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## Patient Perspectives in OMERACT Provide an Anchor for Future Metric Development and Improved Approaches to Healthcare Delivery in Connective Tissue Disease Related Interstitial Lung Disease (CTD-ILD)

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### Abstract

**Objective**—The impact and natural history of connective tissue disease related interstitial lung disease (CTD-ILD) are poorly understood; and have not been previously described from the

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### CONFLICT OF INTEREST

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patient's perspective. This investigation sought insight into CTD-ILD from the patients' perspective to add to our knowledge of CTD-ILD, identify disease-specific areas of unmet need and gather potentially meaningful information towards development of disease-specific patient-reported outcome measures (PROMs).

**Methods**—A mixed methods design incorporating patient focus groups (FGs) querying disease progression and life impact followed by questionnaires with items of importance generated by >250 ILD specialists were implemented among CTD-ILD patients with rheumatoid arthritis, idiopathic inflammatory myopathies, systemic sclerosis, and other CTD subtypes. FG data were analyzed through inductive analysis with five independent analysts, including a patient research partner. Questionnaires were analyzed through Fisher's Exact tests and hierarchical cluster analysis.

**Results**—Six multicenter FGs included 45 patients. *Biophysiologic* themes were cough and dyspnea, both pervasively impacting health related quality of life (HRQoL). Language indicating dyspnea was unexpected, unique and contextual. *Psycho-social* themes were Living with Uncertainty, Struggle over Self-Identity, and Self-Efficacy - with education and clinician communication strongly emphasised. *All questionnaire items* were rated 'moderately' to 'extremely' important with 10 items of highest importance identified by cluster analysis.

**Conclusion**—Patients with CTD-ILD informed our understanding of symptoms and impact on HRQoL. Cough and dyspnea are central to the CTD-ILD experience. Initial FGs have provided disease-specific content, context and language essential for reliable PROM development with questionnaires adding value in recognition of patients' concerns.

## Keywords

Communication; connective tissue disease; focus groups; interstitial lung disease; patient experience; patient reported outcome measures; questionnaire

## INTRODUCTION

Interstitial lung disease (ILD) is a common complication of connective tissue diseases (CTD)[1], and a leading cause of death in systemic sclerosis (SSc)[2,3], rheumatoid arthritis (RA)[4], and idiopathic inflammatory myopathies (IIM)[5]. Patients with CTD-ILD also report impaired health-related quality of life (HRQoL) and significant depression [6,7]. The impact of CTD-ILD on patients' lives and their experience of ILD are largely unknown.

Patients provide a unique insight through their experience of disease and its impact on living. This information is an essential consideration in designing randomized controlled trials (RCTs) and disease management strategies for clinical practice [8–14]. As an example, qualitative research with patient focus groups identified *fatigue*, an outcome measure previously overlooked by investigators of RA RCTs, as important to RA patients and subsequently validated as a reliable outcome measure for use in RCTs that was sensitive to change correlating with RA disease activity [11,12].

Patient-reported outcome measures (PROMs) reflect the intensity of disease-related symptoms and/or the impact of the disease on HRQoL including physical functioning, self-care, emotional well-being and mental health, fatigue, sleep, and ability to participate in

family, social and leisure activities; as well as work within and outside the home – participation. The international consensus effort, Outcome Measures in Rheumatology (OMERACT), emphasizes PROM instruments that integrate assessment of patients' priorities, perceptions, language, and the early involvement of patients in the development process to *define important disease-related domains/areas* to enhance instrument validity [15]. These concepts are supported by funding and regulatory agencies [14].

We sought to assess patients' perspectives of living with CTD-ILD and identify aspects of high importance to them. Per FDA guidance, focus group (FG) data created the preliminary conceptual framework [14] including symptomatic, functional and psychosocial needs as well guidance for PROM development.

## METHODS

A convergent mixed method design incorporated focus group interviews and a subsequent quantitative self-administered questionnaire [16].

Six FGs were conducted with English-speaking adults (aged 18–90 years) from a convenience sample of patients from 4 academic referral centers. *A priori*, it was decided that both homogenous (e.g. exclusively RA-ILD) and heterogeneous (varied CTDs) FGs would be conducted. Informed, written consent and institutional review board approvals were obtained.

