
- Stress
- Limited attention span
- Distraction



## Strategies

- Determine what family members want the patient to know, while letting them know that direct questions would be answered directly.
- Clarify concerns of caregivers
- Explain advantages of being open with the patient and costs of patients not being informed.



- Enter into a “contract” with the relative that you will not tell the patient, but will explore the patient’s understanding of their condition.
- If the patient is clearly aware, seek the patient’s permission to tell the family.



## Clinician Barriers

- Anticipate disagreement with patient and family
- Medial and legal concerns
- Lack of interpersonal skills
- EOL discussions not routine part of care and not reimbursed



## Clinician Barriers (continued)

- Our own feelings about death
- Attachment to the patient and family
- Fears about handling emotional response
- Clinicians' emotional responses



- “Caring for dying patients evokes feelings of one’s own mortality. A universal struggle with the finitude we human beings have. The degree to which one has reconciled these emotions affects one’s ability to attend to the fears of another.”  
(Steinhauser et al 2001)



## Clinician Barriers (continued)

- Fears of causing pain or bearing bad news.
- Lack of knowledge of advance directive laws
- Lack of training in delivering bad news
- View death as “enemy to be defeated.” (Larson)



- “Fearless healing...to heal one must witness pain without fear. Healers can hear pain, healers give people permission to show pain, healers are not afraid to see pain” (Emanuel)



## Goals

- Improve Communication skills
- Adopt patient centered model of care
- Focus on improving quality of life
- Develop clinical models in which discussions of end of life issues occur early



## “Guiding Principles”

- Don't promise anything you can't deliver
- Allow patient and family to express despair
- Reinforce that patient won't be abandoned.
- Be aware of power dynamics.
- Make time.



- Use straightforward language
- Avoid excessive detail
- Provide information in manageable amounts
- Avoid jargon
- Attend to non-verbal communication



## Communication Techniques

- Open-Ended Questions
- Empathic responses
- Reflective statements (It sounds like you are worried.)
- Paraphrasing



## Communication Techniques

(cont.)

- Seeking Information
- Acknowledging Feelings
- Summarizing
- Reframing
- Self-disclosure when appropriate
- Using Silence
- Exploring



## Communication skills

- Empathic statements
- Open ended questions
- “Can you tell me about the history of your illness?”
- “How is treatment going for you and for your family?”
- “What has been the most difficult for you and your family?”



## Communication techniques

- Exploring
- Can you tell me more about what information you need?
- Can you tell me more about that?



## Where to Start

- Who should be present
- Who should deliver the news
- How much detail does the patient want to know.



## S-P-I-K-ES

- S- Setup
- P- Perception
- I- Invitation
- K- Knowledge
- E- Empathize
- S- Summarize and Strategize (Back et al.)



## Family Conferences

- “Family meetings have the potential to optimize interdisciplinary care, create a climate of inclusion and empowerment for families, promote communication and contribute to families’ experience of care.” (Fineberg and Bauer)



## Family Meetings

- Include:
- Preparation
- Introductions
- Agenda Setting
- Facilitation of Discussion



## Family Meeting Guidelines

- Explore what the family knows
- Allow questions
- Soliciting patient and family reactions
- Invite members to articulate their concerns
- Allow for respectful debate
- May or may not reach consensus on goals and direction
- Summary and conclusion (Fineberg and Bauer)



## Where to Start

- i.e. “To make sure we are on the same page, can you tell me what your understanding of your disease is”
- Or
- “What have the doctors been telling you about your illness?”



## Areas to address

- Prior Losses- “If you’ve lost a family member, how did they die and what was that like for you?”
- Practical – “What practical problems is the illness creating?”
- Communication with others- “Are there any family members or loved ones who need to know what is going on?”(Larson)



## Areas to Address (continued)

- “As you think about the future, what is most important to you?”
- Is faith (religion) important to you in this illness?(Larson)



## Exploration

- You said you don't want to suffer – what type of suffering are you talking about?
- You said that you don't want to be a burden to your family – what do you mean by that?
- You said that you don't want to be kept alive as a vegetable – what does that mean to you? (Balaban, 2000)



## Ways to ensure understanding

- “Who are you going to tell about this visit when you get home?”
- “To make sure I did a good job explaining this, can you tell me what you are going to say?”



- “patients must receive excellent pain and symptom management, clear information and guidance about their disease related and palliative care options, psychosocial support, and, if desired, an opportunity to work on life closure. There is little or nothing to lose in initiating palliative care discussions earlier and more systematically in a patient’s final trajectory and so much is lost when these discussions are avoided.”(Quill, 2000)



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