Early integrated palliative approach for idiopathic pulmonary fibrosis: A narrative study of bereaved caregivers’ experiences

Charlotte Pooler¹, Janice Richman-Eisenstat²,³ and Meena Kalluri²,³

Abstract

Background: Idiopathic pulmonary fibrosis has an uncertain and rapid trajectory after diagnosis. Palliative care is rarely utilized, although both patients and caregivers experience a distressingly high symptom burden. Most patients die in hospital.

Aim: The purpose of this study was to explore bereaved caregivers’ experiences and perceptions of an early integrated palliative approach implemented at a Multidisciplinary Interstitial Lung Disease Clinic.

Design: A narrative approach was used, with thematic and content analysis of open-ended interviews.

Setting/participants: The clinic is located in a large western Canadian city. Caregivers of deceased patients were recruited through purposive sampling. The eight participants were either spouses or adult children.

Results: Five major themes were identified: Having a Terminal Disease; Planning Goals and Wishes for Care; Living Life and Creating Memories; Feeling Strain and Responsibility; and Nearing the End. Caregivers had little understanding of prognosis prior to advance care planning conversations at the clinic. Advance care planning conversations enabled caregivers to know and support patients’ goals and wishes. Caregivers described feeling informed, prepared, and supported when death was near. They expressed neither distress nor anxiety related to patients’ symptoms or strain of relationships.

Conclusion: Collaboration and close communication among caregivers, respirologists, and home care enabled effective symptom management and out of hospital deaths. Patients and caregivers had opportunities to enjoy events, create memories, determine preferences, and make plans. Further research on an early integrated palliative approach in Idiopathic Pulmonary Fibrosis is warranted related to quality of life, experience with death and dying, and caregiver bereavement.

Keywords
Pulmonary fibrosis, family caregivers, palliative care, advance care planning, multidisciplinary, death, end of life, symptoms, signs, respiratory

What is already known about the topic?

- Idiopathic pulmonary fibrosis (IPF) patients and their family caregivers experience a distressingly high symptom burden.
- Palliative care is recommended but rarely utilized.
- Most IPF patients die unprepared in hospital in the absence of early advance care planning (ACP).

What this paper adds?

- Advance care planning (ACP) with an integrated palliative approach for idiopathic pulmonary fibrosis (IPF) was positive for bereaved family caregivers.
- Bereaved caregivers felt engaged, empowered, and supported to achieve patient-identified goals, create memories, and reduce symptom burden.
- Early ACP provided reassurance and alleviated fears, distress, hopelessness, and relationship strain.

Implications for practice, theory, or policy

- An early palliative approach, including effective symptom self-management and advance care planning, is imperative to achieve patients’ goals and reduce family caregiver strain.
- Community supports are important to reinforce and support the family caregiver role.

¹Palliative and End of Life Care & Community Programs, Continuing Care, Alberta Health Services, Edmonton, AB, Canada
²Faculty of Medicine & Dentistry, University of Alberta
³Alberta Health Services, Edmonton, AB, Canada

Corresponding author:
Charlotte Pooler, Palliative and End of Life Care & Community Programs, Continuing Care, Alberta Health Services, Edmonton Zone, #402, 10216 124 Street, Edmonton, AB T5N 4A3, Canada.
Email: charlotte.pooler@ahs.ca
Table 1. Early integrated palliative care approach.

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<th>Patient and family caregiver support</th>
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<td>Community care:</td>
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<td>• Pharmacists</td>
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<td>• Pulmonary fibrosis support group</td>
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Symptom management

Initial and ongoing symptom assessment; pharmacological and non-pharmacological interventions

Pulmonary rehabilitation

MDC-ILD respirologist led rehabilitation program in the community and home

Advance care planning

Advance care planning conversations in initial patient/caregiver encounters

Enabled patients to remain home and avoid unnecessary hospitalization


discussion minimized anxiety, provided information and support Conversations and action plans supported by clinic health and home care teams Information regarding community spiritual and psychosocial resources provided

MDC-ILD: Multidisciplinary Collaborative Interstitial Lung Disease.

