From Consulting to Caring: Care Redesign in Idiopathic Pulmonary Fibrosis

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Patients with idiopathic pulmonary fibrosis have a large and unmet symptom burden resulting in poor quality of life and poor quality of death and dying. The Kaye Edmonton ILD (interstitial lung disease) Clinic at University of Alberta developed a multidisciplinary collaborative model to deliver early integrated palliative care to patients with idiopathic pulmonary fibrosis. The multidisciplinary collaborative model involves three key elements: (1) the creation of a specialized, multidisciplinary allied health clinic and community teams; (2) the adoption of a care philosophy emphasizing proactive care, anticipatory guidance, and advance care planning in an outpatient setting; and (3) continuous and dynamic collaboration between the clinic and community teams to identify and meet the spectrum of needs of patients with end-stage lung disease.

KEY TAKEAWAYS

1 Development and dissemination of dyspnea assessment tools and treatment protocols are necessary for improving symptom management.

2 Multidisciplinary teams with trained allied health members in the clinic and community can facilitate the integration of a palliative approach to chronic lung diseases.
Interprofessional collaboration among skilled teams to support patients and families at home is key to ensuring continuity of care, providing patient and family education, and facilitating patient preferences. Dedicated resources and time are required to develop this social capital.

Care philosophy needs to shift from an acute reactionary approach to a proactive anticipatory approach. Multidisciplinary collaborative teams must prioritize symptom management, advance care planning, and anticipatory guidance early in care. Planned and proactive care reduces acute care utilization, creates safety nets of care in the community, and improves communication between patients and their caregivers and care teams. The transformation of practice culture must occur at the individual and organizational levels. These components must be part of medical training.

Rapid and effective communication with use of cell phones improves networking between specialist and community teams to coordinate care and to support patients and caregivers throughout the disease trajectory, thereby reducing fragmentation in care.

Although our model is a work in progress and challenges remain, we have found that when clinicians take ownership of respiratory palliative issues, prioritize them, and work collaboratively with available community partners, patient-centric care can be delivered.

"Gentleman, we have run out of money; now we have to think." —Winston Churchill

The Challenge

Idiopathic pulmonary fibrosis is an incurable, fibrotic lung disease that is associated with high morbidity and mortality. Despite the approval of antifibrotic drugs, the quality of life remains poor: patients seek acute care for the treatment of worsening symptoms and die in hospitals without palliative interventions at the end of life.

"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."
Traditional care models lack the infrastructure, care philosophy, and provider training to address the needs of these 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 whom 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 that would systematically address escalating needs from diagnosis to death.

**The Goal**

Our goal was to create an integrated approach for the palliative care of patients with idiopathic pulmonary fibrosis that would systematically identify and address escalating symptoms, improve advance care planning, reduce hospitalizations at the end of life, promote living well, and facilitate dying with dignity (Figure 1).
Early Integrated Palliative Approach Care Components

- Evidence based IPF care
- Linking patients with community supports (medical & non-medical)
- Systematic needs assessment
- Patient education & early caregiver engagement
- Symptom therapies & self management action plans
- Advance care planning & anticipatory guidance

Source: The Authors
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

Figure 1. Essential components of care required to deliver an early integrated palliative approach in an outpatient practice. IPF = idiopathic pulmonary fibrosis. Click To Enlarge.

The Execution

Creation of Multidisciplinary Teams

The clinic team consisted of two physicians with expertise in interstitial lung disease (M.K.) and palliative respiratory care (M.K. and J.R.E.), a clinic nurse coordinator, a physiotherapist, and a registered dietitian (Figure 2). The interstitial lung disease specialist (M.K.) invited a colleague with expertise in symptom management and end-of-life care to team up for the purposes of (1) providing care jointly and (2) developing expertise in ILD-specific palliative approaches over time. Together, we developed a practice agreement to ensure that the clinic staff focused on palliative needs in addition to disease-based care.
IPF Multidisciplinary Collaborative Care Model

Source: The Authors
NEJM Catalyst (catalyst.nejm.org) © Massachusetts Medical Society

Figure 2. Composition of our multidisciplinary interstitial lung disease collaborative care model, which was designed to deliver early integrated palliative care from diagnosis to death. IPF = idiopathic pulmonary fibrosis, ILD = interstitial lung disease specialist, PCP = primary care physician, RN = registered nurse, RT = respiratory therapist, PT = physiotherapist, RD = registered dietician, OT = occupational therapist, NP = nurse practitioner, O2 = oxygen. Click To Enlarge.

