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## Burden, resilience and coping in caregivers of patients with interstitial lung disease

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### Abstract

**Rationale:** Prior work has described the experience of caregiving in idiopathic pulmonary fibrosis, but the effect on caregivers in interstitial lung disease (ILD) has not been explored.

**Objectives:** Describe the burden, resilience, and health related quality of life (HRQoL) of caregivers of people with ILD.

**Methods:** In a mixed methods study, ILD caregivers completed questionnaires and participated in focus groups. A qualitative thematic analysis of the focus group transcripts was conducted.

**Results:** Thirty seven caregivers completed the survey, and 15 participated in the focus groups. 65% were female; the average age was 66 (SD=13). The mean Short Form-36 role emotional and mental health scores were 18 (SD=4) and 46 (SD=7). The focus groups identified 4 major themes: emotional burden, changes in relationship, coping strategies, and unmet needs of caregivers.

**Conclusions:** Caregiving for patients with ILD significantly impairs HRQoL, particularly, emotional health. Increasing resources could improve the caregiving experience in ILD.

### Keywords

interstitial lung disease; caregivers; quality of life; burden

### Introduction

Interstitial lung diseases (ILD) form a diverse and heterogeneous group of diffuse parenchymal lung diseases including connective tissue related interstitial lung disease (CTD-ILD), hypersensitivity pneumonitis (HP), and idiopathic pulmonary fibrosis (IPF) (1–5). There is significant morbidity, mortality, and impaired health-related quality of life

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(HRQoL) with these diseases. With the introduction of antifibrotic therapies for IPF and the more frequent use of immunosuppressive drugs in CTD-ILD and HP, patients with ILD may have longer life expectancies, although many still experience disease progression, live with significant symptoms both from their disease and the medications used to slow disease progression, and may eventually require supplemental oxygen (2, 4, 6–8).

Less is known about how ILD affects the people who take on the caregiving responsibilities (spouse, child, or friend) for patients with this condition (9, 10). A family caregiver is defined as “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition.” (11) Family caregivers serve a critical role in the health and health care of our patients. Prior qualitative studies of caregiving in IPF have demonstrated a significant burden on caregivers, with feelings of helplessness, loss of independence and ability to pursue personal interests, strain on personal relationships, and anxiety about the future as common themes (10, 12). Finally, caregiver burden and strain can affect patient outcomes. In a study of older care recipients who had caregivers with high burden, there was an increased risk of mortality and hospitalization(13). In lung transplantation, the only definitive therapy for progressive ILD, previous work has demonstrated relationship of caregiver to recipient may affect outcomes, including graft survival (14). Although caregiving is known to create a significant burden in IPF and other types of chronic diseases, there is a knowledge gap, across the spectrum of ILD, on repercussions on daily life and quality of life. A better understanding of the experience of caregiving in ILD could lead to the development of targeted resources and interventions aiming to support ILD caregivers.

Given this paucity of research on caregivers of patients with ILD and the central importance of caregivers to the care of many ILD patients, we sought to evaluate the perspective of of caregivers for patients with ILD. The aim of this study is to evaluate the quality of life, burden, and resilience of caregivers of patients with ILD

## Methods

### Study Design:

We chose to use a qualitative and quantitative approach to this complex question. We felt the benefits of having caregivers express in their own words the major challenges, while also gathering empirical data, would help give us a complete perspective on the nature of caregiving in LD The qualitative data was analyzed using statistical methods described below, and the qualitative methods were analyzed using a grounded theory approach (15). Results from both approaches were combined to allow a multi-domain evaluation of caregiving in ILD.

### Study Population:

A convenience sample of caregivers of patients with ILD were recruited during clinic visits and through an invitation email sent to the email list (n=332) of the University of California, San Francisco (UCSF) ILD clinic which is a tertiary care clinic. Caregiver could choose to

participate in both the survey and focus group or to solely complete the survey. The institutional review board of UCSF approved the study prior to initiation and deemed this study exempt as we did not use patient identifiers, therefore we did not collect written informed consent.

### **Survey:**

The caregiver survey included questions regarding the caregiver experience in addition to validated instruments to measure HRQoL, burden and resilience. The Short-Form Health Survey (SF-36) version 1 is a 36 question survey that measures HRQoL across eight emotional and physical domains (16). Each scale is transformed into a 0–100 scale, where a score of 100 indicates no disability. The physical component summary (PCS) and the mental component summary (MCS) are representative scores that describe the physical and mental dimensions (16). The SF-36 has been validated in ILD (17, 18) and has demonstrated validity and reliability in other chronic lung diseases (19).