*Home Living, Alberta Health Services – Edmonton Zone.

Idiopathic pulmonary fibrosis (IPF) is an incurable fibrotic lung disease with an uncertain trajectory and median mortality of 2–3 years. IPF patients and family caregivers report uncontrolled and distressing high symptom burden which increases at end of life. 

Breathlessness and cough are uncontrolled and distressingly high symptom burden which pared. Lack of preparation and poor symptom management has been linked to poor bereavement outcomes, and caregiver suffering and expressed needs for both patients and families. 

Compared to lung cancer, patients with IPF have more dyspnea at end of life, yet may not receive opiates. 

Despite prognosis and high symptom burden, a palliative approach is underused, and most patients die in hospital. Hospital deaths are described as “unexpected”: end of life is neither recognized nor discussed, and caregivers are unprepared. Lack of preparation and poor symptom management has been linked to poor bereavement outcomes, including complicated grief in other populations.

Family caregivers provide invaluable support to IPF patients, including at end of life. Yet informational, educational, and support needs for caregivers of patients with IPF are infrequently recognized or met, resulting in strain, burden, and distress throughout the disease course and at end of life.

Patients with IPF and their caregivers identified fear, helplessness, role ambiguity, and caregiver suffering and expressed needs for active participation and early palliative care. Caregivers of patients with IPF expressed hypervigilance, anxiety, distress, and uncertainty in managing symptoms of cough and dyspnea, which contribute to poor quality of life for both patients and caregivers.

Factors that positively influenced caregivers’ experiences at end of life included dignity, respect for wishes, effective symptom management, privacy, patient comfort, kindness and compassion, communication, information and anticipatory guidance for caregivers. Factors that decreased quality of life and increased suffering for caregivers were unmanaged symptoms, unmet patient needs, futile treatment, lack of joy or hope, and insufficient support of practical, informational, and emotional needs.

In addition to disease-specific therapy for patients with IPF, a palliative approach with early advance care planning (ACP), support for caregivers, and optimizing quality of life and dying are recommended. Although description of community collaboration is limited, a community case conference model demonstrated a positive effect for patients and caregivers related to care concerns, quality of life, anxiety, and depression. There is a need for qualitative research to explore ACP conversations in the pulmonary population. An integrated palliative approach for patients with IPF was implemented at our Multidisciplinary Collaborative Interstitial Lung Disease (MDC-ILD) Clinic in collaboration with community and home care services (Table 1). This study explored bereaved caregivers’ experiences of IPF patients’ end-of-life care with the palliative approach initiated at the first visit to the clinic.

**Methods**

Ethics approval was obtained from the University of Alberta Health Ethics Review Board (2016: Pr000060045) and operational approval from the health authority. Data were collected between June and December 2016. A narrative approach was used to obtain and relay caregivers’ stories, experiences, and perceptions. Participants were recruited...
through purposive sampling from the MDC-ILD clinic located in a large western Canadian city. Recruitment was through intermediary, third person contact by letter of invitation. Ten letters were mailed out by the clinic administrator to patient families after a minimum of 3 months bereavement. Eight spouses or adult children contacted the Primary Investigator (C.P.) directly; C.P. has no association with the clinic. IPF was diagnosed using ATS 2011 criteria, although some participants used the term ILD in the interviews. Ongoing analysis confirmed data were rich, stories repetitive, and saturation attained after eight interviews. Due to risk of identification, aggregate characteristics of participants and patients are presented (Table 2).32

Interviews were conducted at C.P.’s office or by telephone, in accordance with participant preference. Interviews averaged 56 min (range: 34–85 min), recorded after verbal or written consent obtained, and then transcribed verbatim and de-identified. Participants were asked to start the story about caring for their family member near end of life (Table 3). C.P., who has extensive training and experience in both qualitative research and chronic pulmonary illness, conducted the interviews and led the analysis. Context, beginnings, ends, sequences, and emotions were examined within the text for relevance and meaning. Data were organized, patterns and themes were identified, and text reconstructed along timelines and themes.30,31 Excerpts from the transcripts are presented to illustrate the themes.

