Original Article

A Questionnaire based Study to evaluate the perception of palliative care in patients with Pulmonary Fibrosis

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ABSTRACT:

Background: Pulmonary fibrosis is a disease in which tissue deep in your lungs becomes thick and stiff, or scarred, over time. The present study was done to evaluate the perception of palliative care in patients with IPF and caregivers. **Materials & Methods**: This study was conducted in year 2012. It included patients with IPF. This study was a interview type of study involving patients and their care takers. This included (1) patients with IPF (n-6); (2) family caregivers of patients (n - 6); and (3) family caregivers of decedent IPF patients (n-3). Participants were asked to introduce themselves and respond to the Focus Group Guide that served as opened ended prompts to promote discussion. Comments were recorded on a digital tape recorder and transcribed to an encrypted flash drive. We included various themes in this study. We identified several themes: (1) frustration with the diagnostic process and education received, (2) overwhelming symptom burden, (3) reluctance to engage in advance care planning. We captured the different perspectives of the patient, caregiver, and caregiver of the decedents during the focus groups. **Results:** We included 6 patients and 6 caregivers and 3 Caregiver decedent. All the patients were males (100%) and age ranges from 56- 82 years. Caregivers of patients were spouse (6) and daughter (3). Diagnosis of IPF ranged from 2-10 years. Table II shows focus group guide which includes six question and caregivers had to answer these. These were what a caregivers know about illness, what a caregiver understand the illness, what changes one has observed in a patient, are caregivers ready to face the emergency, if both patient and caregiver has discussed about emergency situation and what a caregiver feels during this conversation. **Conclusion:** IPF is a disease with a median survival of three to four years after diagnosis, a special care should be given to the patients suffering from disease. Patients and caregivers have burden about the emergency situation so proper education is required to eliminate the stress.

Key words: Caregiver, lungs, Pulmonary fibrosis

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INTRODUCTION

Pulmonary fibrosis is a disease in which tissue deep in your lungs becomes thick and stiff, or scarred, over time. The formation of scar tissue is called fibrosis. As the lung tissue thickens, lungs can't properly move oxygen into bloodstream. As a result, your brain and other organs don't get the oxygen they need. Idiopathic pulmonary fibrosis (IPF) is a progressive fibro proliferative lung disease that affects millions of population. The life span of patient with IPF is very short and the prognosis of IPF is poor.[1] After being diagnosed by majority of diagnostic aids, it has only 3-4 years of survival rate. The management involves lung transplantation but very few opt his treatment modality and only 15-20% of population underwent lung transplant. IPF belongs to a large group of more than 200 lung diseases known as interstitial lung diseases (ILDs), characterized by the involvement of lung interstitium.[2] The interstitium, the tissue between the air sacs in the lung, is the primary site of injury in ILDs. However, these disorders frequently affect not only the interstitium, but also the airspaces, peripheral airways, and vessels. Lung tissue from people with IPF shows a characteristic histopathologic pattern known as usual interstitial pneumonia (UIP).[3] UIP is

therefore the pathologic counterpart of IPF. The term 'idiopathic' is used because the cause of pulmonary fibrosis is still unknown. IPF usually occurs in adult individuals of between 50 and 70 years of age, particularly those with a history of cigarette smoking, and affects more men than women. The diagnosis of IPF requires exclusion of other known causes of ILDs and the presence of a typical radiological pattern identified through high resolution computed tomography (HRCT). In the right clinical setting, it is possible to make the diagnosis of IPF by HRCT alone, obviating the need for surgical lung biopsy.[4] The patients complains of shortness of breath, cough and fatigue with the progression of disease and at the end fibrosis of lung. The quality of life deteriorates as disease advances. 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.[5]
The present study was done to evaluate the perception of palliative care in patients with IPF and caregivers.

MATERIALS & METHODS

This study was conducted in year 2012. It included patients with IPF. This study was a interview type of study involving patients and their care takers. This included (1) patients with IPF (n-6); (2) family caregivers of patients (n - 6); and (3) family caregivers of decedent IPF patients (n-3).
For the collection of data, interview was done in conference room. There were four note takers; the note takers were one palliative care nurse practitioner, one PhD nursing student and two research coordinators. Participants were asked to introduce themselves and respond to the Focus Group Guide that served as opened ended prompts to promote discussion. The focus group guide was developed by the authors 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. The duration for session was approximately 1.5 h. Comments were recorded on a digital tape recorder and transcribed to an encrypted flash drive.
We included various themes in this study.
We identified several themes: (1) frustration with the diagnostic process and education received, (2) overwhelming symptom burden, (3) reluctance to engage in advance care planning. We captured the different perspectives of the patient, caregiver, and caregiver of the decedents during the focus groups.
Results thus obtained were subjected to statistical analysis for correct inferences.

RESULTS

Table I shows the data of participants. We included 6 patients and 6 caregivers and 3 Caregiver decedent. All the patients were males (100%) and age ranges from 56- 82 years. Caregivers of patients were spouse (6) and daughter (3). Diagnosis of IPF ranged from 2-10 years.
Table II shows focus group guide which includes six question and caregivers had to answer these. These were what a caregivers know about illness, what a caregiver understand the illness, what changes one has observed in a patient, are caregivers ready to face the emergency, if both patient and caregiver has discussed about emergency situation and what a caregiver feels during this conversation.

