Interstitial lung disease awareness among patients with connective tissue diseases in Spain

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BACKGROUND

- Interstitial lung disease (ILD) is a common feature in connective tissue diseases (CTDs).
- CTDs are a heterogeneous group of multiorgan systemic autoimmune diseases that include diseases like rheumatoid arthritis (RA), systemic sclerosis (SSc), systemic lupus erythematosus (SLE), Sjögren syndrome (pSS), idiopathic inflammatory myopathies (IIM) and mixed connective tissue disease (MCTD).[1,2]
- Due to the important burden associated with ILD in these diseases, it is necessary to develop tools to inform patients, especially with the help of their physician.[3,4]

OBJECTIVES

The objective of this **global survey** was to understand **patients' level of awareness** about the **risk of developing ILD due to CTDs**. Here, we present data for Spain-based patients.

METHODS

- This was a cross-sectional online survey of patients living with CTDs in Spain, aged ≥18 years, with or without ILD.
- Participants had a self-reported medical diagnosis of ≥1 CTDs and were followed by a specialist doctor (e.g. rheumatologist, internal medicine doctor, pulmonology).
- Recruitment was carried out via patient organizations sharing the survey link with their patient community, links shared on Boehringer Ingelheim social and local media channels, and QR codes on posters/flyers in clinical settings.
- The survey ran from 26 February to 15 March 2024.

RESULTS

- **218 patients with CTDs completed the survey**, 87% females, with a mean age of 52 years. The distribution of CTDs patients was as follows: RA 40,8%, SSc 28,4%, SLE 13,7%, pSS 11,9%, MCTD 3,2% and IIM 1,8%.
- **The mean (SD) time between the first symptom and CTD diagnosis was 3.61 (6.03) years**. When ILD was present it was detected 6.29 (11.23) years after CTD onset.
- **A high proportion of patients without ILD and/or previous to CTD-ILD were unaware of the risk of lung manifestations**, particularly in RA (70%) and MCTD (67%) (Fig 1, orange):
  - 44% recalled being informed about the risk in other organs (Fig 1, gray)
  - 44% were aware of risk in other organs but not the lungs (Fig 1, yellow)
  - 12% mentioned that risk of lung involvement was mentioned but they could not remember the details (Fig 1, yellow)
- **Risk of CTDs organ involvement was mentioned by their physician in 72%**, especially among SSc (95%) and SLE (97%) patients. Skin (52%), joints (51%) and lungs (50%) were the most mentioned organs overall. Risk level of developing lung manifestations was described by their physician in 36% of patients.
- **For patient monitoring**, Chest X-Ray (50%), lung or pulmonary function test (42%), doctor's breathing check (39%), Chest CT/HRT or CAT scan (39%), or stethoscope (39%) emerge as tests most done to check the lungs across all CTDs (Fig 2).
- For more information on risks, complications or recommendations related to CTDs, **patient organizations or support group websites were key information sources** (88%).
  - 99% considered appropriate to be informed about the risk of lung manifestations
  - 84% would like to obtain this information in more detail from their physician

Figure 1. Half of patients only diagnosed with CTD or with CTD prior to their ILD diagnosis were made aware of the risk to the lungs; 44% of those not aware recall mention of risk (but not specifically to lungs)

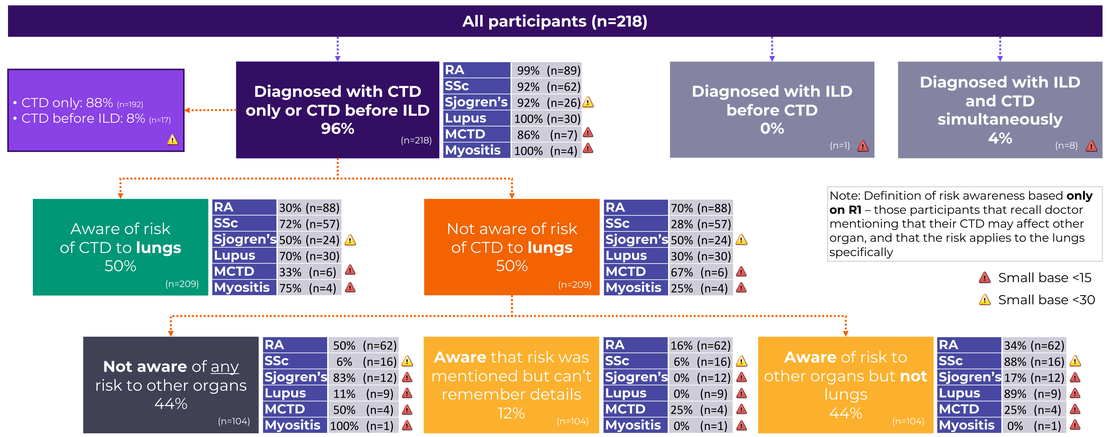

Figure 2. Monitoring tests done to check the lungs across all CTDs

Variable	Detail	TOTAL (n=218)	CONDITION DIAGNOSED FIRST: RA (n=89)	SSc (n=62)	SLE (n=30)	SJÖGREN'S (n=26)	MYOSITIS (n=4)	MCTD (n=7)
Tests done to check lungs/breathing/lung function (Q2)	Chest X-ray	**108 (50%)**	34 (38%)	42 (68%)	17 (57%)	8 (31%)	3 (75%)	4 (57%)
	Lung or pulmonary function test (PFT)	**91 (42%)**	15 (17%)	54 (87%)	8 (27%)	7 (27%)	3 (75%)	4 (57%)
	Doctor listened to breathing with a stethoscope	**85 (39%)**	19 (21%)	36 (58%)	18 (60%)	6 (23%)	3 (75%)	3 (43%)
	Chest CT, HRCT or CAT scan	**84 (39%)**	17 (19%)	45 (73%)	10 (33%)	4 (15%)	4 (100%)	4 (57%)
	Oxygen saturation	**72 (33%)**	15 (17%)	35 (56%)	11 (37%)	6 (23%)	2 (50%)	3 (43%)
	Echocardiography	**68 (31%)**	6 (7%)	47 (76%)	8 (27%)	3 (12%)	1 (25%)	3 (43%)
	Diffusing capacity of the lungs for carbon monoxide (DLCO)	**53 (24%)**	5 (6%)	38 (61%)	4 (13%)	2 (8%)	1 (25%)	3 (43%)
	6 Minute Walk Test (6MWT)	**46 (21%)**	3 (3%)	32 (52%)	4 (13%)	3 (12%)	1 (25%)	3 (43%)
	Lung Ultrasound	**2 (1%)**	1 (1%)	-	1 (3%)	-	-	-
	Other/None of these	**9 (4%)**	1 (1%)	3 (5%)	3 (10%)	1 (4%)	1 (25%)	-
	Not asked because they were not monitored	**75 (34%)**	48 (54%)	1 (2%)	9 (30%)	14 (54%)	-	3 (43%)

Abbreviations: RA - Rheumatoid Arthritis, SSC - Scleroderma or systemic sclerosis , SLE - Lupus MCTD - Mixed Connective Tissue Disease

0-25% 26-50% 51-75% 76-100%

CONCLUSIONS

- There is an unmet need for CTD patients to be informed about their risk of organ involvement, including ILD.
- It would be important to develop strategic tools directed to help physicians caring for CTD patients, to adequately inform and facilitate patient awareness about these risks.

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N.º 481