The presence of ILD was confirmed by histology and/or computed tomography and restrictive pulmonary physiology on pulmonary function testing (defined as a forced vital capacity or total lung capacity of <80% predicted +/- a diffusing capacity of carbon monoxide <80% predicted), with at least one of the following features: (a) symptoms of dyspnea and/or cough; (b) peripheral oxygen desaturation at rest or with exertion. Patients were excluded if they had a screening echocardiogram suggestive of catheterization diagnostic of pulmonary hypertension, or if the etiology of ILD was not related to a CTD (e.g., hypersensitivity pneumonitis). Diagnoses of CTD were made by a rheumatologist and CTD-ILD by both rheumatologists and pulmonologists.

### Patient Focus Groups

FGs included two open-ended questions: “how have you experienced your disease since the diagnosis of ILD?” (to capture personal impact) and “how has the disease changed since the diagnosis of ILD?” (to capture pathophysiologic manifestations of disease)[11,12]. The World Health Organization Quality of Life (WHOQOL-100) [17], a generic HRQoL instrument comprising six broad domains: physical health, psychological state, level of independence, social relationships, spirituality, and environment, was used by the moderator to ensure comprehensiveness. The protocol was developed with an expert qualitative researcher using trained FG moderators. FGs were audio-recorded and transcribed verbatim; four were video-recorded. Participant demographics were abstracted from the medical record. A medical professional moderated or assisted the FGs assuring discussions remained focused on CTD-ILD-related experiences. Non-verbal communication for context, gestures, and emotion was recorded.

**Analysis Approach**—Transcripts underwent independent analysis guided by inductive methodology [18,19]. Each of the 6 transcripts was deconstructed and coded by at least 5 analysts (SiF (n=6), DL (n=6), SM (n=6), LS (n=6), AC (n=2)), SC (n=2), SaF (n=2), MT (n=2)), who then engaged in a mutual iterative process whereby core themes were identified with saturation of the thematic and coding structure being reached [20]. At every level of this process, a patient research partner (DL), participated in analyses, coding, and development of themes.

### Post-Focus Group Questionnaire

After each FG, participants completed a questionnaire of items generated from a brainstorming exercise in which >250 pulmonary and rheumatology ILD experts suggested concepts they thought to be ‘important’ in a 1-year RCT in CTD-ILD [21,22] (Fig. 1). Respondents were asked to provide additional concepts in the questionnaire. Items were rated on a 7-point Likert scale (from 1 ‘not all important’ to 7 ‘extremely important’).

The purpose of the questionnaire was to 1. determine the level of importance ascribed by patients to items thought important to physician experts and discover concepts overlooked by the physicians, 2. ascertain complementary information in addition to FG data, based on the premise that “empirical research results obtained with different methods are like the pieces of a jigsaw puzzle that provide a full image of a certain object if put together in the correct way” [23–25].

**Analytic Approach**—The mean, median and proportion of ratings qualifying as ‘moderately’ to ‘extremely’ important (score 4–7) were calculated. Cluster analyses determined items with highest importance, beyond differences expected by chance [26]. Differences across CTD subtypes were compared using Fisher’s exact tests.

## RESULTS

Six focus groups included 45 participants: IIM-ILD (n=11), RA-ILD (n=13), SSc-ILD (n=17), and various other CTD diagnoses (n=4) (Table 1). Themes, sub-themes, and concepts were consistent and remained predominant across FGs. Differences that emerged were non-dominant and related to the specific underlying CTD (e.g. digital ulcers in SSc FGs).

Two over-arching spheres emerged: *Biophysiologic* and *Psychosocial* (Table 2).