Caregiver burden was assessed using the revised Zarit Burden Interview (ZBI), a 22 item questionnaire with a maximum score of 88 (20). ZBI measures the caregiver's health, psychological well-being, social life, finances, and the relationship between the caregiver and the patient. Higher scores indicate greater burden. This survey has demonstrated reliability and validity in caregivers of patients with dementia and has been used in caregivers of patients with chronic obstructive pulmonary disease (21, 22)

Caregiver resilience was assessed using the Connor-Davidson resilience scale, a 10 item questionnaire where higher scores indicate greater resilience. This questionnaire has established reliability and validity, and has been used to assess resilience in lung transplant recipients and caregivers of lung transplant recipients (23). Average scores in a national random sample were 32.1 (24). Surveys were filled out on paper in clinic or electronically through an email link and all data were entered into RedCap.

### **Focus groups**

The same interviewer (RS) conducted three focus groups using a guide created to facilitate the discussion (Table 1). Focus groups were held at UCSF. Open-ended questions ensured that all key topics were covered. More precise questions were used to gather details of responses; however, there was minimal intervention from the moderator as caregivers were enthusiastic about the topic and the discussion progressed on its own. The moderator was closely listening to the discussion to ensure the groups were covering all the topics included in the focus group guide and intervened when necessary. Sessions were digitally recorded and transcribed verbatim using a professional transcriptionist ([rev.com](http://rev.com)).

### **Data Analysis**

Questionnaires were scored according to published criteria and results were analyzed using means and standard deviations. When there was missing data (missing rate 0–2% for each question), the average values of the other responses from the caregiver survey were used to impute a value. STATA v. 13.0 was used for all statistical analyses.

Focus group transcripts were analyzed using the grounded theory approach (15). Two members of the research team (RS and JM) performed the analysis. Transcripts of the first two focus groups were independently read and analyzed. Both investigators identified preliminary code categories within these transcripts. The codes were discussed and modified to create a consensus draft codebook organized around major thematic categories. This draft codebook was then applied to the same two transcripts for refinement and revision. We held an additional focus group to ensure there was reliability of the major themes found in the first 2 groups. Theme saturation was obtained after the initial 2 focus groups. Both investigators then coded all 3 focus group transcripts using the final codebook. Agreement on the final major themes was obtained through iterative discussion. Representative quotes were selected for each of these key themes.

## Results

### Survey

There were 37 caregivers who responded to the survey. Of those, 14 also participated in the focus groups. 1 person participated in the focus group, but did not respond to the survey. Caregivers were more likely to be female, white, and college educated (Table 2). The majority of caregivers were spouses of people with ILD. There was diversity in the diagnosis of the patient, with 41% of patients have non-IPF ILD's, including HP and connective tissue disease related-ILD. There was also a range in severity of illness, with 30% not requiring supplemental oxygen, 27% using supplemental oxygen with exertion, and 43% using supplemental oxygen all the time.

About half of the caregivers felt they had no choice in taking on the responsibility of caregiving, and over half were unable to take any respite from caregiving (19/37, 51%). Caregivers had physical component summary scores (mean 50 + 7) on the SF-36 similar to national averages (25). However they had lower MCS (mental component summary) scores (mean 37 + 7). In particular, scores on the role emotional domain were quite low (mean 18 + 4). Caregivers had low burden (mean Zarit Burden Index score 21 + 12) and were fairly resilient (CD Resilience Score 33 + 5), which may have contributed to their perception of low burden. Caregivers of patients who used oxygen (n=26) had a significantly higher perceived burden (mean Zarit Burden Index score of 23.8 + 12 for those with oxygen vs. 11.7 + 8 for those without oxygen, p=0.01) and lower PCS score (47.8+7 vs 53.7 + 2, p=0.02). There was no difference in scores by diagnosis, gender, or educational status. Questionnaire data are summarized in Tables 3 and 4.

### Focus Group

Fifteen caregivers participated in the three focus groups (5 in the first, 6 in the second, and 4 in the third) (Table 4)

The transcript analysis highlighted four major themes: emotional burden of caregiving, change in role/relationship, coping strategies and caregiver needs.