Table 2. Bereaved caregiver participants and patients with IPF.

<table>
<thead>
<tr>
<th>Participant relationship</th>
<th>Participant gender</th>
<th>Patient gender</th>
<th>Patient age in years: early 50s to early 80s</th>
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<tbody>
<tr>
<td>Adult child</td>
<td>Female</td>
<td>Male</td>
<td>50s 60s 70s 80s</td>
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<tr>
<td>Spouse</td>
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Patient data provided by family caregiver in interviews.

Results

Five major themes were identified: (1) having a terminal disease; (2) planning goals and wishes for care; (3) living life and creating memories; (4) feeling strain and responsibility; and (5) nearing the end. The two themes, having a terminal disease and nearing the end, were chronologically at the beginning and end phases of both the interviews and narratives.

Table 3. Hearing the story: interview topic guide.

Examples of opening question/statement

- We want to hear of your experience caring for XX at the end of life ... So, just start where you feel comfortable starting ...
- So, really it’s a conversation, mostly on your side. So start where you think you should start about telling me your story. And about where you think you should begin. We’re focusing on or near the end of life, but that is a short or a longer period of time

Additional topics, questions as necessary

- Can you tell me a little bit about when XX died?
- Did you and XX talk about his or her death beforehand?
- Where preferred to die
- Any concerns, thoughts
- Were those preferences supported?
- Were you given the information that you wanted or thought you needed? For example, about XX’s condition, about what was going to happen near the end or in the final hour? For example, change in condition
- Were you involved in the decisions the way you wanted

Can you describe any symptoms XX had near the end of life? How was that for you? How were those symptoms managed or relieved? Do you think there could have been more done? Do you wish there could have been more done?

What did you know about XX’s illness?
What do you think XX knew about his or her illness?

Was XX in hospital in the last year of his or her life?

Did XX and you receive help from any other health or voluntary services in the last year of his or her life?
Were there things that helped during this time?
Where there things that would have helped?

Notes, comments

Open-ended questions and topics were developed from the literature
Most participants addressed these topics spontaneously
One participant was asked about advance care planning
Minimal probing was needed and no follow-up interviews were necessary

Insert patients’ name or role for XX, for example, your mom for XX.
Having a terminal disease

When asked to share their story about end-of-life care, all but one of the participants started with the moment when they received the diagnosis of IPF or were told the terminal nature of the disease. The exception occurred with a participant who had another family member that had been previously diagnosed and died of the disease. Opening of the narrative in this moment of time when asked about end of life demonstrated gaps in obtaining a diagnosis and understanding the severity of IPF, including its rapid progression and trajectory. Patients and caregivers often struggled to obtain a diagnosis or information prior to referral to the clinic, such as this participant whose husband was referred just months before he died:

It wasn’t even told to us that my husband could have pulmonary fibrosis until the 12th of February. And then he was gone the 11th of August. So it was very quick. (F1)

Other participants knew the diagnosis of their family member, but were not informed of the poor prognosis until they met with the clinic team. In these instances, the diagnosis had little or no meaning about what they were to anticipate about the disease or illness:

I think people don’t want to upset people or don’t want to scare them but it’s really just so much scarier guessing. The first year or so was really frustrating because we could see mom declining but not really to any extent. And then the doctor referred us to the transplant specialist and just said “This is kind of your only option.” And that shocked us. “Well, what do you mean we need a lung transplant?” And so we met Drs. M and J in January of (pause) 20XX. And by the time they met my mom, they said “She’ll be gone within a year.” And we said “What? What are you talking about?” We had no idea. We were completely unprepared. So it was really kind of from then that I consider her dying or her end of life starting because I had no idea she was dying until then. We knew then, because we had it explained to us. (D1)

