

Original Article

Palliative Care in Diffuse Interstitial Lung Disease: Results of a Spanish Survey[☆]



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ABSTRACT

Introduction: Interstitial lung diseases (ILD) and, in particular, idiopathic pulmonary fibrosis, may have a significant impact on patient survival. Recent studies highlight the need for palliative care (PC) in the management of ILD patients. The aim of this study was to determine the current situation of PC in patients in Spain.

Methods: A 36-question survey addressing the main aspects of PC in ILD patients was designed. The survey was sent via email to all members of the Spanish Society of Pulmonology and Thoracic Surgery. Participation was voluntary.

Results: One hundred and sixty-four participants responded to the survey. Ninety-eight percent said they were interested in PC, 46% had received specific training, and 44% reported being responsible for PC in their ILD patients. Symptom control and end-of-life stage were the most frequent reasons for referral to PC teams. Regarding end-of-life, 78% reported consensual agreement with patients on the limitation of therapeutic efforts, 35% helped prepare an end-of-life advance directive, and 22% agreed on the place of death.

Conclusion: Despite the well-known need for PC in patients with ILD and the notable interest of the survey participants in this subject, there are clear formative and organizational gaps that should be addressed to improve care in this area in ILD patients in Spain.

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Cuidados paliativos en la enfermedad pulmonar intersticial difusa: resultados de una encuesta de ámbito nacional

RESUMEN

Palabras clave:

Enfermedad pulmonar intersticial difusa

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Final de vida

Introducción: Las enfermedades pulmonares intersticiales difusas (EPID) y, concretamente, la fibrosis pulmonar idiopática, pueden tener un elevado impacto en la supervivencia de los pacientes. Recientes estudios destacan la necesidad de implementar los cuidados paliativos (CP) en el manejo del enfermo con EPID. El objetivo del estudio fue conocer la situación actual de los CP en nuestro país.

Métodos: Se diseñó una encuesta de 36 preguntas, que abordaba los principales aspectos de los CP en el paciente con EPID. Esta encuesta fue remitida a través de correo electrónico a todos los miembros de la Sociedad Española de Neumología y Cirugía Torácica, cuya participación fue voluntaria.

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Resultados: Cientosesenta y cuatro participantes respondieron a la encuesta. El 98% manifestó tener interés en los CP, 46% habían recibido formación específica. El 44% refirió ser el responsable de los CP en sus pacientes EPID. El control de síntomas y la fase final de vida fueron los motivos más frecuentes de derivación a los equipos de CP. Referente a la fase final de vida el 78% refirió consensuar con los pacientes la limitación del esfuerzo terapéutico, el 35% realizar un documento de voluntades anticipadas y el 22% consensuar el lugar de fallecimiento.

Conclusión: A pesar de la conocida necesidad del CP en los pacientes con EPID y el notable interés de los participantes de la encuesta en este tema, existen claras lagunas formativas y organizativas, que deberían ser contempladas para mejorar la atención sobre esta área de salud en los pacientes con EPID de nuestro país.

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Introduction

The World Health Organization defines palliative care (PC) as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.¹

In the past 20 years there has been a significant deployment of specialized PC facilities,² aimed at improving the quality of life of cancer patients. However, the need for PC is not limited to a single disease. Higginson et al., for example, showed that the early introduction of PC in the care of patients with advanced lung disease and refractory dyspnea improves symptom control,³ and the most recent national health strategies have underlined the importance of extending PC to terminal patients with other non-oncological diseases, irrespective of the diagnosis.⁴

The term “diffuse interstitial lung disease” (DILD) covers a wide array of diseases that share clinical, radiological and histological characteristics.^{5,6} DILD can have a significant impact on patient survival, particularly in the case of idiopathic pulmonary fibrosis (IPF).⁷ This disease, which has an estimated average survival of between 3 and 5 years, comparable to some malignant diseases, has a high impact on the life expectancy of patients and symptom control, particularly dyspnea and cough. Together, this leads to an increase in depressive symptoms and loss of quality of life.⁸

Recent studies have found that patients with DILD require PC in several domains, including physical symptoms and psychosocial and spiritual factors, and that the patient's status can improve if they are promptly referred to appropriate PC units.^{9,10} However, studies suggest that at present patients are generally referred only at very advanced disease stages.¹¹

The manner in which pulmonologists assimilate PC into their daily practice with DILD patients has seldom been investigated in the literature. The aim of this study was to evaluate the current status of PC in Spain by surveying members of the Spanish Society of Pulmonology and Thoracic Surgery (SEPAR).

Methods

This study was jointly sponsored by the multidisciplinary DILD unit of the Hospital de la Santa Creu i Sant Pau (S.B., AM.A., D.C.) and the executive committee of the DILD area of SEPAR which was responsible for the design, analysis, and publication of the results (J.A.R.P., A.R.O., O.A., D.C.).

International recommendations for optimizing studies based on internet surveys were followed when designing this study,¹² which was conducted between October 2015 and September 2016.

SEPAR members were invited to participate in the survey, which consisted of 36 questions in different formats, including multiple-choice and open-ended questions. The aim was to examine the main areas of PC: training, organization, treatment options,

and planning for end of life. The Google Drive application was used to prepare the questionnaire. The final version was approved by a specialist in PC (M.V.), and was sent by electronic mail to all SEPAR members (n : 3920) under the supervision of the SEPAR webmaster (J.G.). The full version of the questionnaire is available in the attached document.

Two separate invitations to take part in the survey were sent to SEPAR members during the first half of 2016. Electronic mails were checked to ensure responses were not duplicated, and if so, the second response was deleted. The personal information of the respondents was not recorded at any time, and no incentives were offered for completing the questionnaire.

When the survey was completed, the web platform was used to transfer all responses to a database for statistical analysis that was coordinated by a qualified statistician (F.A.). The analysis was performed using SPSS software version 16 for Windows (IBM Corp., Armonk, New York, USA). The results of the descriptive study are listed as numbers and percentages. All authors participated in the preparation of the final manuscript.

Results

In total, 164 professionals from all autonomous communities of Spain participated in the survey. The main sociodemographic characteristics are summarized in Table 1.

Table 1
Respondents' sociodemographic characteristics and training in palliative care.

	No. (%)
Participants	164
Females	101 (61.6)
Years of experience	
Less than 5 years	19 (11.6)
Between 5 and 10 years	34 (20.7)
Between 10 and 15 years	35 (21.3)
More than 15 years	76 (46.3)
Place of work	
Primary care center	3 (1.8)
Secondary hospital	37 (22.6)
Tertiary hospital	15 (9.1)
University hospital	107 (65.2)
Others	2 (1.2)
Specialist area	
General respiratory medicine, with interest in DILD	94 (57.3)
Dedicated DILD clinic	35 (21.3)
Respiratory medicine, not dedicated to DILD	28 (17.1)
Others	7 (4.3)
Training	
Respondents with training in PC	75 (46)
Respondents with specific training in PC in DILD	3 (2)

Values expressed in absolute number and percentage.

DILD: diffuse interstitial lung diseases; PC: palliative care.

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