**Theme 1: Emotional Burden of Caregiving**—Participants highlighted the emotional stress of caregiving for a patient with ILD. The emotions they expressed ranged from anger,

frustration, helplessness, guilt, and fear. They expressed frustration with the paucity of information around their diagnoses and the treatment choices. “They don’t know nothing about it, that’s what’s discouraging. The doctors will give you answers, what their surmise of it may be, but they don’t know what it is, or where it came from” (Focus group 1, caregiver 1) Chronic cough was the symptom that was most challenging for caregivers to experience, “and if you’ve been around anybody who coughs all the time, it’s enough to drive you crazy.”(focus group 3, caregiver 1) Caregivers also experienced guilt over feeling upset about the cough. Additionally, caregivers expressed fear of the future. Many of them were also of advanced age, with their own medical issues, and feared that they may not be able to care for their partner in the future. Moreover, caregivers expressed fear of hypoxia and desaturations, and how having supplemental oxygen in case of an emergency was reassuring for them, “*we have oxygen in the house which I can’t tell you what a relief it is to me because now I know, if he does need it, I don’t have to call up 911*”. (Focus group 3, caregiver 3)

**Theme 2: Change in Role/Relationship**—A common theme throughout the discussions was the changes in the caregivers’ role in their relationship with the recipient, and the impact that the diagnosis of ILD had on their relationship. Many of the caregivers commented on the increased number of physical tasks and household chores they have had to take on. “*Things we used to split. Now I had to do them all ...the groceries and the cooking, the cleaning.* (focus group 1, caregiver 3) Some of the male caregivers developed a respect for the work their loved ones had been doing for many years. “*The thing that I’m finding now is, I have to do all the things that she’d done for so many years for me...it’s almost like the good Lord turned everything around to let me know and appreciate all these things that she was doing that I took for granted.*” (focus group 1, caregiver 2)

In addition to having more physical responsibility, caregivers noted an increase in the amount of emotional support they had to provide. Many caregivers noted the difficulties their loved ones have with talking because of cough and dyspnea and commented on the impact that had on their lifestyle and their relationship. “*Life is just different in every conceivable way. It’s better if he doesn’t talk so I do all the talking and then, I have nothing to say and then, it’s boring. It’s hard to have a conversation...we really don’t talk about interesting things anymore...it changes the dynamics of your marriage,* (focus group 3, caregiver 1) In many ways, caregivers felt they need to make extra effort to keep their relationship alive.

**Theme 3: Coping Strategies**—Despite the significant burden of caregiving and impact on their relationships, caregivers developed several successful coping strategies. One strategy was making sure the caregiver had personal time. “*I am 100% believer that the caregiver has to take care of themselves, otherwise if you get sick, who’s going to take care of them*”.(focus group 1, caregiver 3). Another strategy was embracing the extended support network. “*... very close friends and family, and I would call on them when I needed help. I would ask my sister to come stay for a couple of days so I could get out and do something.* (focus group 1, caregiver 3).

Many caregivers commented on the importance of simplifying life to make room for the additional time they spend caring for their loved one. *“I’ve made my life simpler because I was the cook, and the maid, even before this. We make that simpler for me”*, (focus group 1, caregiver 4)

Finally, communication with the extended support network was helpful. *“What I would do is I would write these update emails, and it was very cathartic for me. I would send it out, and then everybody would respond to her, and she’d see all of their wonderful responses, and it helped both of us”* (focus group 1, caregiver 3)

**Theme 4: Caregiver needs**—Caregivers identified several areas where their needs could be addressed better, including maintaining hope and optimism, receiving practical advice, and utilizing home assessments to help with supplemental oxygen and exercise. These concepts are described further in Table 5. They expressed the importance of education about the loved one disease and lung transplantation. They also wanted more practical advice including how to use oxygen, set up the home to be safe and accessible for the patient, and the role of pulmonary rehabilitation. Caregivers felt it was important to be included in physician visits, and some expressed the desire to have the opportunity to speak to the physician or nurse without their loved one to express specific concerns. Caregivers identified education sessions offered through pulmonary rehabilitation programs as a time where they should be included in order to get skills to better support their loved one at home. Finally, caregivers felt that an ongoing support group would be a helpful place to meet other caregivers and share their stories. Most caregivers felt it could be easier to participate in a caregiver specific-support group without their loved one.