### A. Biophysiologic Themes

In this sphere two themes were prominent across all focus groups:

(1) *Cough and Difficulty Breathing* (Dyspnea). (1) *Cough*: was experienced by almost all participants; it was classified as “dry”, “cracking”, “itchy”, or “phlegmy”. Participants distinguished cough related to ILD from other aetiologies (e.g., asthma, heartburn) and indicated external (e.g., dust, air conditioning, fumes from cleaning products, perfume) as well as internal and behavioural (e.g., emotional distress, laughing) triggers. ILD-related cough adversely impacted physical function, social participation, activities of daily living,

and sleep quality. Paroxysms of coughing prolonged the duration of self-care and household activities, requiring time for recovery.

*Difficulty Breathing (Dyspnea)*: like cough, was a central theme across all FGs. Traditional descriptors such as ‘shortness of breath’ or ‘breathlessness’, were seldom voiced; instead, phrases such as “winded”, “trouble getting a deep breath in”, “can’t catch a breath”, “can’t get that deep inhale”, “losing your breath”, “huffing-puffing”, “chest tightening” with inspiration or “wind/breath is cut/caught” were used. Uncomfortable sensations related to inspiration like “too big of a breath ... the bottom of my lungs will cramp”, “it’s like a catch inside”, “it hurts” to take a deep breath, or “can’t breathe in without it squeezing my chest” were frequently described.

Participants seldom referred to the actual act of breathing. Instead, difficulty breathing was indicated by the ability to perform activities central to functionality or life priorities. For instance, participants described being unable to complete sentences when reading to or bathing their children/grandchildren or described varying lengths of time to complete a task. Recovery in the midst of or after the performance of simple activities, e.g. dressing/bathing was frequently described.

A relationship between cough and difficulty breathing was well-described: cough arose from activities demanding inspiration such as talking, laughing and with exertion (e.g., walking, lifting, bending). One participant described “cough as I go to the deep draw (*inhale*)”. The converse was often described with cough exacerbating dyspnea creating a ‘terrifying’ inability to ‘catch air’.

Both *Cough* and *Difficulty Breathing* were associated with frustration, shame, anger, and isolation among participants; coughing created embarrassment and conspicuousness, curtailing social engagements. A loss of participation in pleasurable activities, such as walks, dancing, or playing with children was described.

Cough and difficulty breathing were symptoms to which participants repeatedly returned and discussed at great length. Other less prominently described symptoms were short-term memory loss, concentration difficulties, dizziness, headaches, and myalgias; of which fatigue was most commonly reported. Participants could not distinguish whether the source of these symptoms was ILD or systemic CTD related manifestations, medication effects, or other factors.

## B. Psycho-social Sphere

Three broad themes emerged in the *Psycho-Social Sphere*: (1) *Living with Uncertainty*, *Struggle Over Self-Identity*, and (3) *Self-Efficacy*.

- (1) *Living with Uncertainty* contained sub-themes relating to uncertainty surrounding diagnosis, disease course, prognosis and management of ILD.
  - a. *Healthcare Provider Communication* was a potential source of reported uncertainty, disappointment, and anxiety. Participants described lack of sufficient disease-related information, particularly how ILD relates to

CTD, and when to seek urgent medical attention. Participants voiced desires for detailed information on their lung status, and for support groups.

A marked concern was the delay in ILD diagnosis with many reporting that, despite having a CTD diagnosis, they reported their respiratory symptoms were dismissed as ‘anxiety’, ‘obesity’, or ‘your asthma’. IIM-ILD and RA-ILD was frequently diagnosed as infectious pneumonia instead of ILD.

- b. *Health Status and Disability* contained concepts that fell into short- (i.e. daily) and long-term categories. Short-term included having sufficient physical reserve to complete errands (e.g. shopping) and gauging time needed for simple acts, such as dressing. Long-term captured uncertainty related to life expectancy and progressive disability creating difficulties in life-planning. Participants reported heightened appreciation of the present moment and enjoying life.

*Struggle Over Self-Identity* involved preserving autonomy and individuality with changing physical ability. Participants described numerous methods of concealing limitations from others to preserve a semblance of normalcy. Despite support from loved ones, participants described feeling isolated but also a keener sense of empathy for others’ limitations.

