Brief Report

Beyond Idiopathic Pulmonary Fibrosis Diagnosis: Multidisciplinary Care With an Early Integrated Palliative Approach Is Associated With a Decrease in Acute Care Utilization and Hospital Deaths

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Abstract

**Context.** Idiopathic pulmonary fibrosis (IPF) is a progressive, incurable interstitial lung disease with heavy symptom burden and poor quality of life. The last year of life is characterized by increased acute care utilization and hospital deaths. Clinical guidelines recommend early integration of palliative care but are rarely implemented. In 2012, we reorganized our clinic into a multidisciplinary team comprising two pulmonologists (expertise in interstitial lung disease and palliative respiratory care, respectively), nurse, respiratory therapist, physiotherapist, and a dietitian. We adopted an early integrated palliative approach with a focus on early symptom management and advance care planning starting at the first clinic visit. We designed a Multidisciplinary collaborative (MDC) care model with emphasis on community-based care to manage patients in their homes and support caregivers.

**Objectives.** Exploratory analysis of this model’s association with acute care utilization in the last year of life and location of death was undertaken.

**Methods.** Data from deceased IPF patients before and after 2012 (non-MDC and MDC care model, respectively) were collected, and statistical analysis was performed.

**Results.** Patients in MDC care were 24.2 times less likely to have respiratory-related emergency room visits (95% CI: 3.12–187.44, \( P = 0.002 \)), 2.32 times less likely to have respiratory-related hospitalizations (95% CI: 0.95–5.6, \( P = 0.064 \)). The odds of achieving a home or hospice death in MDC care were 9.2 times compared to non-MDC care, who die mostly in the hospital (95% CI: 1.14–75, \( P = 0.037 \)).

**Conclusions.** MDC care model for IPF was associated with reduced health care use in the last year of life and more home deaths. J Pain Symptom Manage 2017; - : - . © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

**Key Words**
Idiopathic pulmonary fibrosis, interstitial lung disease, palliative care, multidisciplinary collaborative care, home deaths, early integrated palliative approach

Introduction

Idiopathic pulmonary fibrosis (IPF) is a fatal, fibrosing lung disease with a high mortality and morbidity.\(^1\) Although it is a terminal disease, palliative care is infrequently offered and rarely implemented, thus perpetuating patients' high symptom burden.\(^2\) Unmet

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care needs escalate health resource utilization. The emergence of antifibrotic therapies that slow down lung function decline has changed the treatment landscape, but patient-centered goals of symptom management and maximizing quality of life remain elusive. Current models of care within the interstitial lung diseases (ILDs) centers are not designed to meet these patient-centered goals in IPF.

The combined qualitative research data and patient charters are a call to action for integrating palliative approach, focusing on practical symptom assessment and management while facilitating patient and caregiver engagement. Although recommended in clinical guidelines, there are no descriptions of such care models in IPF.

In 2012, we reorganized our traditional ILD clinic into a multidisciplinary collaborative (MDC) with emphasis on patient-centered care. We use an early integrated palliative respiratory approach and collaborate closely with the patient’s community health care network to meet their needs and better support caregivers. The key elements of our MDC model are: 1) advance care planning (ACP), early discussions about patient’s goals with emphasis on living life fully, 2) development of self-management action plans for dyspnea, and 3) engagement of primary care and allied health home care to provide support within a patient’s home (Fig. 1).

We postulate that this model: 1) decreases respiratory-related emergency room (ER) visits and hospitalizations, and 2) facilitates care and death in patient’s preferred location. In this study, we reviewed consecutive IPF deaths in our ILD clinic from 2009 to 2016 and compared acute care utilization and hospital deaths before and after institution of our MDC model in 2012.

Methods

We identified deceased IPF patients in the clinic between the years of 2009 and 2016 for inclusion in this analysis. Patients were divided into two cohorts: those who received MDC care and those who received care prior to the implementation of MDC model in 2012 (non-MDC care). Patients who died while on the transplant waitlist (n = 5) were excluded from the study because they no longer accessed our MDC care. The University of Alberta Research Ethics Office approved the study.

All data were extracted from electronic or paper charts. Duration of follow-up was calculated from the date of the first visit until the time of death. The number of respiratory-related ER visits and hospitalizations were the number of times a patient was seen in the ER and hospitalized for worsening of respiratory symptoms in the last year of life or after first visit to clinic (where referral was received <12 months before death). As one component of ACP, patient’s preferred location of care, and death was documented in their charts and compared with the actual location of care and death.
Descriptions of Non-MDC and MDC Care

Non-MDC care (2009–2012) is the traditional model where an ILD specialist and nurse see patients and provide guideline-based care with follow-up at 4- to 6-month intervals.

