The Irish Lung Fibrosis Association (ILFA)

Poster PA1727

Impact of Pulmonary Fibrosis on the Lives of Patients and Carers in Ireland in 2022

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Introduction

The Irish Lung Fibrosis Association (ILFA www.ilfa.ie) was established in 2002 to support patients with pulmonary fibrosis (PF) and their families in Ireland.

Aim

Assess the impact of PF on patients and their family caregivers across a range of domains.

Methods

- Online survey distributed to ILFA members
- Eligibility for inclusion: PF patient, post-lung transplant patient (after prior PF) or a carer/family member of a patient.
- Date of survey: 5-21 July 2022.
- Domains:
  - Patients
    physical symptoms, activities of daily living, emotional & financial aspects, impact on working life, oxygen supply & energy costs
  - Carer/family member
    emotional & financial aspects

Results

- 155 respondents
- Median response time for completion: 7.1 minutes.
- Patient-reported physical symptoms were as expected for PF.
- However, some were also reported by carers (e.g. fatigue, sleep disturbance).
- Both patients & carers reported emotional (e.g. concern for family, anxiety) and financial worries (on heating/electricity costs, financial impact of PF on family, health insurance/medication/oxygen costs).

Respondent demographics

	Patients (n;%)	Carers/family members (n;%)
Respondents	102 (100%) PF: 89 (87%) post-transplant: 13 (13%)	53 (100)
Male	53 (52%)	3 (6%)
Aged <60Y	22 (22%)	34 (64%)
Aged 61-70Y	40 (39%)	13 (25%)
Aged ≥ 71Y	40 (39%)	6 (11%)

Employment status

	Patients (n; %)	Carers/family members (n; %)
Respondents	102 (100%)	53 (100%)
Working full-time	12 (12%)	21 (40%)
Working part-time	6 (6%)	12 (23%)
Seeking work	1 (1%)	2 (4%)
Looking after home/family	7 (7%)	5 (9%)
Retired	53 (52%)	9 (17%)
Did you have to stop working/retire because of PF?	59 (58%)	
Unable to work due to illness/disability	22 (22%)	1 (2%)
Other	1 (1%)	3 (6%)

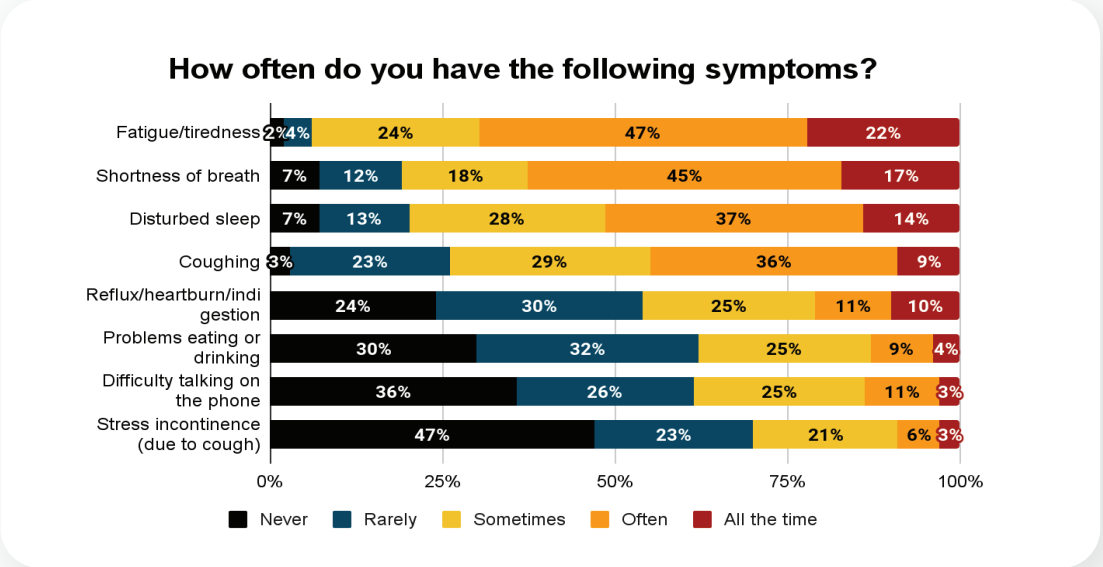
PF patient profile*

	Respondents (n)		n (% of respondents)
Diagnosis type	88	IPF	77 (88%)
		other ILD	11 (13%)
Time since diagnosis	77	<1 year	8 (10%)
		1-2 years	11 (14%)
		2-3 years	21 (27%)
		3-5 years	16 (21%)
		>5 years	21 (27)
Taking antifibrotic	76	yes	47 (62%)
		no	29 (38%)
On oxygen	102	yes	70 (69%)
		no	32 (31%)
If on oxygen, reporting difficulty with prescription or supply	32	yes	6 (19%)
Living arrangements	102	Live alone	16 (16%)
		Live with partner or others	86 (84%)
Do you have a family member/friend who helps you with daily activities?	102	Yes - spouse/partner	62 (61%)
		Yes - other	13 (13%)
		No	27 (13%)

