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The palliative care needs of patients with idiopathic pulmonary fibrosis: A qualitative study of patients and family caregivers

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ABSTRACT

Objectives: To explore the perceptions of palliative care (PC) needs in patients with idiopathic pulmonary fibrosis (IPF) and their caregivers.
Background: IPF carries a poor prognosis with most patients succumbing to their illness at a rate comparable to aggressive cancers. No prior studies have comprehensively explored perceptions of PC needs from those currently living with the disease, caring for someone living with the disease, and who cared for a deceased family member.
Methods: Thematic analysis of focus group content was obtained from thirteen participants.
Results: Four themes described frustration with the diagnostic process and education received, overwhelming symptom burden, hesitance to engage in advance care planning, and comfort in receiving care from pulmonary specialty center because of resources.
Conclusions: Findings support that patients and caregivers have informational needs and high symptom burden, but limited understanding of the potential benefits of PC. Future studies are needed to identify optimal ways to introduce early PC.

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Introduction

Idiopathic pulmonary fibrosis (IPF) is a progressive fibroproliferative lung disease that affects approximately 128,000 individuals in the US annually.[1] The prognosis of IPF is poor, with most patients succumbing to their illness at a rate comparable to aggressive cancers.[2] Median survival from diagnosis is 3.8 years; however, patients may succumb to a rapid death within 6 months.[3,4] Although transplantation is an effective surgical therapy,[5,6] less than 20% of patients ever receive a lung transplant.[4] The remaining 80% have few treatment options. As fibrosis advances and lung function deteriorates, patients experience a progressive increase in shortness of breath, cough and fatigue. These symptoms are distressing to patients and family caregivers and present a challenge in maintaining quality of life as the disease relentlessly progresses.[7,8] Despite the fatal prognosis, patients and caregivers often fail to understand the poor prognosis.[9]

An extensive literature review supports that discussion of palliative care by clinicians who manage the care of patients with advanced lung diseases, such as chronic obstructive pulmonary disease, occurs less frequently than for other life-limiting conditions, such as cancer.[9–12] Patients with IPF represent a group of individuals with a chronic respiratory disease who are without disease-reversing treatment options and, absent lung transplantation, inevitably face progressive decline and death.[1] Prior work supports that location of death too frequently occurs in an acute care setting, without the benefit of support available through advance care planning including the introduction of palliative care.[13–15] Prior studies have detailed the impact of IPF on quality of life,[16] advocated for early introduction of palliative care as a means to reduce symptom burden,[10,13,17] and explored patient perceptions of needs.[18] However, no prior studies have explored patient/family caregiver perceptions of palliative care needs from the viewpoint of those currently living with the disease, caring for someone living with the disease, and who cared for a deceased family member.

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The aim of this study was to explore the perceptions of patients with IPF and their family caregivers regarding their learning and supportive care needs, frequency of conversations about advance care planning, and familiarity with palliative care. Findings from this study will provide preliminary information about potential barriers and means to address these from the patient/family caregiver perspective.

Methods

Design

Thematic analysis[19,20] of focus group content obtained from interviews with patients with IPF and their family caregivers.

Setting

The University of Pittsburgh Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease at UPMC, a multidisciplinary center devoted to research and treatment of interstitial lung disease with a focus on IPF. The University of Pittsburgh Dorothy P. and Richard P. Simmons Center for Interstitial Lung Disease (ILD) at UPMC, setting for this study, was established in 2001 as a multidisciplinary center devoted to research and treatment of interstitial lung disease with a focus on IPF. The Simmons Center for ILD is one of forty designated Care Centers in the Pulmonary Fibrosis Foundation Care Center Network. Care Centers are dedicated to improving the clinical care of those living with pulmonary fibrosis and utilize a best practices model to achieve this goal. http://www.pulmonaryfibrosis.org/medical-community/pff-care-center-network. The Center evaluates over 15–20 new patients with ILD monthly; of those 6–10 have a newly confirmed diagnosis of IPF. The center has seen more than 4500 patients with interstitial lung disease (>1000 with IPF). UPMC is also an internationally recognized transplant center with an annual range of 68–109 lung transplants over the past 5 years (2010–2015). Although transplantation is an effective surgical therapy,[5,6] we reported that 43% of our patients at our center were referred for lung transplant evaluation, but only 13% of patients ever receive a lung transplant due to several factors including later referral, appropriate candidacy, and disease course variability.[4]