Individualized community teams were developed according to patient needs and available resources in each patient's local community (Figure 2). These teams consisted of each patient's primary care practitioner as well as available home-care respiratory therapists, nurse practitioners, occupational therapists, physiotherapists, pharmacists, and private-sector oxygen vendor respiratory therapists (many of whom were available to do home visits). Respiratory therapists, when available, were accessible 24-7. The clinic physicians identified these preexisting community resources and networked with them to provide care without incurring additional costs.
Training

Neither of the authors had had any formal palliative care training and therefore developed expertise by working together in combined clinics. We then worked collaboratively to train the other team members in systematic needs assessment, symptom management, and patient and caregiver education. This training included didactic PowerPoint sessions as well as hands-on time during patient encounters in clinic and during home visits over a period of 1 year.

"Such collaboration avoids fragmentation of care and ensures that the same teams can continue to manage the patient over time, regardless of the stage of the disease or the physical location of the patient. This continuity is key to facilitating patient preferences for end-of-life care and home death."

The specific training topics included (1) systematic approaches to the assessment of breathlessness and other symptoms; (2) the development of action plans for dyspnea/breathlessness and infections; (3) oxygen titration, activity pacing, and energy conservation; (4) nasal care; (5) dietary modifications; (6) management of the adverse effects of medication; (7) how to initiate and conduct appropriate advance care planning; and (8) teaching patients and caregivers innovative self-management strategies involving the use of buccal opiates to treat breathlessness and associated crises.

We also focused on whom to call for the management of concerns (e.g., medical deterioration, financial concerns, social isolation, caregiver burnout, spiritual needs); how to contact appropriate resources (e.g., primary care providers and specialists, social workers, respite services, chaplains, recreational therapists); and how to navigate the system, access resources, and manage patients at home.

Throughout the training process, we emphasized mutual learning and took several steps to build partnership, trust, and competence in home-based palliative care. For example, we:

> Accompanied community partners during joint home visits to model how to assess and treat symptoms as well as how to troubleshoot problems effectively in order to avoid unnecessary acute care visits.

> Encouraged direct calls and emails from members of the community care teams.
Provided patients, families, and team members with 24-7 contact numbers for medical support and emergency medical services where such services were available.

Clinic Workflow

**Pre-clinic telephone assessment:** The clinic nurse coordinator interviews the patient and caregiver in advance of the clinic visit in order to (1) determine needs and priorities, (2) develop a care plan involving disease and symptom management as well as patient education, and (3) identify needed community supports. The interview findings and the care plan are discussed in a team meeting that is attended by all members of the clinic team, each of whom develops a workflow in his or her domain prior to the patient encounter.

**Clinic visit:** In addition to providing evidence-based care, the clinical team focuses on needs assessment, symptom management, and caregiver engagement as essential elements of routine care. All members of the team see patients in tandem and jointly develop a comprehensive care plan. During the visit, time is allocated for discussions of advance care planning and anticipatory guidance. Predetermined workflows based on the pre-clinic team meeting allow for an integrated palliative approach, thereby making care patient- and family-centered. An average clinic visit can last up to 2 hours.

**Patient Empowerment**

During the clinic visit, the multidisciplinary collaborative team provides education on disease management, symptom care, and anticipatory guidance to enhance self-efficacy. Self-management strategies are developed to treat anticipated dyspnea and crises at home when possible, with the patient and caregivers participating in these discussions. We encourage patients and families to self-manage anticipated dyspnea instead of waiting for it to occur. In doing so, they learn how to recognize their own risks for breathlessness, how to minimize them, and how various management strategies (e.g., the use of the proper oxygen dose, the appropriate oxygen-delivery system, and buccal hydromorphone) can allow them to stay comfortable at home.

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A patient education binder containing generic information on idiopathic pulmonary fibrosis, tailored advice (e.g., how to eat, talk, take a shower, dress, and ambulate without experiencing a dyspnea crisis; how to travel with oxygen; how to continue to participate in recreational activities, etc.), and specific action plans is provided to the patient at the end of the visit. The binder covers several topics, including the use of oxygen, how to relieve nasal/sinus congestion, how to conserve energy, how to cough and clear phlegm effectively, whom to contact in case of deterioration, and the patient's preferences and wishes regarding end-of-life care (e.g., “do not intubate,” “do not resuscitate,” “do not hospitalize,” etc.).

As new topics are discussed at follow-up visits, written information sheets on these subjects are added to the binder. For example, when discussing advance care planning, we provide an information sheet on action items for planning (e.g., choosing a funeral home, banking, power of attorney, medical proxy, having a will, legacy options, etc.). This information sheet also lists Web-based resources that can be consulted for additional information on planning. The community teams reinforce these strategies frequently to ensure compliance.