## Discussion

In this study, we surveyed and conducted focus groups to better understand the demographic characteristics, HRQoL and burden of caregivers of patients with a variety of ILD’s. The results of this study demonstrate the substantial repercussions that ILD has on the lives of caregivers.

This effect on caregivers was demonstrated from the qualitative results of our focus groups, and quantitatively demonstrated by the reduced mental composite score (MCS of the SF-36) compared to population averages (37 vs 54) (25). This reduction appears to be primarily driven by the “role emotional” component of the questionnaire, where the mean score of our respondents was well below the population average (18 vs 51) (25). The role emotional questions ask about the impact of emotional factors (such as feeling depressed or anxious) on the respondent’s ability to dedicate time to work or other activities, accomplish goals, and perform work and other activities as carefully as usual. In caregivers of patients who use oxygen, there was an increase in perceived burden as evidence by a higher score on the Zarit Burden Index, and a decrease in the physical composite score, indicating that the use of supplemental oxygen, more than the particular diagnosis that the patient receives, significantly impacts caregiver HRQoL. Remarkably, our results suggest that caregiver resilience is similar to the population average (24). This finding is similar to a study of resiliency in caregivers of transplant recipients and suggests that caregivers retain their



ability to endure and provide support for their loved ones despite tremendous emotional distress (26).

The qualitative input from caregivers provides some areas for intervention which may help to improve caregiver HRQOL. Multiple studies have evaluated interventions in caregivers in other populations, including dementia. Interventions have ranged from educational platforms to improve understanding of dementia and methods of self-care, to improvement in communication and care coordination (27–29). Within the lung cancer community, an initial descriptive study of caregiver burden in non-squamous cell lung cancer (NSCLC) provided the basis for an ongoing study of a palliative care intervention for caregivers of patients with lung cancer, which included a nurse liaison to help separately address caregiver issues and work with the caregivers family physician, when necessary, to support the caregiver ([ClinicalTrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT02531464) identifier: NCT02531464)(30). Based on our data, we believe that there is ample opportunity to develop and test specific interventions to support caregivers of patients with ILD. For example, caregivers want to be included in all areas where education is provided, ranging from clinic visits to pulmonary rehabilitation programs. This represents a relatively easy and high-impact way the medical team could improve care. Dedicated support groups for caregivers only could represent another opportunity for caregivers to receive support and share common experiences without fear of making their loved ones more anxious. Finally, we believe that our data support the need for an intervention study focusing on the psychological burden of ILD. This could represent psychosocial support for caregivers, early and increased use of palliative care to support patients and caregivers, and using technology as a platform to allow caregivers to connect to each other, educate themselves, and facilitate care coordination.

There are limitations to our study. Some of the patients cared for by the caregivers surveyed and interviewed were recently diagnosed with ILD, and these caregivers may not have had a lot of burden from advanced disease yet. Importantly, we had a range of diagnoses and variety in gender and ethnicity in participants, and the median duration of caregiving was 3 years. Patients were enrolled at a single, academic center and may not be representative of the general population with ILD, or populations from different geographic and cultural backgrounds. Additionally, not all patients who filled out questionnaires participated in focus groups which may have led to a selection bias for those caregivers who felt more effected by the ILD diagnosis.

In conclusion, caregiving across the spectrum of ILD, similar to studies in IPF, significantly impacts the life of the caregiver. This is most explicit in the realm of emotional stress, and efforts to relieve caregiver stress through education, involvement in care, and access to caregiver-specific resources (e.g. support groups) may be effective interventions to improve caregiver quality of life. Futures studies should evaluate the effectiveness of novel interventions for caregivers of patients with ILD.

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**Table 1.**

Focus group Interview Guide

- 
1. How do you view your role as a caregiver? What emotional/mental support do you give to your loved one?
  2. How has caregiving changed with time?
  3. How has caregiving changed your life?
  4. What coping mechanisms do you use to deal with the stress of caregiving?
  5. What do you think could be done to make caregiving for ILD patients easier?
    - a. What interventions do you think would facilitate being a caregiver
  6. What are some barriers to caregiving?
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**Table 2.**