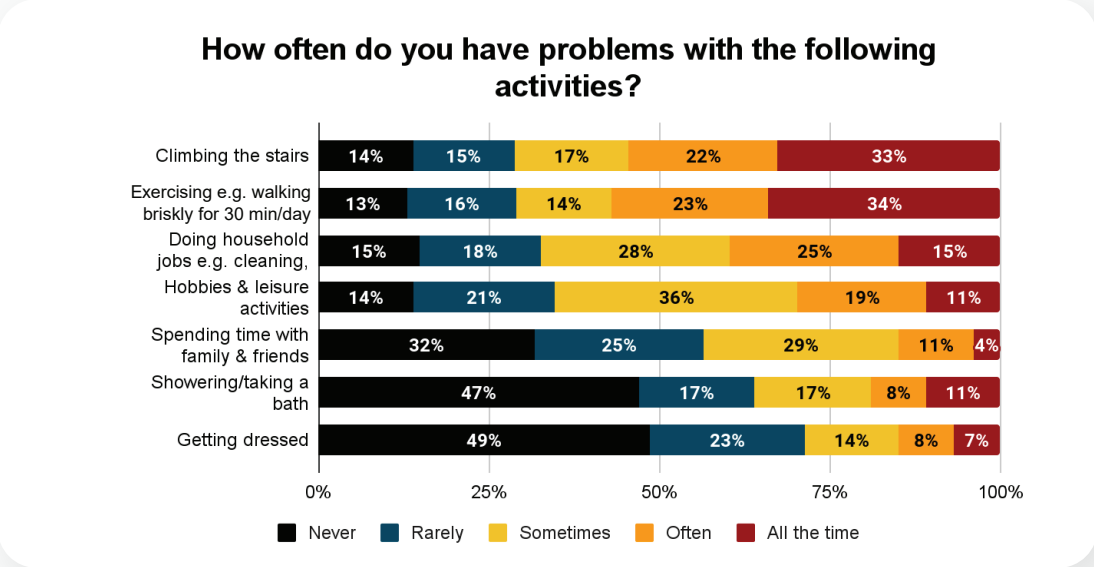
*some responses not available for all patients