_Comprehensive Care Plan_

As mentioned above, the patient and caregivers are provided with a comprehensive care plan at the end of the clinic visit. This plan might cover the following areas:

- **Disease-specific management**: The clinic team reviews the antifibrotic regimen, orders bloodwork for adverse effects monitoring, and addresses side effects, if any. We identify and treat comorbidities and refer patients to the interstitial lung disease pulmonary rehabilitation program and our lung transplant service when appropriate.

- **Breathlessness**: We prescribe oxygen flows to maintain nadir exertional oxygen saturation at >90% and provide advice on the use of appropriate oxygen-delivery interfaces (e.g., nasal cannula, OxyMask™, non-rebreather mask, etc.). We liaise with the vendor respiratory therapist to ensure that the oxygen needs at home are regularly monitored and met. We review activities and provide specific advice on how to pace and/or modify activity to conserve energy and reduce breathlessness.

- **Self-management of dyspnea**: We provide patients, caregivers, and the community teams with a written action plan covering the use of hydromorphone oral syrup for the treatment of baseline, exertional (incident or episodic), and crisis (unanticipated) dyspnea. We coach them in clinic on how to use medications appropriately. All doses mentioned below are only starting doses and will need titration to effect.
  - **Baseline dyspnea**: We start with 0.1–0.2 mg buccal hydromorphone for narcotic-naïve patients; 0.1 mg orally 4 times if baseline dyspnea scores are high even with appropriate
oxygen flows.

- **Exertional dyspnea (incident or episodic):** We start with 0.1–0.2 mg buccal hydromorphone at a minimum of 5–0 minutes before exertion for anticipated (incident) dyspnea (e.g., dressing, showering, going out, exercise routine).

- **Crisis dyspnea (unanticipated):** We start with 0.2 mg buccal hydromorphone every 10 minutes as needed until relief is obtained. Effective dose through the buccal route usually settles the breathlessness crisis within 5–10 minutes. We prescribe sublingual lorazepam (1 mg) to treat anxiety associated with crises. At end of life, we prescribe buccal Nozinan® (5 mg; 25 mg/mL) every 4–6 hours as needed for agitation during breathlessness crisis.

- **Nasal care:** We recommend frequent lubrication (every 2–4 hours) with sinus rinses or sprays with increasing oxygen flows.

- **Infection care:** We provide an antibiotic prescription for chest infection for future use.

- **Constipation:** We advise patients to take PEG (polyethylene glycol) 3350 (1–3 tsp daily) when constipated or when using opiates and to call the home-care registered nurse when unsure what to do or when assistance is needed.

- **Education:** We provide targeted education on a variety of relevant topics described above (e.g., symptoms, general disease, reflux, diet, weight management, etc.). We also provide education and resources related to advance care planning and palliative care as needed.

- **Contact information:** We provide the telephone number of a home-care respiratory therapist to call for support, reassurance, and/or home assessment. We advise patients to call the home-care registered nurse when they are not sure what to do or are in need of assistance.

**Collaborative Care: Home Visits and Teleconferencing**

All clinic notes, education materials, action plans, and advance care planning are shared with the community teams through the electronic medical record (EMR) and/or fax. (The community teams currently use a different medical record system, but in the near future we will be adopting the same EMR across all facilities, thereby improving access.) The clinic nurse coordinates care and liaises with the home-care nurses or respiratory therapists after the clinic visit as needed. Such coordination ensures continuity of care and provides the patient with support and access to care outside clinic hours. When the patient calls for support, the home-care staff is familiar with his or her care plan and can provide individualized advice or facilitate home palliation as needed.
Patient preferences regarding care and death were documented in 84% of our cases within the first 3 clinic visits and in 100% of cases by the time of death, in contrast to rates of 13% to 17% that have been reported in other clinics."

Collaborative networking between teams through joint home visits (involving a clinic physician along with home-care staff [e.g., registered nurse, respiratory therapist]) allows for continuity of care when patients are no longer able to travel to the clinic. When home visits are not possible, we communicate rapidly through the use of cell phones to facilitate problem-solving during crises that otherwise would lead to acute care use.

Effective symptom management also requires collaboration with the community pharmacist to ensure rapid and sufficient opioid dosing as the condition progresses and symptoms escalate. Joint telehealth sessions or teleconferences involving members of the clinic and community teams are organized when the patient can no longer visit the clinic. Such collaboration avoids fragmentation of care and ensures that the same teams can continue to manage the patient over time, regardless of the stage of the disease or the physical location of the patient. This continuity is key to facilitating patient preferences for end-of-life care and home death.

