

IN DEPTH

The death of Patient X and the failure of the system

Patient advocate says communication issues make up the bulk of complaints causing families stress

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An 88-year-old man with a week to live was sent to spend his last days in palliative care, but miscommunication put him back in hospital instead. (Chris Kreussling)

We'll call him Patient X — an 88-year-old man suffering from kidney failure, bladder cancer and dementia.

His longtime physician tells him nothing more can be done. The man confirms his wish for palliative care. The doctor phones the patient's wife. He later described her as "relieved."

But what follows is not the calm, peaceful ending Patient X wanted. Instead, he wound up back in hospital, the advice of his personal physician ignored, his family given false hope in a mire of miscommunication.

Patient X died one week later.

"He spent his final days being poked and prodded with unnecessary and futile treatment," his physician would later complain.

"He could have spent his final days in peace and comfort with the focus on palliative care and symptom control in the hospice house."

Did not rise to the 'level of unsatisfactory?'

Patient X's story is told in a [decision posted last month by B.C.'s Health Professions Review Board](#), a kind of appeal court for people unsatisfied with the outcomes to complaints to the bodies which govern medical professions.

The case went to the board after the man's physician complained to the College of Registered Nurses about the palliative care coordinator — a nurse — at a hospice house.

While the names are redacted, the issues at play will be familiar to anyone who has tried to navigate a medical system which can, by turns, seem extraordinarily compassionate and inexplicably cruel.

The decision sheds light on the private battles which impact public care.



The palliative care coordinator claimed that after speaking with her supervisor and an MD consultant, the decision was made to return Patient X to hospital. (Getty Images/Cultura RF)

After two investigations, the College of Registered Nurses found the nurse's conduct, "could not be said to rise to the level of unsatisfactory." They sent a letter, telling her to avail herself of "resources regarding communications."

That's a decision the review board has called into question, suggesting a formal reprimand instead.

"What troubles me is that the registrant appears to neither understand nor acknowledge that had she followed a communication protocol consistent with her job description, the patient would likely have had the benefit of palliative care prior to his death," writes Deborah Lynn Zutter, the chair of the review board panel.

"Instead, the registrant describes herself as victimized by the complaint process."

'Nobody should need' a patient advocate

As chair of the health care advocacy group Patients Canada, Michael Decter says the decision highlights a "big mismatch" between what Canadians want from the health care system and what they get — particularly as it relates to end-of-life care.

"Canadians say they would like to die not in a hospital. They would like to die at home or they would like to die in palliative care in a hospice," he says.

"And the reality is that we've failed pretty spectacularly to move those numbers. The majority of Canadians still die in a hospital."



Patients Canada chair Michael Decter says Canadians have consistently said they don't want to end their lives in hospitals. (CBC)

Decter says greater transparency is needed about decision-making that affects families and patients. But poor communication too often gets in the way.

"The last thing patients need when they're in a horribly stressed condition towards end of life and so are their families, is to be caught in the middle of some professional squabble," he says. "It's just completely wrong."

Surrey-based patient advocate Connie Jorsvik says the problems outlined in the review board decision are depressingly familiar — the details change from case to case, but the underlying issues remain the same.

"Nobody should need me. Nurses should be advocates. Social workers should be advocates. Doctors should be advocates for their patients," she says.

"It's not happening. And the communication isn't happening."

'This put me in an impossible position'

The review board decision cites hundreds of pages worth of investigative notes including versions of events taken from the doctor, the nurse, her supervisor and Patient X's wife and son.

The physician who made the complaint has 36 years experience as a doctor. He had known Patient X and his wife for 20 years.

He referred Patient X for palliative care on the morning of July 22, 2013.

The doctor claimed the palliative care coordinator called him the same afternoon to say she had spoken to another doctor and her nursing supervisor. The three of them recommended another week of active treatment.

"This put me in an impossible position," the doctor writes.

"Now the family had been given false hope. They believed that my recommendations were wrong."



Patient X's doctor resigned his privilege at a local hospital the day after his advice was ignored and his dying patient returned for treatment. (Radio-Canada)

The nurse told a college investigator that following any referral, she speaks with the patient about the program. The patient must want to be admitted.

She claimed Patient X said he didn't want to go into palliative care, and his tearful wife felt they hadn't been given a choice. She said she discussed the referral with her supervisor and an MD consultant who recommended continued treatment for the patient's pneumonia.

“Because the communication from all the hospital staff was so poor, she [wife] never felt that she was really informed about what was going on, or that she had a part in the decision making”

— B.C. Health Professions Review Board

The nurse claimed that when she called the family doctor he swore at her and demanded the name of the consultant.

The MD consultant also spoke with investigators, through email. She claimed the nurse presented her with a scenario on the phone where treatment seemed reasonable; but she never met Patient X and had no clinical involvement.

Regardless of what exactly happened, the college's interview with Patient X's wife makes clear the impact.

She recalled the nurse telling her that her husband "could be saved."

"She stated that she never wanted it to be the way it was for her husband (e.g. his course in hospital) and that, in hindsight, it would have been better to have him in hospice care, so that his last days could have been made more comfortable," the decision states.

"Because the communication from all the hospital staff was so poor, she never felt that she was really informed about what was going on, or that she had a part in the decision making ... although she could tell that her husband was dying, she had no idea of how long it would take or what to expect."

'This is clearly a difficult job'

The doctor who lodged the complaint resigned his privilege at the hospital the day after Patient X returned to the facility and began a new course of active treatment.

The nurse's manager claimed the doctor in question had a history of "going off" on nursing staff. But the doctor denied this and said the college should have checked with nurses at the hospital about his demeanour.

Despite the nurse's assertion the doctor had sworn at her, the review board decision says there's no evidence that ever happened.

"This is clearly a difficult job," the decision says. "To defend one's behaviour by alleging that the other person 'misbehaved' suggests a lack of ability to deal with people in difficult situations."

The review board said the original investigation didn't consider the harm caused by sending Patient X back to hospital.

"As I read the cumulative investigation, the hospital notes document the numerous treatments the patient endured until his death," Zutter writes.

The decision concludes with a finding that the outcome of the College of Registered Nurses' investigation — a letter to the nurse and no greater finding of fault — was unreasonable.

Zutter says the college's inquiry committee should decide whether the nurse should be asked to consent to a reprimand. And if not, give their reasons.

The college now has to decide whether to abide by that ruling or seek a judicial review of the decision in B.C. Supreme Court. The college wouldn't comment on the case while weighing those options.

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