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Dying patients want doctors they can trust

Patients say confidence and communication key

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EDMONTON -- What do dying people and their families want and are they getting it?

To find out, Canadian researchers at five hospitals asked 440 older patients dying of chronic, progressive diseases and their families to rate the importance of 28 issues related to end-of-life care. The patients chosen -- averaging 71 years of age -- had end-stage heart, lung or liver disease, which meant 50 per cent were not expected to live beyond six months.

Researchers found "trust and confidence in the doctors looking after you," was rated as the most important issue by both patients and their families.

"Not being kept alive on life support where there is little hope for a meaningful recovery" and "that information about their disease be communicated by the doctor in an honest manner," were ranked second and third in importance.

They were also asked to rate how satisfied they were in having their wants met.

Considering that health-care systems in the industrialized world were built to care for people with acute illnesses, perhaps it's little surprise that patients with chronic illnesses are not getting what they want, that there's not a good system for dying.

The issue that was rated most important, but which got very low satisfaction was "upon discharge from hospital, to have an adequate plan of care and health services available to look after you at home," says Dr. Jim Kutsogiannis, an assistant professor in public health sciences and critical care medicine at the University of Alberta, and one of the researchers.

Recognizing that there's a disconnect is the first step to improving the system, he adds.

What surprised him the most about patients' responses is that "to be able to die in the location of your choice (home or hospital)" was rated number 24 in importance, when previous research had suggested most people would prefer to die in their own homes.

Ironically, much of that earlier research focused on out-patients and those with cancer, when the majority of Canadians die in hospital and die of non-cancer causes, Kutsogiannis says.

"More and more hospitals are caring for people with chronic disease that slowly deteriorate," he explains. "They're admitted to hospital and we make them a little bit better, because we can't cure them, but enough for them to barely make it back home. Then they get worse and they come back , and this happens again, and again and again, until most die while on life support or within six months of being taken off life support."

That patients indicate it's not important to them where they die, likely reflects concerns that there is not enough funding and resources in the community to look after them, and that the burden, after they're discharged from hospital, falls on family, Kutsogiannis says. Patients ranked "to not be a physical or emotional burden on their family," number five on the list of what's most important.

What's needed is palliative care for the chronically ill that mirrors the program started 30 years ago for cancer patients, he says. Some issues can be addressed immediately, but he expects it will take the system five to 10 years to adapt to what chronic care patients and their families have identified as their most important needs.

Research nurse Sara Currie, who interviewed patients and their families at Edmonton's Royal Alexandra Hospital for the study between November 2001 and June 2003, says a lot said relief of symptoms such as pain, shortness of breath and nausea was important. The issue was ranked seventh, nationally.

End-of-life care has to be customized, one-size does not fit all, Kutsogiannis says. Physicians could find out about their patients' needs by sitting down with them and family members for about an hour and just talking to them about what they want and reaching an agreement.

"Then you can get on to providing adequate care whether it be adequate home care or social supports, or if they want aggressive treatment, explaining the limitations and helping them understand that it's not going to save the person," Kutsogiannis says, noting this approach needs to be included in doctors' medical training.

The population is growing older, which means the demand for end-of-life care is only going to increase. Physicians, the health-care system, government and the public must work together to meet their needs.

From the responses the questionnaire collected from patients' families, most of whom were in their 50s, boomers have high expectations for the end-of life care they plan to receive and they plan to be more vocal than their parents to get what they want, Kutsogiannis says.

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