Communicating Difficult News:

Preparing to have the conversation about end-of-life care
January 22, 2009
Stratis Health’s Minnesota Rural Palliative Care Initiative
by Lores Vlaminck, RN, BSN, MA, CHPN

About...Lores

★ Grandmother of 4 wonderful grandkids!
★ Wife of one awesome man
★ Nurse Consultant for
  • Home Care
  • Hospice
  • Assisted Living
  • Palliative Care

Objectives

• Describe integration of appropriate communication techniques by the interdisciplinary team, including conducting family meetings and interacting with other professionals
• Identify tools and resources for team members in initiating best practice in enhancing communication of difficult news
• Define tools for patient/family and health care team members to document conversations and family conferences.
Why the Need for Change?"

- Because our patients say we are not "doing it very well"
- Examples:
  - The right parties are not present
  - Privacy was not maintained
  - Too much information too fast
  - Too little information too late
  - Medical jargon
  - Not enough time to absorb
  - Don't understand the options and choices
  - Etc…

Communication Realities

- Styles
- Priorities
- Techniques
- Patterns
- Family History

Communication

- Communication as major element
- Crucial to palliative care
- Terminal illness is a family experience

- White et al., 2001
Communication

- Imparting necessary information so that individuals may make informed decisions
- Requires interdisciplinary collaboration

Myths of Communication

- Communication is deliberate
- Words mean the same to sender/receiver
- Verbal communication is primary
- Communication is one way
- Can't give too much information

Barriers in Communication for the Patient and Family

- Fear of mortality
- Lack of experience
- Avoidance of emotion
- Insensitivity
- Sense of guilt
Barriers in Communication for the Health Care Professional

- Fear of not knowing
- Disagreement with decisions
- Lack of understanding culture or goals
- Personal grief issues
- Ethical concerns

Patient/Family Denial

<table>
<thead>
<tr>
<th>Patient denial</th>
<th>Family denial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protecting self and/or family</td>
<td>Protecting self and patient</td>
</tr>
<tr>
<td>Acceptance = “giving up”</td>
<td>Acceptance = “giving up”</td>
</tr>
<tr>
<td>Fear of mortality</td>
<td>Fear of future without patient</td>
</tr>
<tr>
<td>Fear of own mortality</td>
<td></td>
</tr>
</tbody>
</table>

Family Systems

- Lack of continuity among family caregivers
- Lack of coping skills
- Perceived/real lack of support among family
- Cultural influences relate to communication
- Trying to protect family members from bad news
Family Systems

- Open Family System
  - Self-esteem of individual members high
  - Few secrets if any
  - Communication is direct/clear/open
  - Power equally distributed
- Closed Family System
  - Many secrets
  - Low self-esteem
  - Double messages
  - Double binds

Factors Influencing Communication
Financial / Educational / Physical

- Financial insecurity
- Educational level influences ability to understand impact of illness
- Sleep deprivation/physical exhaustion
- Physical limitations

Factors Influencing Communication
Coping / Grief

- Changes in family dynamics/roles
- Family caregivers
- Anticipatory grieving of loss of self or another

Friedrichsen et al., 2001
Difficulty in Predicting Life Expectancy

- Cancer Diagnosis
- General Decline
- LCD Guidelines
- “Frequent Flyer”

Physician Reluctance/Fear

- Emotions
  - Personal
  - Patient/family
- Fear of failure
- Scrutiny from peers
- Accusations from patient/family
- Past personal experience with death
- Personal mortality
- Other

Strategies for Purposeful Communication

- Buckman Protocol
  - S.P. I.K.E.S
- EPEC
  - Setting the Stage
- Other
Shared Decision Making

Between Physician and Patient:
- **Physician's Responsibility**: Inform and recommend best treatment option(s)
- **Patient's Responsibility**: To choose or refuse treatment option(s)

S.P.I.K.E.S.
- **Set up the interview**
- Assess the patient's perception
- Obtain the patient's invitation for more information
- Give knowledge and information
- Address the patient's emotions and empathize
- Strategy and summary

**Set up the Interview**
- Arrange for privacy
- Involve significant others
- Sit down
- Make connection with the patient. Be "present"
- Manage time constraints and interruptions
Setting

Items of Comfort and Necessity

Environmental Settings
(LTCF/Clinic/Acute/Home Care, etc)

- Identify private room with will accommodate staff support and family
- Provide a speaker phone as needed for family that cannot attend
- Chairs for all attendees
- Notepaper and pens
- Kleenex
- Coffee/water
### Assess the Patient’s Perception

- Ask what the patient’s understanding of his/her disease process with open ended questions?
  - “What is your understanding of the results of the last MRI/CT scan?”
  - “What did your cardiologist tell you at his/her last visit?”
  - “What questions do you have of your treatment plan?”

### Obtain the Patient’s Invitation for More Information

- Ask the patient how much they would like to know about their medical information
  - (lab results, CT scans, biopsies, etc)
- Offer another MD appt if desired
- Assess the need to know
  - Details or Basic

### Give Knowledge and Information

- Warning the patient you have “bad” news helps to prepare
- Avoid medical jargon
- Avoid excessive bluntness
- Give information in small amounts and check frequently for patient understanding
- Avoid saying, “There is nothing more we can do for you”
Address the Patient’s Emotions and Empathize

- Observe the patient for emotions
- Identify the emotion and reason. If unsure, ask the patient
- Be “present” with expressed and unexpressed emotions

Strategy and Summary

- Persons handle anxiety better if there is a “plan” and options
- Reinforce the goals that have been shared between the patient-physician-family
- Revisit any previous steps
- Offer future opportunity for discussion
- Name a place and time for next “visit”

Family Conference
Invitation List for Consideration to Conference

- Patient
- Family
- Support persons as identified by patient
  - Social
  - Spiritual
  - Friend/neighbor
- MD, NP, PA

Invitation List for Consideration to Conference

- Social worker
- Primary RN/LPN
- Home health aide/CNA
- Ombudsmen
- Pastor/Chaplain
- Other

Role Play

- Individuals rehearse the conversation
- Plan the role that team members will play
- Identify conflicts, concerns, previous history of conversation
Information

Five Questions

- What does the patient want to know?
- Who needs to be there?
- When should we meet?
- Why are we meeting?
- Where should we meet?
- How should we share the information?

Initiating Systems Change

- Identify stakeholders for task force
  - Nursing/social services/physician-advance practice nurse/chaplain/patient/family/other
- Assess current system and practice
- Identify gaps and barriers-focus groups
- Describe the impact of change
  - Financial
  - Personnel
  - Spatial
  - Education
  - Patient/family satisfaction

Initiating Systems Change

- Develop performance improvement plan
- Develop policy and procedure
- Provide education and support for all staff involved in systems change
- Evaluate outcomes utilizing:
  - Patient/family satisfaction
  - Stakeholder's evaluation and satisfaction
  - Other
Advocacy Role

- Emotional Responses
  - Patient
  - Family
  - Health Care Team

Resolving Conflict

- Try to take a step back
- Identify your own emotions
- Define the conflict
- Obtain agreement on the conflict
- Talk about it

Jeffrey, 2004; Stone et al., 1999

References

- Center to Advance Palliative Care
  - www.capc.org
- EPERC Fast Fact #16
- EPERC Fast Fact #11
References

- EPERC Fast Fact #6
- Kettering, T. *The elephant in the room*. Retrieved June 10, 2005 from
  - www.bartow.k12.ga.us/psych/crisis/elephant.htm

Lores Vlaminck, RN, BSN, MA
3063 Darcy Drive NE
Rochester, MN  55906

Office-507-288-6050
(C) 507-358-4301