Participants

Participants were a convenience sample of patients and family caregivers recruited between November 2014 and February 2015 from our IPF clinic and support group. Because perceptions may differ in those currently living with the disease, those caring for these individuals, and those who lost a family member to the disease, participants were assigned to one of three groups, defined by their role. Groups were stratified by participant role to capitalize upon shared identity within groups. Based on literature identifying appropriate group size, the target enrollment was 3–5 participants per group (Table 1). The groups consisted of: (1) current patients with IPF ($n = 5$); (2) family caregivers of current patients ($n = 5$); and (3) family caregivers of decedent IPF patients ($n = 3$). Potentially eligible patients and family caregivers were identified during clinic visits and support group meetings and informed about the study, its risks and benefits; we obtained written informed consent from participants. Participants were provided with lunch and parking vouchers. The University of Pittsburgh Institutional Review Board (PRO14090433) approved the study.

Table 1
Demographics and clinical information.

	Participant	Age	M/F	CG relationship	Since Dx (yrs)	Most recent FVC%	Most recent DLCO%	Oxygen
1	P	68	M		3	125	26	Y
2	P	69	M		1	81	70	Y
3	P	85	M		9	98	63	Y
4	P	71	M		11	65	50	N
5	P	64	M		4	66	67	N
6	CG		F	S				
7	CG		F	S				
8	CG		F	D				
9	CG		F	S				
10	CG		F	S				
11	CG (D)		F	S				
12	CG (D)		F	D				
13	CG (D)		M	S				

P, patient; CG, caregiver; D, decedent; S, spouse; D, daughter; FVC, forced vital capacity; DLCO, diffusion capacity of the lung for carbon monoxide; O_2, supplemental oxygen.

Data collection

Focus groups were conducted in a private conference room by facilitators; both of whom are experienced qualitative researchers, and have previous experience in facilitating focus groups regarding palliative care content: [Nurse faculty (MRQ) and palliative care PhD prepared researcher (DK)]. They had no direct or indirect involvement with patient care of these research participants to maintain objectivity. There were four note takers; the note takers were one palliative care nurse practitioner, one PhD nursing student and two research coordinators from the Simmons Center. We chose focus groups (as opposed to individual interviews), given that this methodology allows for participants to describe their experiences in an environment that promotes reflection and synergy with other participants, resulting in a shared voice that represents the experiences of several individuals with a common characteristic (i.e., a diagnosis of IPF).[21] Participants were asked to introduce themselves and respond to the Focus Group Guide that served as opened ended prompts to promote discussion (Table 2). The focus group guide was developed by the authors (KOL, MQR, and DK) following a review of the literature to identify evidence gaps regarding knowledge, attitudes, and preferences advance care planning and palliative care in individuals with serious pulmonary disease. Each session lasted approximately 1.5 h. Comments were recorded on a digital tape recorder and transcribed to an encrypted flash drive.

Data analysis

A thematic analysis conducted by experienced qualitative analysts at the University of Pittsburgh Quality Data Analysis Program

Table 2
Focus group guide.

1. If you knew then, what you know now, what would you have done differently?
2. What was your understanding of your/your loved one's lung disease?
3. What changes in your/your loved one's health status were most challenging to you?
4. Did you feel prepared during the course of your/your loved one's illness?
5. Did you and your loved one ever talk about what you/he/she would want to happen in the event of hospitalization with a life threatening condition?
6. Often we talk about hospice and palliative care to help manage a life limiting illness. Tell me what these words mean to you.

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