MDC care is the innovative model to deliver specific disease assessment and management with early integrated palliative approach for IPF. Clinic MDC team consists of an ILD expert, a palliative respiratory care expert, nurse, respiratory therapist, physiotherapist, and a registered dietitian. Patients and their caregivers are core members of the team. The team performs patient-centered assessments, engages patients and caregivers through collaborative goal setting and shared decision-making, and provides practical advice on symptom self-management with periodic reassessment needed (without the necessity of a clinic visit). In addition to asking about personal support networks, hopes, goals, and wishes, we document patients’ goals of care and preferred location of death as part of ACP, starting at the first visit. The same MDC team provides care from diagnosis to death, ensuring continuity of care. Patient education occurs in three locations: MDC clinic visits, ILD-specific pulmonary rehabilitation programming, and in their homes from community allied health supports. The clinic team collaborates with community care providers to intervene as appropriate when changes in physical and social functioning occur. MDC patients are seen in the clinic at three-month intervals and in between clinic visits by the community care team consisting of a primary care provider and home care. The home care team includes nurse practitioner, respiratory therapist, occupational therapist, physiotherapist, and registered dietitian. If deterioration occurs, the patients, caregivers, or their community care team contact us for advice. This patient-centered network allows us to identify deterioration early and intervene expeditiously. We ensure that patients and caregivers know whom to contact in case of questions or deterioration.

Data Analysis

Demographic data were analyzed descriptively. Exploratory Poisson analysis was used to determine the association between care models and ER visits; a purposeful multivariable model was created with the variables that improved model fit and discriminative ability was created, and a series of receiver-operating characteristics were performed to determine which care model would provide the best discriminative ability for dying at home or not. All statistical analyses were performed using IBM SPSS, version 24.0 (IBM Corporation, Armonk, New York) and Stata, version 14. A $P$-value of $\leq 0.05$ was deemed statistically significant.

Results

Thirty-two patients were included in the analysis: 22 in MDC care and 10 in non-MDC care. Baseline demographics including comorbidities, lung function, and duration of follow-up were similar between both groups (Table 1).

Association Between MDC Care Model and Respiratory-Related ER Visits and Hospitalizations

Respiratory-related ER visits and hospitalizations are reported in Table 2. Univariate exploratory Poisson analysis demonstrated that the type of care model was significantly associated with ER visits (incidence rate ratio $[\text{IRR}] = 24.2$; $\text{SE} = 25.28$; $95\% \; \text{CI}: 3.12–187.44$, $P = 0.002$). These data suggest that MDC care patients were 24.2 times less likely to have respiratory-related ER visits than non-MDC. No MDC patient had more than one ER visit. Even after adjusting for covariates such as age, diffusing capacity of the lungs for carbon monoxide, and comorbidities (which were significant at $P < 0.20$) in an exploratory fashion, the type of care remained statistically significant ($\text{IRR} = 12.3$; $\text{SE} = 13.3$; $95\% \; \text{CI}, 1.49–102.07$, $P = 0.02$). A univariate exploratory negative binomial regression model showed increasing evidence against the null hypothesis that both models have similar impact on respiratory-related hospitalizations ($\text{IRR} = 2.32$; $\text{SE} = 1.05$; $95\% \; \text{CI}, 0.95–5.6$, $P = 0.064$). These data suggest that MDC patients were 2.32 times less likely to have respiratory-related hospitalizations than the non-MDC. We believe that the difference in hospitalizations is clinically significant. None of the covariates were significantly associated with the outcome ($P > 0.20$), and thus, no further adjustments were done.

Association Between MDC Care Model and Location of Death

The preferred place of care and death was documented in all cases only in the MDC care (Table 3). Ninety-one percent of MDC patients preferred a home or hospice death (77% and 14%, respectively), and 85% died in their preferred location, with 55% dying at home (Table 3). Exploratory penalized
maximum logistic regression model showed that patients in the MDC model were more likely to die at home or hospice compared to non-MDC, who die mostly in the hospital (odds ratio = 4.59; SE = 3.6; 95% CI: 0.98 to 21.4, P = 0.05). When adjusting for covariates such as gender, age, diffusing capacity of the lungs for carbon monoxide, forced vital capacity, and comorbidities in an exploratory fashion, the type of care remained statistically significant (odds ratio = 9.2, SE = 9.92, 95% CI 1.14 to 75, P = 0.037). The area under the curve (AUC) was 0.85, which can be interpreted as good discrimination (AUC = 0.70 to 0.80).

**Discussion**

Our review suggests that MDC care with an early integrated palliative approach in IPF reduces respiratory-related acute care utilization in the last year of life and facilitates dying in the patients’ preferred location. Traditionally, ILD clinics use multidisciplinary teams to achieve accurate diagnosis as per American Thoracic Society 2011 guidelines, but the extension of a multidisciplinary team in ongoing and day-to-day management of IPF beyond the confines of a clinic is not well described. The IPF patient and caregiver journey is dominated by uncontrolled dyspnea and its adverse impact on quality of life and dying.6,10,12 Most patients resort to acute care for relief of symptoms throughout life, with increasing ER visits and hospitalizations in the last year.7,21 The majority of IPF patients die in hospitals4,7,22 despite home being their preferred place of care and death.4 Patients described in these studies were seen in specialty centers with multidisciplinary teams but presumably

