

Study: Many terminally ill patients feel abandoned by their doctors

March 9 2009

Terminally ill patients and their family caregivers often feel abandoned by their doctors and feel a sense of "unfinished business" with them, according to a new study by an oncologist at the Seattle Cancer Care Alliance.

The study results, published today in the <u>Archives of Internal Medicine</u>, identified two themes: before death, abandonment worries related to loss of continuity of communication between patient and physician; and at the time death or after, the patient's family's <u>feelings of abandonment</u> from a lack of closure with the physician.

"Doctors often don't realize how important this issue is for <u>patients</u> and their families," said lead author Anthony Back, M.D., an expert on patient/physician communication. "Something as simple as a phone call can go a long way toward allaying abandonment concerns," he said.

The study found that physicians also reported a lack of closure when patients died, but they did not associate this with abandonment.

"At first glance, continuity and closure may seem mutually exclusive but these elements reflect different needs occurring at different times in the dying process," the authors write. "Early on, patients and <u>family</u> <u>caregivers</u> fear that their physicians, whose expertise and caring they have come to depend on, will become unavailable."

Near death or afterward, the patient's family may experience a lack of



closure of their physician relationship. Physicians also report similar feelings. "Most physicians are not consciously aware of having abandoned their patients. Instead, they report a lack of closure or a feeling of unfinished business," Back said.

The paper, "Abandonment at the End of Life from Patient, Caregiver, Nurse and Physician Perspectives," contains many direct quotes from patient and physician participants who were asked to answer a series of questions about their perceptions and needs about continuity and closure.

For example, this is what one patient told the researchers about the impending loss of the relationship with the doctor: "I think that it's important that you still have that contact with them even though there isn't anything they can do to make you better."

Back and colleagues at the University of Washington School of Medicine lay out a simple plan for how physicians and nurses can achieve continuity and closure before and after a patient dies.

Before death, continuity can be achieved by assuring patients that they will be available to see them and by maintaining contact, often by phone, as death approaches. Closure can be addressed by anticipating and acknowledging the probable last visit with a patient. After a patient dies, the researchers recommend that physicians call the family caregiver as an act of closure.

For his own patients, Back said he schedules appointments to see patients after they enter hospice care or he calls them if they are too sick to come to the office. He also makes calls to say goodbye and talks to family members as well.

The authors say that this study is the first empirical research on the subject that provides a longitudinal, prospective view using ongoing



interviews with doctors, nurses, patients and family caregivers that began at the time the patient had advanced disease and continued through death and into the beginning of bereavement.

"The significance of our study is that it provides empirical grounding for a central professional value of non-abandonment," said Back, also an affiliate member in the Clinical Research Division at Fred Hutchinson Cancer Research Center.

Source: Fred Hutchinson Cancer Research Center

Citation: Study: Many terminally ill patients feel abandoned by their doctors (2009, March 9) retrieved 10 April 2024 from

https://medicalxpress.com/news/2009-03-terminally-ill-patients-abandoned-doctors.html

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