## Clinical and Demographic Characteristics of the Sample

Characteristic	n=37
Age (mean $\pm$ SD)	66 $\pm$ 13
Gender	24 (65%) female
Race	28 (78%) White
Education	
High School	10 (28%)
AA	12 (33%)
Bachelors or higher	14 (40%)
Disease	
IPF	20 (59%)
HP	5 (15%)
CTD-ILD	4 (12%)
NSIP	2 (6%)
Sarcoidosis	1 (3%)
Other	3 (9%)
Duration of Disease (year) (median, IQR)	1 (0, 4)
Supplemental Oxygen	
No	11 (30%)
With activity	10 (27%)
All of the time	16 (43%)
Relationship	
Spouse	30 (81%)
Friend	1 (3%)
Relative	6 (16%)

Abbreviations: IPF (Idiopathic Pulmonary Fibrosis), NSIP (nonspecific interstitial pneumonitis), HP (hypersensitivity pneumonitis), CTD-ILD (connective tissue disease related interstitial lung disease). Values in table represent number of patients with that characteristic (n, with a percentage) unless otherwise stated.

**Table 3.**

## Caregiver survey results

Variables and Measures	Response (n=37)
Did not feel you had a choice in taking on this responsibility n(%)	19 (51%)
Have not been able to take respite n(%)	19 (51%)
Zarit Burden Interview (mean $\pm$ SD)	21 $\pm$ 12
Resilience (mean $\pm$ SD)	33 $\pm$ 5
SF 36 (mean $\pm$ SD)	
Physical function (mean $\pm$ SD)	52 $\pm$ 6
Social function (mean $\pm$ SD)	51 $\pm$ 8
Role physical (mean $\pm$ SD)	25 $\pm$ 3
Pain (mean $\pm$ SD)	51 $\pm$ 10
General health (mean $\pm$ SD)	55 $\pm$ 7
Vitality (mean $\pm$ SD)	54 $\pm$ 10
Role emotional (mean $\pm$ SD)	18 $\pm$ 4
Mental health (mean $\pm$ SD)	46 $\pm$ 7
Physical Component Summary Score (mean $\pm$ SD)	50 $\pm$ 7
Mental Component Summary Score (mean $\pm$ SD)	37 $\pm$ 7

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**Table 4.**

Characteristics of caregivers participating in focus groups

Participant	Age	Gender	Education*	Race	Disease of care recipient	Use of supplemental oxygen	Disease duration (years)
1	69	Female	Bachelors	White	IPF	Wth activity	NR
2	85	Female	Masters	White	IPF	At night and with activity	NR
3	62	Male		Hispanic	IPF	At night and with activity	NR
4	60	Female	2 year	White	NSIP	None	NR
5	83	Male	2 year	White	IPF	All of the time	NR
6	74	Female	2 year	White	Chronic HP	All of the time	14
7	70	Female	Masters	White	IPF	Wth activity	1
8	75	Male	High School	White	IPF	At night and with activity	3
9	74	Male	Bachelors	Asian	IPF	All of the time	6
10	70	Female	Advanced professional Degree	Asian	IPF	All of the time	6
11	68	Male	AA	White	CTD-ILD	No	2
12	85	Female	Bachelors	White	Chronic HP	All of the time	3
13	70	Female	Masters	White	Chronic HP	Wth activity	10
14	65	Female	High School	White	IPF	All of the time	3

\* 2 year education indicates completion of an Associates' degree or 2 years of college. Abbreviations: IPF (Idiopathic Pulmonary Fibrosis), NSIP (nonspecific interstitial pneumonitis), HP (hypersensitivity pneumonitis), CTD-ILD (connective tissue disease related interstitial lung disease), NR (not reported)

**Table 5.**

Description of themes of caregiver unmet needs

Caregiver Needs	Description
Hope	<i>"We didn't get enough hope. We didn't get a glimmer of hope until we came here."</i>
Practical Advice	<i>A lot more solid information in a small group where it was more applicable to use your own situation.</i>
Home Assessment	<i>have someone do a home assessment when things get to the point where how do you keep track of all these wires It would be really nice to have someone come in and make an assessment and say "This can make it easier."</i>
Disease Education	
Transplant	<i>Why is it so hard to get a lung transplant? What is the reasoning behind it?</i>
Inclusion in care	<i>I think that the pulmonary rehab program leaving the spouse or the caregiver out is a big mistake. I think that there should be a component either include them in that part of the program because they'd say "What are you doing?" "Well, are you going die at home on a tread mill?" "Are you going to lift the weights at home?" "What he's supposed to do now for maintenance?"</i>
Opportunity to discuss with other caregivers	<i>I think it's really good to be here without the person with ILD because you can speak honestly. I could never say this stuff.</i>