

Reviewing the Needs of Patients with Diffuse Interstitial Lung Diseases: Advocating for the Role of a Mediator between Patients and Specialists in the Spanish NHS

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My interest for ILDs (Interstitial Lung Diseases) comes from my personal experience with IPF (Idiopathic Pulmonary Fibrosis): there were several cases in my own family that, together with my medical formation, lead me to co-founding and presiding a patients and relatives' association in 2008. Knowing the situation first hand, I decided to find a way of helping others who could be interested and affected by ILDs. So, since 2015, I have been delivering an online support and advice service for those who have reached out to me through my blog [1] and my Facebook page [2].

Idiopathic Pulmonary Fibrosis is the paradigm of a group of pathologies known as Interstitial Lung Diseases. Since 2000, when an international consensus statement on the diagnosis and treatment of IPF was published [3], there have been identified more than 300 ILDs [4]. They all generally share two symptoms: dry cough and dyspnoea. ILDs develop gradually, their impact is very low and their diagnosis is highly complex. Moreover, its appearance goes unnoticed because their symptomatology is very similar to others, such as asthma's, COPD's, bronchitis' or lung cancers. For all these reasons, since 2011 [5] it is recommended that ILDs should be diagnosed by a multidisciplinary team: a pulmonologist, a radiologist, an anatomopathologist and even a rheumatologist. In this short article I would like to share with you the inequalities that the Spanish healthcare system creates for ILDs patients and how, an external counsellor, can be of help to navigate overwhelming bureaucratic difficulties.

The Spanish healthcare system is highly segmented: it is lead by the Ministerio de Sanidad (Ministry of Health) and every Comunidad Autónoma (autonomous region) has its own health department. Thus, healthcare jurisdictions are transferred to the corresponding division in each region. These are coordinated and backboneed by a national board known as Consejo Interterritorial de Salud (Inter-territorial Health Council). This administrative network, that should respect and comply with the rights and duties enshrined in the Spanish Constitution, leads to developing these rights and duties under corresponding local legislations. Hence, every region regulates their needs on their own terms and times. In spite of being a system designed under the premise of shortening distance between patients and services, it still creates disparities and inequality.

A representative example of these disparities appears when a patient wants to apply for a second medical opinion, a right present in the Ley de Autonomía del Paciente (Patient's Autonomy Law) [6]. The majority of regions recognise this possibility for patients of ILDs, but there are some, as Castilla y León [7], that do not consider ILDs severe enough to offer patients this service.

In the case of IPF, a pathology with a still today fatal prognosis (3 to 5 years of survival to its diagnosis without any pharmacological treatment), access to a second medical opinion may have a significant impact on the course of their illness. Particularly, it may prevent them from conducting a pulmonary biopsy (a rather common procedure for diagnosing other lung pathologies), since it has proved to be counterproductive for some cases of Familial Pulmonary Fibrosis (FPF) that show specific gene mutations. Unaware patients who do not have access to this service, and who undertake this procedure, could be facing an unnecessary risk. As a way of preventing this, applying for a second opinion can be the access to specialized and experienced in ILDs medical teams, such as the monographic FPF unit in the Bellvitge Hospital (Barcelona) that focuses in FPF and runs genetic studies both of patients and relatives [8].

In addition to the inequality of treatment between regions, it is necessary to mention that this particularity in the diagnosis of FPF, as well as many others related to ILDs, are still not very well known amongst Primary Healthcare practitioners and Pulmonology Services in the majority of the Spanish hospitals.

Furthermore, until very recently patients would encounter many issues when trying to access any of the two lately approved treatment drugs. Their costs, together with the economic situation faced by Spain since the 2008's recession, would provoke delays in their commercialization.

As Medical Advisor in Pulmonary Fibrosis [9] I facilitate the most updated information on ILDs through my sites. I gather and publish information on any clinical study that is open for patients to participate, specially those taken place in Spain. I help to make visible the issues they face when getting used to life with ILDs and their treatments (e.g. oxygen therapy and its implications), and I inform them about the possibility of applying for a second medical opinion if they have been recently diagnosed or suspect of an ILD. When they decide to go through with their application, I provide guidance on the procedure in terms of bureaucratic requirements and emotional support.

Given the above mentioned difficulties, related to our economic situation and the disparity in the regulation of procedures between regions, I truly consider this support a necessary service that should be sponsored, so that any Spanish citizen who may need it can benefit from its assistance. However, at the moment this is still a goal that has yet to be accomplished.

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