Elements of suddenness and surprise occurred for some caregivers with the rapid deterioration of the disease. Although aware that there was limited time, it was “quicker than expected”:

When she started on the oxygen I think she was only on a level 2 or a level 3, and then it increased to 8 to 10 to 12 to 14 in such a short period of time. I think the most shocking thing is how quickly, even though maybe people have been told you’ve got 3 months, 6 months, whatever months. I think when that day actually comes it’s probably always a shock. The Tuesday we saw her with a team of doctors and Sunday she was gone. That was much quicker than we expected even though we knew it was probably just a matter of maybe a few more months. (A1)

Five participants recommended that palliative care be implemented upon diagnosis. They described that both patients and caregivers would benefit from early integration, including earlier awareness that it is a terminal disease, prompt initiation of symptom management, and improved access to services, supports, and equipment. For example

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 minute of your life. We don’t know, you could live two years, three years, you could live 6 months or a month. But if you could access somebody 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 my 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.” (E1)

Now in hindsight, I really saw the benefits of M and J the way that they did the clinic because mom saw her own mortality then. We started about her maybe moving out of the house and her dying at home didn’t mean THAT house possibly. It meant somewhere ... So that’s when we started having conversations about moving to a place that had some care or an apartment or my aunt lives in assisted living near here, like something like that. (G1)

Planning goals and wishes for care

All participants described early and ongoing conversations enabled patients to express their goals and wishes and motivated their caregivers to respect and support them. Two caregivers acknowledged that health care professionals may find it difficult to discuss the terminal nature of IPF or initiate ACP conversations, but emphasized the importance of doing so:

They talked to us about advance care planning. He understood how it was and me too. And he wanted to die at home so that’s why I took care of him at home. I was involved in that I was accepting of his wishes. And I felt I needed to respect him. (C1)

Their honesty in their conversation was huge as well. Being able to look at her eye and tell her that she’s dying and that she will be dead within the year. And then, taking the time to sit there and hold her hand and wait until she was ready to talk, and answer her questions, and let her know what that death was going to look like, (pause) I think is also really big. (D1)

Several participants stated these conversations were important to help prepare for death, including decisions regarding financial and legal issues, as well as funeral arrangements. Most caregivers knew their loved ones were deteriorating and had a short time remaining because of the open conversations initiated at the clinic and held throughout the patient’s journey:
We knew the end was coming. I didn’t expect her to see Christmas this year, for sure, I was confident that she wouldn’t last until Christmas but I thought maybe spring, summer ... So I really thanked Dr. J for really giving us the extra push that we needed [for funeral arrangements] and not just saying “yeah we know it needs to be done” but actually getting out there and doing it. Mom was obviously part of planning, she decided what she wanted, and you know, made her final wishes known. And that helped my sister and I. (A1)

My husband actually did really well up until September of 20XX. He was still very independent, he needed supervision to help with his oxygen hose when he had a shower, to make sure he was getting enough air. Then in October I noticed he was getting a little less active. Even though he forced himself to go somewhere every day it was more of an effort. But I think he knew he had very little time left and so it was very important to him to do all these things. (E1)

These conversations enabled both patients and caregivers to understand the terminal nature of their diagnosis and thereby focus on living life fully while planning for death. The open discussions also alleviated fears about end-of-life care and death.

