Archivos de Bronconeumología 58 (2022) 191–193

Sociedad Española de **Neumología** y **Cirugía Torácica** SEPAR

ARCHIVOS DE
Bronconeumología
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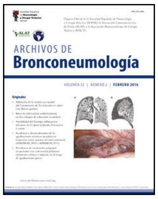

Scientific Letter

Psychological Profile of Patients Diagnosed With Idiopathic Pulmonary Fibrosis

Perfil psicológico de pacientes diagnosticados de fibrosis pulmonar idiopática

To the Director:

Idiopathic pulmonary fibrosis (IPF) is a chronic, irreversible, fibrosing pulmonary disease with a poor prognosis. Life expectancy without treatment is ∼3–5 years from the time of diagnosis.[1] IPF has a profound impact on patients' health related quality of life (HRQL).[2] Holistic management of patients with IPF is considered essential, in addition to any disease-modifying treatment. We conducted this study aiming to describe the psychological profile of IPF patients, further extending our previous findings in this group of patients.[3] Selected questionnaires were used to assess key outcomes: anxiety, depression, demoralization, spirituality, dignity, social support and HRQL perception. It all intended to improve the wellbeing of IPF patients and their families.

In a cross-sectional study design, we investigated IPF patients of the ILD Unit of the Hospital Universitario de la Princesa in Madrid enrolled from 1st May 2017 to 30th November 2017. Inclusion criteria were: diagnosis of IPF according to the 2011 ATS/ERS/JRS/ALAT guidelines.[4] Exclusion criteria were: cognitive impairment (comprehension/expression problems), refusal to participate, and clinical instability. The study protocol was designed according to the STROBE criteria,[5] and it was approved by our Clinical Research Ethics Committee (Register Number 3775). After collecting informed consent, a psychologist with more than ten years of clinical experience interviewed patients and administered the different psychological evaluation instruments as per the protocol.

The questionnaires used were:

- Survival scheme. Based on the taxonomy of Moorey and Greer.[6] This scheme is a model of patient functioning that emerged in psycho-oncology, and describes the ability to adapt, the emotional response, and the coping styles that cancer patients use to knowing their diagnosis or their disease status. Through these questions, the patient's vision of the diagnosis (*What threat represents the disease?*), the type of control that the patient considers exercising over the disease (*What can be done in front of it? Can it be controlled?*) and also the vision of the prognosis that the patient has (*What is the probable prognosis of the disease and how reliable is it?*) are explored. The application of the survival scheme was carried out using the same questions as in cancer.
- Hospital Anxiety and Depression Scale (HADS). This instrument was designed for the detection of affective disorders in non-psychiatric hospital settings.[7]
- HRQL. Only two items of the Global Health Subscale of EORTC-QLQ-C30[8] were used, namely: "How would you rate your overall health status during the past week?" and "How would you rate your overall quality of life during the past week?". It was used following previous research findings and guidelines in similar contexts.[9,10]
- CED-PAL.[10] Brief instrument for the measurement of dignity in palliative care patients. It consists of two factors: preservation of dignity and threat of dignity.
- Questionnaire GES.[11] It consists on eight items that evaluate spirituality as a general factor with three dimensions: intrapersonal, interpersonal and transpersonal.
- Brief Scale of Demoralization.[12] Scale that assesses the demoralization syndrome.
- Brief Scale of Resilient Coping.[13] This scale of four items focuses on the tendency to effectively use coping strategies in flexible, committed ways to actively solve problems despite stressful circumstances.
- Duke-UNC.[14] Questionnaire of quantitative evaluation of perceived social support in relation to two aspects: people to whom intimate feelings can be communicated and persons expressing positive feelings of empathy.

