Innovative patient-centred lung clinic reduces suffering along with costs

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Physicians Meena Kalluri and Janice Richman-Eisenstat believe the model they use to treat patients with a terminal lung disease—which enables more patients and caregivers to manage the disease at home, leading to higher patient satisfaction and lower costs—can be used to treat other chronic and terminal illnesses. Credit: Ryan O'Byrne

A unique clinic for patients with terminal lung disease is leading to dramatic reductions in hospital deaths, better symptom management and lower costs for the health-care system.

The multidisciplinary team at Alberta Health Services' Kaye Edmonton Interstitial Lung Disease Clinic delivers palliative care and encourages treatment at home for patients with idiopathic pulmonary fibrosis (IPF).

Since the clinic model was introduced in 2012, just 33 percent of patients have died in hospital, while 67 percent died at home, in accordance with their wishes.

By contrast, other treatment models in the United States and the United Kingdom have reported hospital death rates ranging from 57 to 80 percent, and rates of home deaths between zero and 14 percent.

Emergency visits and hospital admissions in the last six months of life were also reduced, resulting in 27 percent lower costs of care for clinic patients compared with IPF patients cared for by other respiratory specialists or by non-specialists in the province.

"Not only are we delivering improved quality of care, the cost to the system is lower," said Meena Kalluri, a University of Alberta associate professor of pulmonary medicine, who introduced the new approach. "Why go to hospital if your symptoms are under control at home?"

Kalluri and clinic colleague Janice Richman-Eisenstat, associate clinical professor in pulmonary medicine, recently reported their results under the title "From Consulting to Caring: Care Redesign in Idiopathic Pulmonary Fibrosis" in *NEJM* Catalyst, a journal focused on innovations in health care.

Staying on top of symptoms

IPF causes lungs to stiffen and shrink. The cause is unknown, although links to smoking and chemical exposure in occupations such as growing crops, raising livestock and hairdressing are suspected. Patients often also have heart disease, sleep apnea or chronic obstructive pulmonary disease (COPD).

While a small number of patients receive lung transplants, and anti-fibrotic drugs can slow the progress of the disease, most die of respiratory failure within two to three years.

The most distressing symptom is shortness of breath, also called dyspnea. Kalluri said this symptom is not as well understood as pain, for example, and is often overlooked in treatment.

"I realized there was an urgent need to start doing things differently," she said. "We must not only make the right diagnosis, but also focus on what

the patients are really going through with these incapacitating symptoms and provide relief.

"If you're out of breath, you can't work, you can't do your own housework, you can't go outside. It affects pretty much every aspect of your life."

The Edmonton clinic treats dyspnea aggressively, with 95 percent of patients given opiate treatment on average four months before they die, compared with 71 percent receiving opiates only within the last week of life elsewhere.

Patients and their caregivers, including family members, home care nurse practitioners, respiratory therapists and family physicians, are given an action plan and trained to give medications and oxygen so patients don't reach a crisis and need to go to hospital.

According to Richman-Eisenstat, when patients go to emergency with uncontrolled breathlessness, the standard approach is to do a battery of tests for illnesses such as embolism, pneumonia and even heart attack.

"These tests and treatments are futile, and are often harmful to the patient and traumatic for their caregivers," said Richman-Eisenstat. "Acute heroic measures don't apply for these patients who are in advanced stages of disease or at end of life."

Getting ready for death

The clinic team—Kalluri, Richman-Eisenstat, a nurse co-ordinator and a dietitian—begin advance care planning with patients as early as the first visit. Richman-Eisenstat uses the analogy of having a baby.

"Imagine if you are experiencing nausea and your belly is growing, and you go to the doctor and he never mentions that you are pregnant," she said. "That would be absurd."

"By talking about death and acknowledging what is coming, patients have time to prepare."

Kalluri said medical practitioners shy away from discussing death and dying with patients because it may take away hope.

"What we found in our study is actually the opposite," she said. "Having open, honest information is actually empowering to patients. The families are able to rally around and say what they want to say to each other, do some of the things they want to do.

"Creating memories is a very good way of coping at end of life. It lessens grief."

Richman-Eisenstat said the clinic staff have strategies to help patients manage breathlessness so they can do things like go to a wedding, make it to a movie or attend all three periods of a hockey game.

One woman wanted to put her feet in the sand on a Mexican beach. The team let her know that wasn't realistic given her prognosis. So her family brought Mexico to her apartment, with sand in a pail, Mexican food and fiesta music.

"We tell patients, "You've got to get busy dying,"" she said. "Most people find, in the process, they get busy living."

Patients and caregivers report high satisfaction with the care and training they receive to manage the disease at home.

"She slept through the night, she wasn't tossing and turning," said one daughter of her dying mother, quoted in a clinic study. "She had more energy because she wasn't struggling to breathe. She could talk to her friends. We got family photos."

"I know people think I'm crazy when I say if there's a nice death, he had it," said another caregiver. "I don't know how else to describe it, that anybody could just be gone that quickly without a whole lot of suffering."

The clinic was selected by the Canadian Foundation for Healthcare Improvement as an emerging innovation in palliative care in June 2017.

Kalluri believes the model can be followed for treating other chronic and terminal illnesses.

"It brings me so much hope that we can totally revamp our health-care system to be patient-centric," she said.

"Even though we don't cure, even though the patient passes away, there is beauty at the end of life when you can meet patients' needs, give them some dignity back and support families positively."

More information: From Consulting to Caring: Care Redesign in Idiopathic Pulmonary Fibrosis. *NEJM*. catalyst.nejm.org/idiopathic-p … onary-fibrosis-care/

Provided by University of Alberta