**Living life and creating memories**

The ability to live life and create memories was a predominant theme in the narratives. The integrated palliative approach that included disease-specific education, symptom self-management strategies and open honest communication helped optimize quality of life. Participants described that management of shortness of breath, cough, and anxiety enabled both patients and caregivers to have a better quality of life and experience meaningful activities in the time they had left together:

So having the different medications that M and J [MCD-ILD physicians] used allowed us to do a lot of things. My mom left the house every two weeks. She slept through the night, she wasn’t tossing and turning. She didn’t cough. She had more energy because she wasn’t struggling to breathe, she didn’t have to sleep for 48 hours after taking a shower anymore. She could talk to her friends and her daughters. We were able to go for an overnight trip, we went and did a photo shoot one day and went and got family photos, we drove out to the country. We’d go for drives in the country all the time. There were a lot of things we were able to do because of how M and J treated this disease. I don’t know how they figured it out to approach it this way but they just allowed their patients to get so much more out of life so they’re not struggling with it. (D1)

Patients remained active, making the most of the time they had, up to their last days or even hours. Use of high flow oxygen and action plans enabled participation in activities such as mowing the lawn, picking raspberries, attending hockey games, and baking bread. One patient was admitted to hospital in the last year of life for 3 days. All avoided hospitalization at end of life:

D never coughed and he never complained about being short of breath, and he never complained about being on oxygen 24/7. Which probably made it easier too, for me and for our daughter and son-in-law. No, because he still kept as active as he could be for the disease that he had. And he knew that (pause) life was going to be short now, but he still made the best of it. (F1)

Several participants reflected upon symptom management and their family member’s quality of life during the last months and days. One wondered about her family member being referred sooner:

Not that it would have prolonged her life or anything like that but if he (primary care practitioner) maybe would have referred her sooner, maybe her treatment could have been started sooner, it wouldn’t have been as hard on her at the beginning.

Another stated, the MDC-ILD clinic physicians “wanted to give him the best quality of life for the quantity of life he had left” and shared her memories:

I’d often sit at night and think “I wonder if he’d have gone to football or hockey or the rodeo or any of those things if he didn’t have his drugs.” (Pause). Most people with pulmonary fibrosis don’t want to go to the hospital when they know that they can be home and be on 20L of oxygen. So would you want to be in the hospital or do you want to be home where you can carry on a conversation with your family, create memories, go to ball games. You know there’s not one of them that would pick the hospital. Not one of them. (E1)

**Feeling strain and responsibility**

A few participants described experiences of strain and responsibilities, due to physical work, differing expectations from contracted service providers (such as health care aides and oxygen vendors), insufficient resources for health care, and limited knowledge regarding community supports. For example, several participants mentioned lack of sufficient respite services:

I think we’re so used to doing things for ourselves, we don’t know what people can help with sometimes. Knowing about pharmacies that will deliver your medication. Having groceries delivered. Having someone come sit in the house, in case she woke up, so I could leave and go and get groceries. I had family friends help out when they could but ultimately they have their own life. Even knowing who to call, or someone to call, would be really nice because when you’re the caregiver it’s not a 9 to 5. It’s 24 hours. If something happens in the middle of the night, it happens in the middle of the night. (D1)
These concerns, including fear of leaving the patient alone at home, were not shared by caregivers with their extended family and/or friends at the time. Another participant shared:

I think we need better respite care. Even if it’s an hour a week where you can go for groceries and somebody is there. So that you know that if you leave for an hour, there is somebody there that is qualified, or even if they’re not qualified they can call for help, rather than if you leave them alone. Right? (crying) So if you can have somebody that will be there that says “Okay, you have four hours, (or whatever) go get your hair done, go do your grocery shopping, he’s going to be fine, but somebody is going to be with him that will call you or call for medical assistance.” To me that is the most important. Because you never get a calm moment. (E1)

Some caregivers struggled to meet patient wishes while supporting other family members, attending to their own needs, or needing to travel. Six caregivers worked full time in addition to caregiving responsibilities:

