

Canadians participate as unique US project puts death under the microscope



Features

Chroniques

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In brief

THE DEATH IN AMERICA PROJECT, sponsored by an American philanthropist, is designed to find inadequacies in knowledge about the course and outcomes of care of dying patients. The participating scholars include 3 Canadian physicians.

En bref

LE PROJET DEATH IN AMERICA, parrainé par un mécène américain, vise à dépister les lacunes des connaissances sur l'évolution et les résultats des soins aux patients mourants. Trois médecins canadiens sont au nombre des chercheurs.

Even before he entered medical school, Dr. David Kuhl was aware of the spiritual needs of the dying because he had watched a “tormented” roommate die of cancer. It proved to be a pivotal experience, because it stimulated his interest in palliative care in medical school.

However, medical school had to wait until Kuhl had acquired degrees in sociology and religious studies, and a master's degree in health sciences. In 1988, after graduating from McMaster's medical school, he was asked to help plan the new palliative care unit at Vancouver's St. Paul's Hospital. Ten years later he is the program coordinator, and 1 of only 3 Canadian physicians chosen to participate in a prestigious American project.

Kuhl, Dr. Gerri Frager of Halifax and Dr. Harvey Chochinov of Winnipeg have been named faculty scholars in the \$15-million Death in America Project. Funded by New York philanthropist George Soros, its goal is to address “major inadequacies in our knowledge about the course and outcomes of care of dying patients, and serious weaknesses in our education of health professional students about care near the end of life.”

Only 38 faculty scholars, all from North America, have been selected for the project, with more expected to be named this summer. Their basic job will be to dissect different aspects of death. The maximum stipend is \$111 000 in salary and travel expenses, with the final total for participants being determined by their current salaries.

Chochinov, a psychiatrist at the Manitoba Cancer Treatment and Research Foundation and the University of Manitoba, is studying psychiatric issues surrounding end-of-life care. He says the scholarship has been “a wonderful opportunity” that has allowed him to “accelerate the pace of his research tenfold.”

Frager, a pediatrician at the Izaak Walton Killam Hospital for Children in Halifax, is developing a pediatric palliative care program for children in the Maritimes. She says the scholarship has given her the time to work on a project with “visibility and credibility.”

Meanwhile, Kuhl's 3-year research study, which will explore psychological and spiritual issues with dying patients, will place him at the leading edge of his field. “Medicine embraces healing but the picture has to be complete,” he says. “Dying can be a very meaningful time psychologically, physically and spiritually.” His

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goal is to “enable people to use the end of life as a time of growth.”

Kuhl, who recently began interviewing dying patients, hopes to talk to 20 people throughout the next year. About half of them will have AIDS, the other half cancer. He predicts that the participants may live 6 to 12 months beyond their initial contact with him. The videotaped interviews will continue monthly in the patients’ homes for as long as they are well enough to participate. The interviews are based on the “guided biographies” described in the book *Guiding Autobiography Groups for Older Adults*. Issues such as previous encounters with death, the person’s reaction to the illness, family dynamics, religious and moral principles, and lifetime accomplishments will be explored during the interviews.

Kuhl spends the first session talking to patients about the impact of being told their diagnosis. He says the way in which people receive this information has “incredible impact in either fostering or diminishing hope.

“Each person longs to sustain or foster [hope]. Doctors, in our own pain, are not as aware as we need to be of the impact of what we say.”

He says that physicians have to “listen differently, getting the patient to supply some wisdom.” For example, patients tell him that the right way to be informed of their diagnosis would be for the doctor to “sit beside me, touch me and tell me the way you would tell a close relative.”

He says the people he has met with so far “long for a spiritual component.” For some, this means trying to make sense of religious values taught in their childhood. For others, the spirituality comes from outside organized religion. Many people also harbour unresolved feelings about past deaths, some of which date back decades. During the 35-minute sessions, Kuhl is “surprised by how little I have to say.” Many patients tell him they have “never said these things to anyone” and that they want their doctors to understand their psychological and spiritual sides. Kuhl says that what he is hearing represents “the tip of the iceberg.”

Eventually, he plans to use the interview material to help train family practice residents at the University of British Columbia (UBC); these residents currently receive only 2 weeks of palliative care training. Kuhl would like to see this time increased, and he thinks undergraduate students should also receive more training. He is working

with the new Division of Palliative Care at UBC to develop interdisciplinary courses.

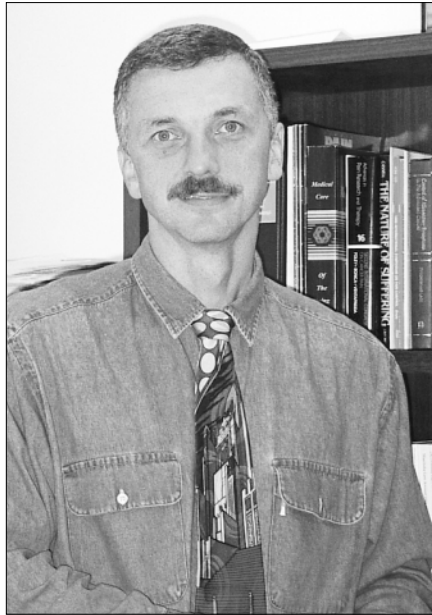
“We need to embrace palliative care from day one of medical school,” he says, and physicians need to “make sure that patients understand their options.” For their part, patients with an “emotional anesthetic” don’t always hear what caregivers say. However, nobody should ever feel the abandonment that accompanies the refrain that “there is no more we can do.”

Once terminally ill patients are physically comfortable, says Kuhl, they want to explore end-of-life issues such as the pain of family relationships and the worth of their lives. Doctors need to improve their skills for helping them deal with these difficult issues by acknowledging the links between body, mind and soul. They need to have “the courage to look in the mirror,” to be prepared to ask the same questions of themselves in order to discover the “mutual truths” with the patient.

This kind of care is too complex for physicians alone, Kuhl adds. He sees family physicians, along with

pastoral and social workers, as key participants in providing end-of-life care.

In the end, Kuhl concludes, palliative care is changing and the term itself has become a misnomer because “we are moving to a broader end-of-life concept.” He predicts that dying patients may be followed for up to 2 years, meaning that palliative care will become a form of long-term care, and most of these patients will die at home, not in the hospital. ?



Dr. David Kuhl: “moving to a broader end-of-life concept”

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