Listening in, researchers learn about end-of-life communication

May 31 2012

What is the best way to talk to someone about prognosis and quality of life when serious illness strikes? It turns out that no one had studied that question through direct observation, until the University of Rochester Medical Center audio-recorded 71 palliative care discussions.

The data is published online in the Journal of Pain and Symptom Management.

Lead author Robert E. Gramling, M.D., Sc.D., associate professor of Family Medicine at URMC, and colleagues with a special interest in palliative care, made several key discoveries:

- In 93 percent of the conversations, prognosis was brought up and discussed by at least one person, with the palliative care team broaching the issue 65 percent of the time. Also, the prognosis information focused more often on quality of life rather than survival, and on the unique individual rather than the population in general. Researchers noted that prior studies support the link between open and honest discussions about prognosis to clinical benefits.
- Both patients/families and physicians/nurses on the palliative care team tended to frame prognosis with more pessimism than optimism. This was unexpected and different than the usual patterns of communication, where talk of a serious illness tends toward avoidance or unbalanced optimism, researchers said.

However, emphasizing accuracy during the palliative care consultation usually leads to treatment decisions that match patient preferences.

- The substance and tone of the conversations varied, depending on whether the patient was present and actively participating. For example, prognosis conversations with family members alone were more pessimistic and contained more explicit information. It is possible, researchers said, this type of conversation takes place out of respect for the patient, who might be sicker in this scenario, or is someone who prefers to avoid information.
- The closer to death, the more likely the palliative care physician was to foretell or forecast events. This might seem logical – that doctors would guide patients and families in what to expect as death approached – but in reality this vulnerable and frightening time is when families often report a void in communication. The URMC data suggests that palliative care consultations respond to this need.

"Good communication might be the single most important element of palliative care," Gramling said, "and through direct observation we have demonstrated how these talks occur and the important dimension they add at the end of life."

The study took place at Strong Memorial Hospital at URMC, which has an in-patient hospice unit and provides more than 1,000 palliative care consultations annually at the hospital. With prior consent from all study participants, researchers placed high-definition digital recorders in unobtrusive locations in hospital rooms before the prognosis discussions took place.

Afterward, researchers coded the conversations based on whom was speaking, the topic, and how the information was framed, and then analyzed the data.

Examples of statements coded for prognosis: "It is unlikely that you will live for more than a month."Also -- "I believe that your breathing will continue to worsen, and we need to prepare for that."

An example of statements coded for length of life: "I expect that you will live for days to weeks, rather than months to years. About 30 percent of people live for a month or more."

An optimistic framing statement: "The good news is I expect you will live for a few more months. | I believe your chances of surviving up to six months are quite good."

An example of a statement coded for quality of life: "But you know you never know. Sometimes people perk up for awhile. And it may be with a little extra blood you'll perk up for awhile and we'll all enjoy it if you do."

Providing a palliative care consultation has become much more complex in recent years. As the demand for these services has risen, so has the breadth of services. No longer is palliative care an either-or proposition – either relieving suffering or treating the illness medically. It has evolved into a combination of the two, along with opening communication with the patient and family so they know what to expect.

"When patients and families clearly understand the road ahead they can make the best decisions, based on their own values, desires, and goals," Gramling added. "Without correctly framing the facts, however, discussions can become unbalanced or lack the context to be helpful."

Provided by University of Rochester Medical Center

Citation: Listening in, researchers learn about end-of-life communication (2012, May 31)