[Home care] came every morning and every evening and took off the cannula and put a breathing mask on her, she had that help. So they were coming in every day. Like morning and evening which kind of was a relief to me ‘cause even though it was a simple job of switching over from the cannula to the actual mask I was kind of glad that at least she was kind of being checked on ... But the home care didn’t start until we absolutely had to. So I went and got all the various things that she needed, equipment and all that kind of stuff. And we all did what she wanted. My dad refused to send her anywhere, he wouldn’t send her to a hospital, but she wouldn’t go anyway. She died at home and she’s the type of person that needed that. It was hard. I was tired and I’d have to go to work and it was brutal. It’s a hard job looking after someone, especially when they’re dying, I think. I’d come home from work and kind of sit with her and but it was so hard I would cry. It was very hard to watch. Anyway. We did whatever we could. (A1)

Seven participants supported their family members to have home deaths in accordance with their wishes. The exception was one participant, who was unable to manage the physical care, and described the positive collaboration of the MDC-ILD clinic with the facility hospice. Several described the physical commitment and monitoring needed to support a home death. This patient desired a home death if end of life became imminent before a lung transplant became available:

Even though I tell people my husband died at home, that is not for everybody and trust me I was very resistant for a very long time. But we don’t have many options, it’s either hospital and intubated and we don’t have a major hospice centre. So you’re very limited in what you can do. And I couldn’t imagine having to sit there and have him be intubated when he was so happy right until the very last minute of his life, by being at home. But to make that choice, it’s a very hard choice to make, very hard. (E1)

Despite the vigilance required, participants described a sense of achievement and gratification from keeping family members out of hospital in accordance with patient’s wishes:

And a couple of times I asked him, “Are you sure you would not like to go into the hospital because maybe they could take care of you better?” and he said “No, no, no I just want you to take care of me.” So that was that. That was my concern, what I was thinking. Maybe they were better equipped. And he wanted to die at home so that’s why I took care of him at home. (C1)

But I’m glad I did what I did (pause) because he didn’t want to pass away at the hospital. [emphatic] He wanted to pass away at home. (long pause). Because when he was in the hospital, he was in the hospital for a week and he said to me, “Don’t ever, ever send me to the hospital to pass away.” And I said “I won’t.” And I didn’t and I’m glad. (F1)

Nearing the end

Participants expressed sorrow and sadness as they described the last days or moments. Some were tearful. When given the option of pausing or stopping the interview, all indicated that they wanted to continue. They shared experiences about family members who were coherent and active until moments or days before death. No caregiver provided a description nor had an example of a crisis, panic, emergency visit, or need for palliative sedation at end of life:

She always said she was going to pass away at Christmas. And she did, at a quarter to 2:00 in the morning. It kind of all happened so fast, the part where the dying process started. She got worse and everybody got together later that afternoon. Her oxygen went down to seventy-something and then Dr. J said to my mom “It’s going to be soon.” (A1)

We had support the whole time and there wasn’t she could be anywhere else and be getting better care. I guess that’s part of it. She’s with us, we love her, we have people there that love her and really that’s all she can get. Some morphine or things like that but really it’s just us being there for her, for her spirit. (B1)

Some participants reflected that death seemed “fast” or “sudden,” even though it was anticipated. While some caregivers were surprised by the quick decline, none were unprepared for the eventual death due to open ongoing discussions with clinicians who explained what to expect:

I don’t think any of us expected him to die that night. My husband, his brother and my son were watching hockey, and
he looked at me and said “I’m really cold, I think I’m going to get into bed.” And if I hadn’t have gone in and checked on him, I would never have known that his breathing changed. Right? But you just kind of get that, where you feel that something’s not right. And his breathing was different. And I said to his brother, “Well, I think you may want to go wake up R if they want a chance to say good-bye.” I think that’s probably one of the most shocking things for me, was how peacefully and how fast he was gone. Even though (our doctor) kept saying, “No really, D, that’s how it’s going to happen!” And I said “No, that’s not possible.” So, little did I know. I know people think I’m crazy when I say if there’s a nice death, he had it. I don’t know how else to describe it, that anybody could just be gone that quickly without a whole lot of suffering. (E1)

Anticipatory guidance for end of life enabled family members to say good-bye:

I started noticing she was retaining water and she was losing her colour a bit and she wasn’t quite awake for about a day. (Pause) So we were giving her everything we could and she was still very restless and that night I slept in the chair beside her bed (crying). And after that, I knew that was it. So I called my sister, otherwise she wouldn’t have been able to make it to say goodbye, because she passed that night. (D1)

It was just so respectful. So they get us all in there quietly and my sister lays down beside mom on the bed and I’m by her head, D is kind of by her but, we were all around her. My dad was at the end of the bed, he was, that was hard for him ... So it was great, because we were able to be there with her at the moment, and just talk to her and when she died, we took her mask off. And we thought, well, she always wanted to be rid of that mask. (B1)

One participant summarized her story from the prognosis through end of life and bereavement, highlighting the importance of initiating early conversations, understanding patient and caregiver goals and wishes, and optimizing time patients and family caregivers have together:

ILD is absolutely a death sentence but how you get from the diagnosis to the end can be managed in a whole bunch of different ways. When you create care teams that are really good at what they do, and really believe in being patient centered, then this is the thing that you end up with, people who are absolutely devastated by the passing of their mom but not traumatized by it. (B1)

Discussion

Main findings/results of the study

In this study, we explored bereaved caregivers’ perceptions of an early integrated palliative approach for patients with IPF. The results highlight the profound impact of early caregiver engagement using a palliative approach initiated at the first visit at the MDC-ILD clinic. This approach with integrated symptom management, pulmonary rehabilitation, and ongoing ACP conversations improved patients’ quality of life, helped fulfill patient-centered goals, and enabled families to create good memories with patients remaining active until end of life. Caregivers, too, experienced a better quality of life. ACP enabled caregivers to know their loved ones’ wishes and goals, and helped prepare for a good death. These conversations facilitated positive caregiver engagement and effective co-management of disease and symptoms. Although all patients avoided a hospital death as preferred, a few indicated this required energy and vigilance. Dedicated resources are necessary to support IPF patients and caregivers in the home.

Consistent with other studies, these participants found the MDC-ILD clinic to be a reliable source of information and support. Participants expressed frustrations during the initial diagnostic phase and having little information prior to referral. Some described knowing the IPF label, but not what it meant until they attended the MDC-ILD clinic, where open conversations about the disease, its management, and trajectory occurred.

These participants expressed support with symptom self-management strategies that lead to effective and rapid relief of dyspnea and cough. Patients and families were prepared to manage predictable symptom crisis at home and linked with appropriate community supports that readily liaise with the clinic. We suggest these caregivers were subsequently able to focus more on living quality of life and creating memories. In sharp contrast to our findings, previous studies with IPF caregivers reported overwhelming symptom burden with a negative impact on function and relationships as well as emotional distress. We suspect that this is due to traditional emphasis in clinics on disease-specific diagnosis and management, without needed attention to patient-centered symptom alleviation and early advance care planning conversations. Therefore, integration of a palliative approach as part of routine IPF care is urgently needed to support positive outcomes for both patients and their family members.

Although ACP conversations are recommended for chronic respiratory disease, they are rarely undertaken in ILD clinics, and delayed or unclear ACP conversations are frequently reported. Early initiation of ACP is essential for IPF patients due to the unpredictable disease course marked by high acute care use. For example, Liang and colleagues recommended that patients and families be informed early about palliative care due to the high risk and mortality of admission to intensive care: of 106 patients with IPF admitted to ICU over 10 years, 34%–50% were admitted to ICU after their first to third clinic visit, and the majority died in ICU.
frequent, and caregivers perceive themselves as passive observers in clinic encounters.\textsuperscript{5,13}