Of the 121 IPF patients seen during the study period in the ILD Unit, 56 (46.3%) agreed to participate in the study. 31 were men (55%) and 25 were women (45%), with a mean ± SD age of 63.5 ± 9.5 years. Regarding the 65 patients who did not participate during the evaluation period, they were 40 men (61%) and 25 women (38%), with a mean ± SD age of 68.5 ± 8.55 years. There were no differences in between participants and non-participants on sex ($p = .400$), but participants were younger ($p = .019$). Participants were married or with a partner (80%), they had varying levels of studies, and they were mostly retired (68%). All IPF patients knew their diagnosis (name of the disease and description), but only 73% knew about the prognosis of IPF. Time since IPF diagnosis was longer than 1 year in more than half of patients. Regarding management of the disease, 93.9% of patients had antifibrotic treatment, 76.8% had home oxygen therapy, but only 21% had received psychological follow-up with the psychologist of the ILD Unit before the clinical visit (Table 1).

The assessment of the survival scheme according to Moorey & Greer's taxonomy showed that most patients understand their diagnosis as a challenge (33.9%) or a threat (30.4%). The most common emotional expressions were anxiety (30.4%) and sadness (26.8%). As for coping strategies, abandonment (claudication), and fighting spirit, together with somatic concern, were what patients used the most.

On general emotional aspects of IPF patients, their main expressed need was the loss of autonomy (46.4%), followed by fear regarding the transplant option (16.1%). Patients had a good

https://doi.org/10.1016/j.arbres.2021.04.025

Table 1
Clinical and main emotional aspects experienced by patients with IPF.

	n	%
Known diagnosis		
Yes	56	100.0
No	0	0.0
Known prognosis		
Yes	41	73.2
No	15	26.8
Time since diagnosis		
<3 months	4	7.1
3 months and <6 months	8	14.3
6 months and <12 months	9	16.1
12 months and < 24 months	14	25
24 months or longer	21	37.5
Type of treatment		
Antifibrotic	52	93.9
Palliative (with or without antifibrotic)	4	6.1
Home oxygen therapy		
Yes	43	76.8
No	13	23.2
Previous psychological treatment		
Yes	12	21.4
No	44	78.6
	n	%
Main feelings or fears		
Loss of autonomy	26	46.4
Weight loss/physical alterations	1	1.8
Control of symptoms	2	3.6
Fear of transplant	9	16.1
Concern for third parties	6	10.7
Disadaptive denial of diagnosis	4	7.1
Disadaptive negation of prognosis	4	7.1
Others	4	7.1
Activities of daily living (ADL)		
Less than two ADL	9	16.1
Moderate	11	19.6
Enough	12	21.4
Adequate	24	42.9
Social and leisure activities		
Only with family	14	25.0
Friends	16	28.6
Activities with some groups	12	21.4
Normal	14	25.0
Familiar communication		
Silence Pact	4	7.1
Claudication	6	10.7
Difficulties of understanding	4	7.1
Overflow	10	17.9
Avoidance	31	55.4
Normal	1	1.8
Needs of family		
Not specific	6	10.7
Emotional Support	31	55.4
Problem resolution	8	14.3
Information related to the disease	9	16.1
Not applicable	2	3.6
Moorey & Greer survival scheme	*n*	%
Diagnostic processing		
Challenge	19	33.9
Threat	17	30.4
Denial	5	8.9
Lost	15	26.8
Emotional processing		
Rage	19	33.9
Anxiety	17	30.4
Guilt	5	8.9
Sadness	15	26.8
Loss	15	26.8
Coping strategies		
Fighting spirit	19	33.9
Somatic concern	17	30.4
Avoidance	5	8.9
Fatalism	15	26.8
Abandonment	17	30.4

Table 2
Descriptive statistics objective evaluation.

	N	Min	Max	*M*	SD
Anxiety	56	3.00	19.00	10.71	4.38
Depression	56	2.00	18.00	7.9	4.19
Quality of life	56	1.00	7.00	4.09	1.54
Demoralization	56	1.00	20.00	10.07	5.38
Intrapersonal spirituality	56	4.00	12.00	9.12	2.07
Interpersonal spirituality	56	2.00	12.00	10.44	1.79
Transpersonal spirituality	56	1.00	8.00	5.57	1.73
Preservation of dignity	56	23.00	45.00	34.98	4.36
Threat of dignity	56	3.00	27.00	14.91	6.30
Dignity	56	34.00	66.00	49.89	8.41
Confidential social support	56	13.00	30.00	24.60	4.72
Affective social support	56	12.00	25.00	20.21	3.29
Global social support	56	25.00	55.00	44.82	7.69

Notes: Min = minimum; Max = maximum; *M* = mean; SD = standard deviation.

or preserved level of activities of daily living (ADL) (42.9%), and a good social activity focused on family and close friends (53.6%), yet with little participation in leisure activities (21.4%). Regarding family communication, most of the family members face the disease with an avoidance pattern (55.4%), with a group of family members feeling overwhelmed (17.9%) (Table 1).