**Tools**

We developed EMR tools for clinic use. The EMR tools included (1) assessment templates for each discipline (e.g., nursing, physiotherapist, dietitian, etc.) and (2) smart phrases to document symptom management advice, advance care planning, and anticipatory guidance to standardize care and documentation.

**Metrics**

1. **Identification of needs and early initiation of symptom-based therapies:** The multidisciplinary collaborative model led to improvement in dyspnea management as indicated by earlier opiate treatment. We noted that, between 2012 and 2016, 95% of 22 patients who died had received opiate treatment at the end of life, with the majority starting at an average of 153 days before death. In comparison, other models have been associated with delayed dyspnea management, with 71% of patients receiving opiate treatment only within the last week of life.

2. **Greater engagement in advance care planning and anticipatory guidance with increase in EMR documentation:** Patient preferences regarding care and death were documented in 84% of our
cases within the first 3 clinic visits and in 100% of cases by the time of death, in contrast to rates of 13% to 17% that have been reported in other clinics.

3. Reduced end-of-life hospitalization and reduced hospital deaths: We observed no emergency visits in the last 6 months of life in 63% of cases and no hospitalizations in the last 6 months of life in 35% of cases. The majority (67%) of patients died at home or in hospice, in keeping with their preferences, and only 33% died in hospitals. Other investigators have reported rates of hospital deaths ranging from 57% to 80% and rates of home deaths ranging from 0% to 14%.

4. Greater adherence to patient wishes for care and place of death: We observed 78% concordance between patient preferences and the actual location of death in a review of our cohort.

5. Improved patient- and caregiver-reported experience measure: A survey of 15 patients and 7 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.

Where to Start

To implement similar models and approaches in idiopathic pulmonary fibrosis care, an organization must:

1. Identify physician experts in symptoms management and advance care planning and include these individuals in care teams to provide concurrent palliative care.

2. Develop multidisciplinary teams, in both clinics and communities, that include dedicated nurses, respiratory therapists, and physiotherapists who can work collaboratively to meet complex and chronic respiratory-care needs.

3. Educate and train all care providers. Training modules for care teams should be developed on the basis of local needs and should focus on holistic respiratory assessments and palliative approaches.

4. Develop practice agreements to ensure that palliative needs are addressed by routine care providers and not just by palliative consultants. Providing symptom relief must be viewed as part and parcel of clinical care. Physicians must take ownership of symptom management and advance care planning and must recognize that their obligation is not to simply treat the disease but to manage the patient who has the disease.

5. Incentivize the provision of full-spectrum, patient-centered, multidisciplinary care. Current payment models do not take into account the time or resources required to provide this type of coordinated, dynamic, and responsive care in the outpatient setting. Our health care system
provides a practice payment plan that guarantees incomes, allowing physicians to focus on providing needed clinical services while also dedicating time to communicating and collaborating beyond the clinic, which would not be possible in a fee-for-service model with associated time pressures.

Hurdles

1. While all health care systems recognize that providing patient-centered care is a priority, the organizational and leadership support that are needed for the implementation of this approach to care is lacking. Funding for the clinic team members and community programs is under perpetual threat of discontinuation, leading to a high rate of staff turnover. The development of highly functioning teams requires a stable environment to build competence, rapport, and efficiency. Dedicated administrative and financial support for staffing is imperative. We sought initial funding for a part-time clinic nurse from nongovernment bodies, with ongoing efforts to find other sources of funding, and we recently lost funding for the clinic physiotherapist.

2. Lack of individual physician engagement and prioritization of palliative care in practice deters the development of holistic care models. There are several reasons for this situation, including discomfort with palliative care and difficult conversations as well as the lack of skills, time, and experience. Medical education must emphasize this competency in palliative care within pulmonary training programs and must provide opportunities for students to observe and practice this needed skill. Most palliative care exposure occurs in inpatient settings where patients are at the end of life, but education focusing on early, integrated outpatient palliative care is rare. The concepts of proactive care and anticipatory guidance must be included in our curricula. Lack of role models who practice integrated palliative care for learners is also a barrier to developing competence.

3. Providing holistic care, continuity, and support outside of clinics requires dedicated time, and current payment models do not incentivize such programs.

4. Lack of guidelines on dyspnea management and palliative care for patients with idiopathic pulmonary fibrosis causes variations in practice between different sites, significantly hampering buy-in from specialist colleagues in hospitals and communities.

Disclosures: The lead author (M.K.) obtained funding for a dedicated nurse and invited a dietitian and a physiotherapist (both of whom were available through general clinic services) to join the clinic. Our health care system (Alberta Health Services) and the provincial ministry of health (Alberta Health) fund
the community-based home-care programs. Therefore, no additional funds were needed to provide ongoing care in the community.

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