| Number of Respiratory-Related Emergency Room (ER) visits and Hospitalizations |
|-----------------|-----------------|-----------------|
| Characteristic   | MDC Care (n = 22) | Non-MDC Care (n = 10) |
| Number of ER Visits |                 |                 |
| 0               | 21 (95%)        | 4 (40%)         |
| 1               | 1 (5%)          | 3 (30%)         |
| 2               | 0 (0%)          | 2 (20%)         |
| 3               | 0 (0%)          | 0 (0%)          |
| 4               | 0 (0%)          | 1 (10%)         |
| Number of hospitalizations |       |                 |
| 0               | 11 (50%)        | 3 (30%)         |
| 1               | 8 (36%)         | 1 (10%)         |
| 2               | 1 (4.5%)        | 3 (30%)         |
| 3               | 1 (4.5%)        | 1 (10%)         |
| 4               | 0 (0%)          | 0 (0%)          |
| 5               | 0 (0%)          | 2 (20%)         |
| 6               | 1 (4.5%)        | 0 (0%)          |
We strongly suspect that specialized multidisciplinary team with an integrated palliative approach is essential to meet these patient care needs. Previous work unequivocally establishes the need for an early integrated palliative approach emphasizing early and ongoing ACP discussion with symptom management in IPF. However, most patients never receive palliative care and those who do receive it too late. \(^{11,22}\) Patients and caregivers express the need for honest and open discussions with their doctors regarding prognosis to aid their ACP.\(^{6,23}\) We strongly suspect that integrated multidisciplinary team with an early integrated palliative approach is essential to meet these patient care needs.

Without an integrated palliative approach. In the absence of such an approach, most patients live and die without control of dyspnea and consequently a poor quality of life. They perceive care in specialty ILD centers to be disease-focused, without adequate attention to symptoms or practical advice to maximize their quality of life and ACP.\(^{6,23}\) In the absence of any survivable reversible disease and appropriately initiated palliative care, symptoms escalate without addressing imminent death, thus characterizing a poor-quality end, hence death for patients and caregivers. We, therefore, embed a palliative respiratory approach within MDC ILD care. Initiation of ACP conversations with all patients and caregivers at first encounter, and ongoing discussions of their symptoms, goals, and hopes, mitigates the problem of waiting for a time or crisis to trigger initiation of palliative care. We report for the first time the feasibility of undertaking ACP early in the MDC clinic setting and early documentation of patient goals, preferred place of care and death as part of ACP in all patients. We suspect that early ACP is critical to achieving reduction in hospital IPF deaths. To our knowledge, achieving a rate of 77% home or hospice IPF deaths has not been previously reported. Sincere and sensitive conversations about living with a fatal illness must become part of clinical IPF practice just as much as accurate diagnosis and prescription of antibiotics.

We believe that in addition to ACP, early and ongoing symptom management is essential to reduce acute care use and hospital deaths. The reported rates of all-cause IPF hospitalization and emergency visits were 49% and 40%, respectively, in a large Medicare cohort.\(^ {25}\) Brown et al. showed that most IPF hospitalizations are related to respiratory worsening (77%).\(^ {26}\) Dyspnea is a key event that triggers acute care use in IPF\(^ {27}\) and is a source of significant distress for patients and caregivers.\(^ {10,12}\) Early dyspnea assessment, development, and implementation of self-management action plans were associated with reduction in acute care use at end of life in our review. Without an effective self-management action plan that includes what to do and whom to contact for help, episodes of crisis dyspnea in the home will invariably lead to 911 calls, ER visits, and hospital admission, followed by intense investigations that invariably do not impact symptom burden. We have previously described our symptom management action plans that are interdisciplinary, easily titrated, and written and shared with the patient, caregiver, primary care provider, and home care team members.\(^ {15,16}\) This approach involves a shift from a disease to a patient-centric approach with a proactive management style using specialized multidisciplinary teams in clinic and beyond. As stated in a recent editorial of the economist: "Death is inevitable. A bad death is not."\(^ {28}\) The article also says, "A better death means a better life, right until the
end.” It is high time to improve the patient and caregiver experience of living and dying with IPF.

Although our study is retrospective in nature and comprises a small sample size with exploratory analyses from one location, our findings have profound implications for clinical care. Unlike a clinical trial, our data represent real-world practice and experience in health care redesign and delivery. Other limitations include selection bias as only deceased patients were included and documentation of reasons for ER visits, as noted by Hutchinson et al. Other factors such as policy change in palliative care, home care services, and increasing awareness may also have contributed to these results. The results of our exploratory analysis will need to be confirmed in a larger controlled study.

Conclusions

An early integrated palliative approach may help reduce respiratory-related acute care utilization and facilitate home or hospice deaths. ACP is a key feature that facilitates early discussion on how patients define quality of life and their preferences regarding death and dying. These discussions help design care delivery in the community in keeping with patient and caregiver needs and preferences. Proactive self-management action plans help preempt dyspnea crises. We developed a MDC care model to deliver this type of care; based on local resources, implementation of this approach across different health systems around the world may require a reorganization and bridging of existing IPF supports among ILD specialty clinics and community networks of primary care and allied health care. With ever increasing strain on health care budgets, such patient-centered models are not just a medical necessity but also an economic one.

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References


