ARTICLE IN PRESS

Heart & Lung ■■ (2018) ■■–■■

Contents lists available at ScienceDirect

Heart & Lung

journal homepage: www.heartandlung.com

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

R.J. Shah, MD [a,*], H.R. Collard, MD [a], J. Morisset, MD [b]

[a] *Division of Pulmonary, Critical Care, Allergy and Sleep Medicine at the University of California San Francisco, San Francisco, CA*
[b] *Département de Médecine, Centre Hospitalier de l'Université de Montréal, Québec, Canada*

ARTICLE INFO

Article history:
Received 30 November 2017
Accepted 11 March 2018
Available online

Keywords:
Interstitial lung disease
Caregivers
Quality of life
Burden

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.

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 (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.

Author Contributions: Involvement in conception, hypothesis, and design of the study: RJS, HRC, JM; acquisition of data: RJS and JM; substantial involvement in the writing and/or revision of the manuscript: RJS, HRC, JM.

[*] Corresponding author. Fax: 415-514-7612.
E-mail address: rupal.shah@ucsf.edu (R.J. Shah).

0147-9563/$ – see front matter © 2018 Elsevier Inc. All rights reserved.
https://doi.org/10.1016/j.hrtlng.2018.03.004

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 ILD. 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. Caregivers 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 chroic 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 int eh focus group guide and intervened when necessary. Sessions were digitally recorded and transcribed verbatim using a professional transcriptionist (www.rev.com).

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?

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 hypersensitivity pneumonitis 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 in the US.[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