The main results found on objectively assessed questionnaire domains are summarized in Table 2: anxiety (10.7 ± 4.4), demoralization (10 ± 5.3), weakness in the transpersonal dimension of spirituality (5.57 ± 1.73) and perception of dignity (49.8 ± 8.4) were identified as the main needs of patients diagnosed with IPF. Regarding depression, its mean ± SD (7.9 ± 4.2) was not above the threshold of 8 to find a probability of a clinical problem. We found a negative correlation between anxiety and quality of life ($r=-.678$; $p<.001$), and with interpersonal spirituality ($r=-.274$; $p=.041$), transpersonal spirituality ($r=-.338$; $p=.011$) (search, focused, connection, transcendence), dignity ($r=-.485$; $p<.001$), confidential ($r=-.386$; $p=.003$) and total social support ($r=-.370$; $p=.005$).

Taking into account how many patients presented scores suggestive of anxiety and depression, we note the high proportion of IPF patients with clinical anxiety (85%) and depressive symptoms (44%). Regarding anxiety, a similar prevalence was found to other studies, but not in terms of depression, not clinically significant.[3] However, demoralization syndrome (loss of meaning in life, hopelessness, helplessness, and feelings of failure[15]) was found in 71.4% of patients. Based on these results, it appears that the demoralization syndrome is a better fit to describe the relationship of depressive symptoms in IPF patients. This may be due to the presence of loss of independence, concern for family, symptom control, and feelings of social isolation together with the fear of imminent death. By definition, anhedonia is one of the characteristic symptoms of depression, but this symptom is not present in patients with demoralization, which means that they can still experience pleasure with different aspects of life. It would be interesting to explore whether the explanation for the greater presence of demoralization is due to the absence of anhedonia, as suggested by these results. In general, it appears that the unpredictable course of IPF represents the main cause of psychological distress, which eventually leads to demoralization, anxiety and depression. It is significant that IPF patients present needs related to the demoralization and spiritual dimension. All the clinical measures (anxiety, demoralization...) correlate with HRQL, spirituality and dignity.

Our results are similar to those found by other recently.[16] The application of a survival scheme involves observing and considering the relationships between the processes of assessment, coping and emotional responses. Previously described results are similar to those seen in early palliative care cancer consultations.[17]

Our findings should help protocolizing interventions without extensive evaluations that can overwhelm and tire patients. The prevalence of demoralization, anxiety, loss of sense of dignity and existential suffering in our cohort of IPF patients highlight the need for a psychological intervention. Some useful tools are the cognitive behavioral therapy,[18] counseling[9] or other therapies that have demonstrated their efficacy in similar profiles, such as dignity therapy,[9] or KIBO.[19] Further, our results indicate which areas of the patient need to be addressed by the entire clinical team in the different follow-up visits, in order to improve HRQL based on their needs.

Some limitations of our study must be highlighted. On tools, evaluation of some aspects were performed with questionnaires originally developed for other diseases, like cancer. The choice of these tools was due to most of patient reported outcome measures (PROMs) are not specifically developed for IPF. Another limitation was moderate sample size. Nevertheless, with a unilateral approach, alpha = .05 and correlations with medium effect size (.3 to .5) the estimated power for the analysis with 56 observations as reported by G*Power 3[20] is .75. Literature evaluating psychological variables in this context is scarce and due to the abovementioned difficulties, most authors report small sample sizes.[3,16] Further research with greater number of participants should be carried out.

To conclude, we found a specific psychological profile of IPF patients, represented by demoralization and non-depression. A holistic approach is needed with an adequate psychological intervention, and inclusion of a psychologist in the multidisciplinary teams would be welcome for a better management of IPF patients.

Funding sources

Air Liquide Healthcare.

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