ACP discussions were led by the MDC-ILD clinic physicians in a sensitive, open, and honest fashion. They usually occurred at the first visit, were ongoing, and collaborative with the home care team. A provincial ACP policy supports collaboration and communication across settings, including acute care, outpatient clinics, and community home care.\textsuperscript{37} In contrast to other reports where caregivers were reluctant to engage in conversations or palliative care,\textsuperscript{7,35} these participants described how valuable the ACP conversations were. ACP conversations enabled them to understand the fatal nature of IPF, prepared them for progression of the disease, know their loved one’s wishes, have discussions, and make choices in keeping with the patient’s preferences. Whereas many bereaved caregivers contend with guilt over things, they did or did not say or do with their loved ones, these participants welcomed the opportunity to create special memories while they still had time due to ACP conversations. In contrast to fear, frustration, and distress expressed by caregivers in other studies,\textsuperscript{7,9} these participants described confidence in being able to fulfill patients’ goals and to manage symptoms at the end of life. Thus, it is essential to support and prepare caregivers well in advance of death, and reduce risk for negative post-bereavement outcomes.\textsuperscript{11} Pre-bereavement interventions that decrease caregiver burden and distress may prevent complicated grief after the death of their loved one.\textsuperscript{11}

One reported barrier for caregivers to engage in ACP is perceived loss of hope.\textsuperscript{7,33} We conjecture that caregivers in this study felt supported by ACP conversations reframed as strategies to live as well as possible within the confines of the disease. This approach to address fears and worries is supported in the literature to alleviate concerns and promote hope.\textsuperscript{26,27,33} ACP conversations become centered about living and making realistic life choices, instead of limited discussions about death, advanced directives, or do not resuscitate orders. We suggest that empowering patients and caregivers with control over symptoms gives hope and promotes well-being.\textsuperscript{26,27,37} Good and timely communication helps allay anxiety, fear by addressing concerns, and providing emotional support when needed.

It is important to note that six participants expressed feelings of caregiver strain and responsibility from physical work, vigilance of symptom monitoring, and lack of respite. However, they contrasted these efforts with satisfaction of times together and success at keeping their family member out of hospital, including at end of life. Furthermore, they did not experience relationship strain or distress from symptom burden as described in the literature. The integrated palliative approach met caregiver needs as identified in the literature, including respect for patient wishes, effective symptom management, and anticipatory guidance.\textsuperscript{6,16–23,26}

**Strengths and limitations.** Limitations of our study include potential selection bias in that participants may have self-selected to those who had a positive experience with the clinic, palliative approach, and end-of-life care. It is limited in that all participants were Caucasian, seven of eight were female, and it is a single center study. Strengths of the study are that it is the first study to report bereaved caregiver experience of home deaths in IPF, utilizing an early integrated palliative approach, and describe outcomes of a palliative approach to this population who are at high risk of suffering, hospitalization, and distress.

**Implications for practice.** Caregivers are an essential component of the care team to provide excellent quality palliative care for patients with advanced respiratory disease. Caregiver needs must be prioritized in clinics and communities, with a patient-centered approach that focuses on disease education, active engagement in co-management of symptoms, and shared decision-making with the patient and clinical team.\textsuperscript{26} Ensuring availability of community-based supports, such as respite services and home care, may ease caregiver strain. For these participants, active identification, assessment, and treatment of patient symptoms relieved distress, improved functional capacity, and maintained social functioning, enabling to live life fully and create memories. Home care collaboration was essential to implement the palliative approach and support end-of-life care.\textsuperscript{26,27,37}

Our study suggests that an early integrated palliative approach in IPF positively influences bereaved caregivers’ experiences. We believe that an early integrated palliative approach in IPF is integral to emotional and psychological well-being of both patients and caregivers. Knowing what to do and who to call if needed during symptom escalation or crisis, caregivers may forgo “911” calls that typically prompt emergency room and acute care admission, in keeping with patient’s preference for care at home. Even in the face of bereavement, our participants felt a sense of achievement in their role as caregivers because of ACP discussions and early integrated palliative approach to care.

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ORCID iD
Charlotte Pooler https://orcid.org/0000-0003-1186-9142

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