Patients

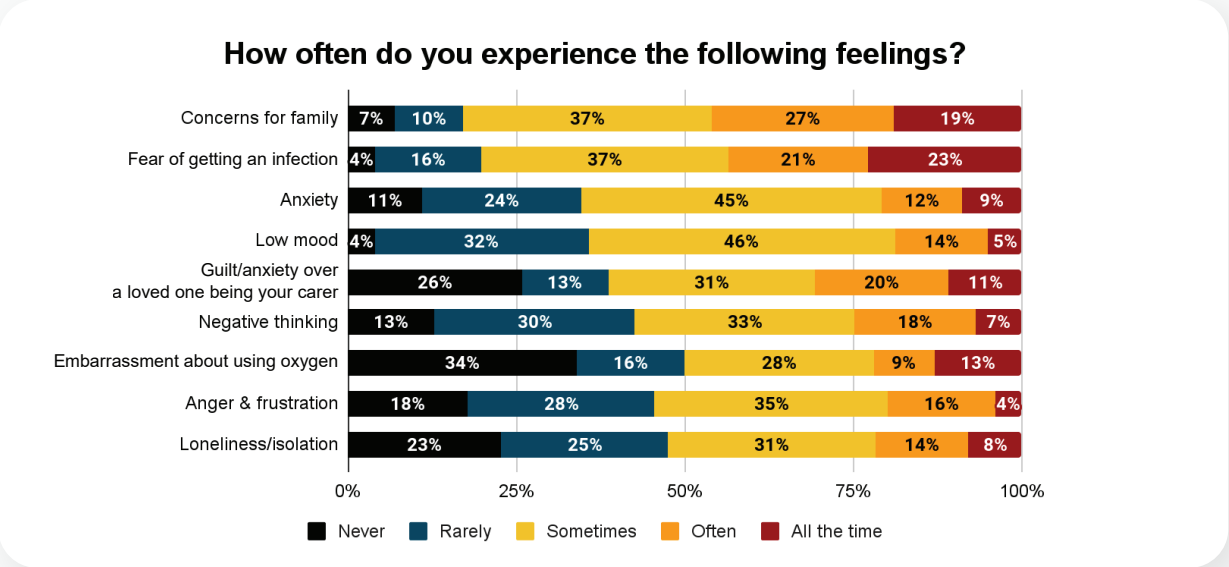
Physical symptoms of IPF



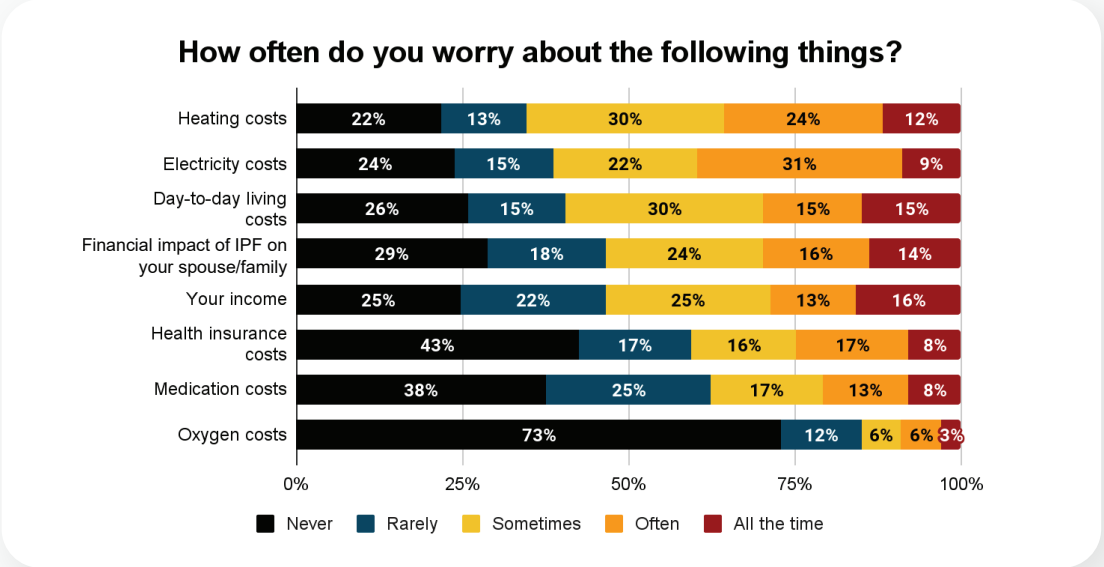
Activities of daily living



Emotional aspects of living with IPF

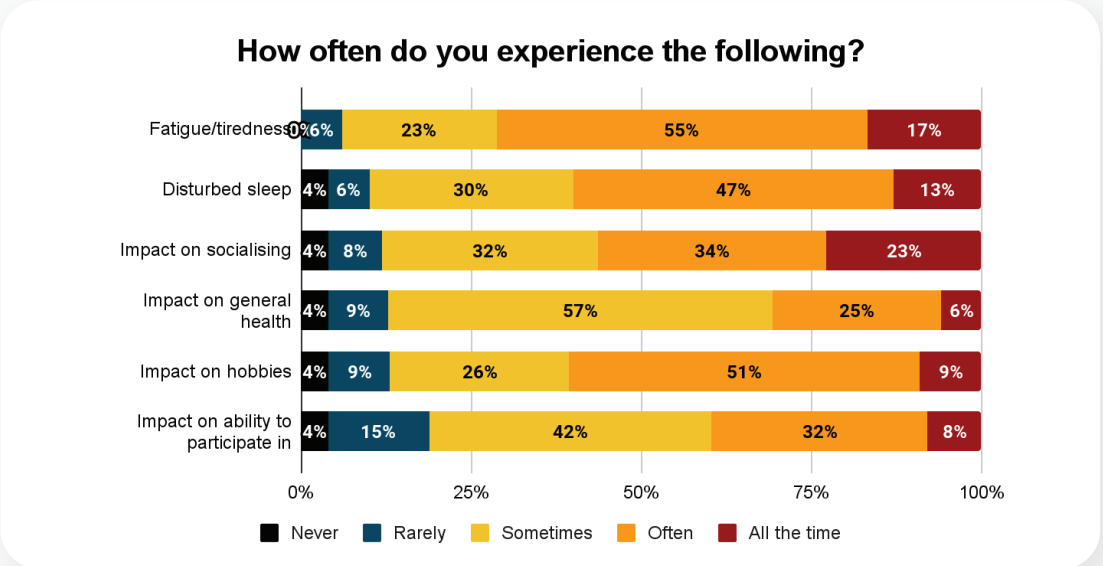


Financial aspects of IPF

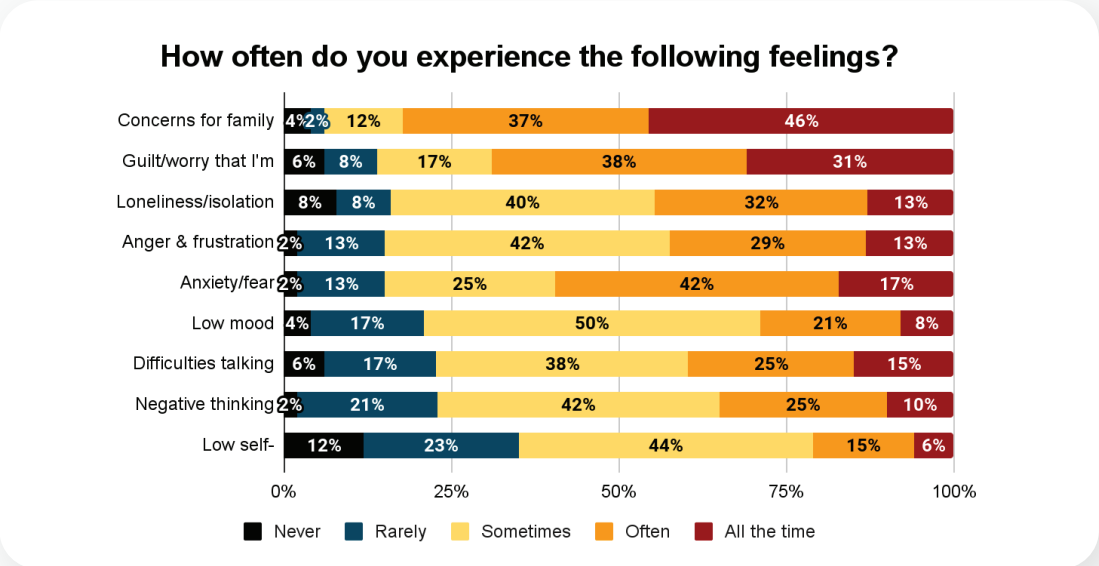


Carers

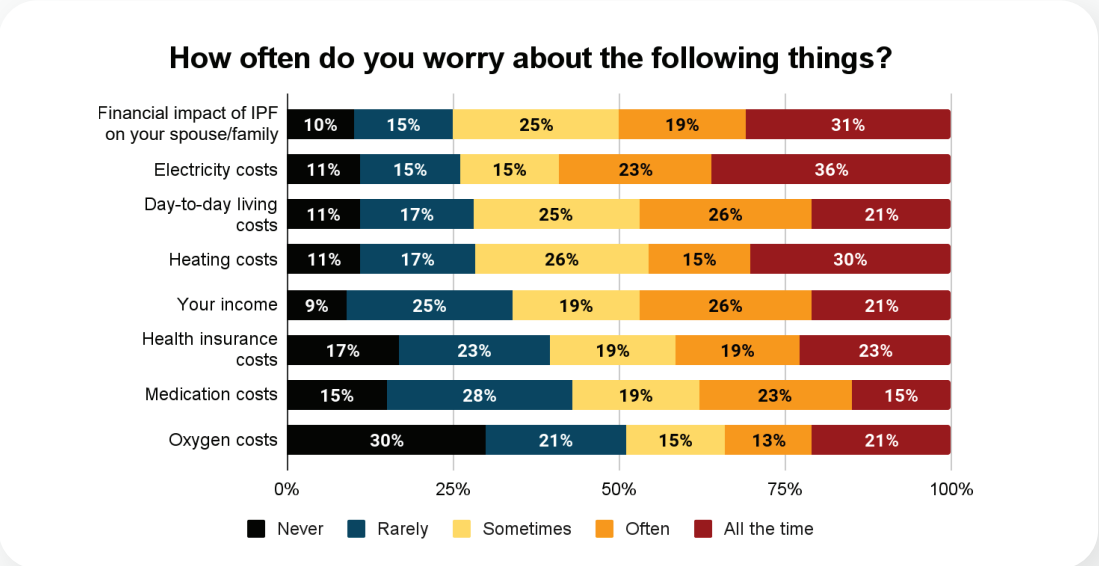
Impacts of being a carer



Emotional aspects of being a carer



Financial aspects of being a carer



Conclusions

The online survey did not impose a significant time burden on respondents.

This methodology is an efficient way to capture a snapshot of patient and carer experiences

Some carers experienced symptoms which were also reported by patients.

In addition to physical and emotional impacts, significant concerns about financial impact of PF were common in patients and carers. These may have been more pronounced because of increased energy prices in 2022.

Acknowledgements

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Conflict of Interest statement

CE is a shareholder and board member of patientMpower, a digital healthcare company. patientMpower was not involved in the development, implementation or analysis of the work presented here.