Table I: Data of participants

Participants	M/F	Age	Relation with Pt	Duration since disease	Most recent FVC
Patient 1	M	56	-	4	112
Patient 2	M	64	-	2	87
Patient 3	M	71	-	5	76
Patient 4	M	82	-	8	98
Patient 5	M	75	-	10	82
Patient 6	M	62	-	7	
Caregiver 1		F	Spouse		
Caregiver 2		F	Daughter		
Caregiver 3		F	Spouse		
Caregiver 4		F	Spouse		
Caregiver 5		M	Spouse		
Caregiver 6		F	Daughter		
Caregiver Decedent 1		F	Spouse		
Caregiver Decedent 2		F	Spouse		
Caregiver Decedent 3		F	Daughter		

Table II: Focus group Guide

1.	What you knew than, now what you know about your loved one's
2.	What do you understand by your loved one's lung disease?
3.	What changes you have seen in your loved one's health status which appears most challenging to you?
4.	Do you feel prepared during the course of your/your loved one's illness?
5.	Have you and your loved one's ever discussed about event of hospitalization with a life threatening condition?
6.	What do you feels when you discuss about illness?

DISCUSSION

The 2002 American Thoracic Society/European Respiratory Society (ATS/ERS) classification of IIPs was updated in 2013. In this new classification there are three main categories of idiopathic interstitial pneumonias (IIPs): major IIPs, rare IIPs, and unclassifiable IIPs. The major IIPs are grouped into chronic fibrosing IPs (this includes IPF and non-specific interstitial pneumonia [NSIP]); smoking-related IPs (i.e. respiratory bronchiolitis–interstitial lung disease [RB-ILD] and desquamative interstitial pneumonia [DIP]); and acute/subacute IPs (i.e. cryptogenic organizing pneumonia [COP] and acute interstitial pneumonia [AIP].[6]

In this study we have explored patient/family caregiver perceptions of their needs from the viewpoint of current patients, current caregivers and caregivers of a deceased family member.

This study was conducted in year 2012. It included (1) patients with IPF (n-6); (2) family caregivers of patients (n - 6); and (3) family caregivers of decedent IPF patients (n-3). All the patients were males (100%) and age ranges from 56- 82 years. Caregivers of patients were spouse (6) and daughter (3). Diagnosis of IPF ranged from 2-10 years.

In this study we included themes like (1) frustration with the diagnostic process and education received, (2) overwhelming symptom burden, (3) hesitance to engage in advance care planning

When we discussed our first theme, all the caregivers and caregiver decedents were not happy with the knowledge about the disease process and they all were frustrated about the diagnostic process involved in their loved one's. Most of them found it unnecessary and means of making money when there loved one's were exposed to diagnostic tests again and again.

Although patients reported receiving information relating to the disease from their clinicians and the Internet, the first theme to emerge was that patients did not find that their informational needs were fully addressed. Sampson and colleagues[7] reported that patients diagnosed with IPF were aware of their prognosis, but had little understanding of the different ways their disease might progress and be managed. Therefore, they continued to seek specific information about treatment options, symptom management and care at the end-of-life.

The second theme that emerged was overwhelming symptom burden. The most common symptoms recorded in patients with IPF was cough. In most of the patients the cough was dry, non productive cough. Patients found frustrated to use oxygen therapy. Cough suppressants and opioids were being used in curing the symptoms. Supplemental oxygen may be beneficial, but comes with its own burden because of the equipment involved to provide the proper prescription. Provision of palliative care could be extremely helpful in this situation, as it could serve as a means to encourage patients to seek treatment for cough and use opioids or request prescription of these drugs for cough suppression.

Additionally they were worried about the cost of medication used in the disease. Bajwah and colleagues[8] interviewed 18 patients with IPF and their family caregivers and reported the profound impact of this disease both physically and psychologically. Belkin and colleagues[9] conducted a study capturing caregiver perspectives on the effects of IPF and reported that caregivers experienced hardships throughout the disease course including dealing with the emotional issues as well as the physical limitations confounded by the demanding effects of use of supplemental oxygen.

The third theme to emerge was hesitance to engage in advance care planning. In our caregiver we found that they were vocal about only wanting positive options, including research opportunities. Patients appeared to lack understanding about the scope of support offered through palliative care, e.g., reducing symptom burden. Prior qualitative studies have reported that even when patients and caregivers understood the

terminal nature of the disease, they did not appreciate that symptoms could escalate rapidly, resulting in death. Palliative care, in this situation, would be especially helpful as the need to consider options could be introduced over several meetings and patients could have symptom burden addressed and encouraged to discuss end-of-life planning. Richards[10] in his study found similar results. However Martinez et al[11] in their study found that few of their patient's caregivers were involved in advanced care planning and they were prepared for that.

CONCLUSION

Author concluded that IPF is a disease with a median survival of three to four years after diagnosis, a special care should be given to the patients suffering from disease. Patients and caregivers have burden about the emergency situation so proper education is required to eliminate the stress. Paliative care may be useful in this context.

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