



Canadian
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Edmonton collaborative care approach for IPF delivers true patient-centered care



Dr. Meena Kalluri, a member of the CPFF Medical Advisory Board, pioneers an innovative IPF care model featured in *NEJM Catalyst* article

When Dr. Meena Kalluri talks about the patient-centred care delivered by the team at the Kaye Edmonton ILD (interstitial lung disease) Clinic and its community partners, her passion and pride is evident.

“When specialists talk about patient-centred care, the focus is still on diagnosis and treatment,” she says. “I believe that is just the bare bones of care. We focus on the individual’s needs after diagnosis and beyond basic medications and monitoring. We’re talking to patients about quality of life, how to live their best life possible, advanced care planning and palliative care to support patient goals and wishes, right from their first visit with us.”

Last month this multidisciplinary, collaborative model to deliver early integrated palliative care to patients with IPF (idiopathic pulmonary fibrosis) was featured as a case study in the March 28, 2019 issue of the prestigious *New England Journal of Medicine Catalyst* journal. You can read the full article [here](#). You may also want to share the article with your own care team members.

The goal of the program, serving about 400 patients each year, is to create an

integrated patient-centered approach for patients with IPF that systematically identifies and addresses escalating symptoms, improves advance care planning, reduces hospitalizations at the end of life, promotes living well and facilitates dying with dignity.

This model of care is the only one of its kind in the world, certainly in Canada or the United States, according to Dr. Kalluri. The *Catalyst* article describes traditional care models: “(They) lack the infrastructure, care philosophy, and provider training to address the needs of IPF patients. Clinicians lack experience in providing anticipatory guidance (e.g. what to expect in the future, how to prepare for deterioration, or what to do and who to call in a crisis). In the absence of this type of care, guidance and support at home, patients in crisis have no recourse but to call 911 and go to the hospital, where they eventually die.”

“The challenge was to develop a care model to help individuals to live their best life while addressing their escalating needs from diagnosis to death,” says Dr. Kalluri. “And for each individual, their needs, preferences, and local resources, are unique.”

Along with multidisciplinary staff in the clinic, (physicians, nurse coordinator, dietitian, respiratory therapists, etc.) the care model relies on partnerships with individualized community teams developed according to patient needs and resources in each patient’s local community. These can include resources such as community home care, community pharmacists, oxygen vendors and support groups.

Patients are empowered from the outset with information and encouragement. Clinic visits can last up to two hours and each patient receives an education binder and training. And caregivers are actively involved from the start.

“We encourage patients and families to self-manage anticipated dyspnea, instead

of waiting for it to happen. In doing so, they learn how to recognize their own risks for breathlessness, how to minimize them, and how various strategies can allow them to stay comfortable at home.”

The results of the program are impressive. Patients receive pain medication when needed and earlier than in traditional care, in which 71 per cent receive opiate treatment only within the last week of life. Patient preferences regarding care and death were documented in 84 per cent of cases within the first three clinic visits, in contrast to rates of 13 to 17 per cent in other clinics.

Hospitalizations were also reduced. There were no emergency visits in the last six months of life in 63 per cent of cases and no hospitalizations in the last six months of life in 35 per cent of cases. The majority of patients, 67 per cent, died at home or in hospice, in keeping with their wishes. Other researchers have reported rates of hospital deaths ranging from 57 to 80 per cent and rates of home deaths ranging from 0 to 14 per cent.

In addition, a survey of 15 patients and seven bereaved caregivers showed high satisfaction with care, with a median score of 4.7/5 for the domains of illness management, relationship with doctors and team, education, quality of communication, self-management, palliative care and engagement.

Here is what one bereaved participant in another article about the program said: “I believe palliative care should be with you from when you’re diagnosed, saying “You know what, you’re terminal, but we’re going to help you live until you die.” I figure you should enjoy every moment of your life. We don’t know, you could live two years, three years, you could live six months or a month. But if you could access someone and say, “This is the disease I have. What steps can I do to stay in my home, be happy in my home and as the disease progresses, who can I have, whether it be nursing staff, any access to anything that’s going to make my life at home easier for myself and my caregivers.”

Quote from study participant in article “Early integrated palliative approach for idiopathic pulmonary fibrosis: A narrative study of bereaved caregivers’ experiences,” published in Palliative Medicine 1-10, 2018

Dr. Kalluri acknowledges that there are challenges and hurdles to implementing true patient-centred care for any disease, as well as ILD. “Physicians and health care systems must make the delivery of such care a **priority**. This requires training and most importantly resources, which can often be re-directed from savings realized in reduced hospital care. In fact, cost savings outweigh resource investment in this type of care, often by many times.”

She has first-hand experience of the frustration caused by the lack of prioritized resources. CPFF funded the nurse-coordinator position for the clinic for two years, with the understanding that the position would be funded by Alberta Health Services going forward. CPFF funding ended on March 31, 2019.

“Despite the excellent results we have shown and the reduced costs to the health care system, we have still not secured funding for this critical position in our clinic,” says Dr. Kalluri. She is not giving up though. She will continue to advocate for this care model, which truly puts patients at the centre of their care in every way.