- (3) *Self-Efficacy*, resilience through coping, describes areas of disease self-management, and disease-related relations with others. Three sub-themes emerged:
  - a. *Symptom Management* describes strategies to lessen the impact of respiratory symptoms; including reorganization of physical space, use of aids, pacing of activities to preserve energy while lessening the need/duration for ‘recovery’, and avoidance of cough triggers. Daily self-assessment of symptoms and health status guided the day’s activities (e.g., re-scheduling, alternate plans).
  - b. *Engagement of Assistance* included how and whether participants elected to enlist support from family and friends. Participants described striking a balance between receiving family support and avoiding negative effects arising from: over-reliance upon family members, self-perceptions of ‘being a burden’, escalating family worry and potential changes in family dynamics.
  - c. *Seeking Knowledge* pertained to searching for disease-related knowledge and discriminating accurate internet content. Exposure to other CTD-ILD patients was stated as particularly valuable with patient support groups needed.

**Post Focus Group Questionnaires (Tables 3 and 4)**—Thirty-one of 45 (70%) post-FG questionnaires (>65% from each FG) were returned. No new items were introduced. *All items* were rated as ‘moderately’ to ‘extremely’ important by >50% of respondents with no differences of ratings across CTD sub-types.

*Via* cluster analysis, 10 items held outstanding importance; of which half pertained to physician communication of health information. Value was placed upon physician’s assessment and test results used to assess ILD disease activity/severity, correlating with FG concepts under *Living with Uncertainty*. High importance was assigned to ‘short of breath’, ‘feeling fulfilled’ and ‘enjoying life’, correlating with FG data.

**Complementary Results of Mixed Methods**—‘Concern for healthcare costs’ was as a priority item on the questionnaire but was not discussed in FGs—indicating an area for FG re-investigation. Multi-dimensional/factorial aspects of ‘sleep’, ‘fatigue’, and ‘eating’ were highly rated on the questionnaire, but did not strongly penetrate the FG data.

## DISCUSSION

To our knowledge, this is the first study in this patient population and was used to inform an international effort (including patients) to identify a core set of domains and instruments in CTD-ILD for use in RCTs [22]. Qualitative data from this investigation provided a *preliminary* conceptual framework for use in patient care and PROM development in CTD-ILD.

The investigation supports that qualitative FG data provide an important vehicle to identifying the content, language, and context for reliable interpretation of patient disease experiences for use in PROM development and other patient-centered quality care ventures. Cough and difficulty breathing (dyspnea) appear to be hallmark symptoms of ILD; this was also found in focus groups of idiopathic pulmonary fibrosis patients [27]. The impact of dyspnea on performance/participation in life activities and HRQoL was prominent and described in words and phrasing not found in current patient-reported dyspnea instruments.

Interestingly, patient-supplied context and language were able to discern dyspnea from fatigue in the FGs – with dyspnea characterized by demands of breathing in activities such as singing or lifting, that clearly alluded to difficulty breathing, chest tightness; and by post-exertion cardiopulmonary recovery prompting very specific language such as ‘wind-cut’. These findings underscore the need for a *disease-specific* HRQoL-PROM that incorporates the language and context of living with ILD.

Differences found between FG and questionnaire findings support that multiple convergent methods of data collection provide complimentary and more comprehensive views of the patient experience. Discussion time with other CTD-ILD patients may have been viewed as a precious opportunity, resulting in prioritization of topics in the FG. For example, given time restraints, the FG discussions may have self-selected topics of ‘uncertainty of prognosis’ or ‘cardiopulmonary recovery’ over highly-rated questionnaire items such as ‘fatigue’, ‘sleep’ or ‘health care costs’.



The FG script was designed to emphasize patient experiences of ILD at time of diagnosis and over time with prompts to clarify content, context, and implicit meaning; whereas the post-FG questionnaires were generic and devoid of descriptive context. A lack of context impairs researchers' inferences into what respondents actually mean by the rating. For example, the questionnaire item "how much you cough", was important to only 73% respondents, however, multidimensional discussions of *cough* such as etiology, complex inter-relations with dyspnea and social impact pervaded FGs. The questionnaire item would optimally be replaced by several items reflecting patients' perceived complexities of 'cough'.

Sleep received sporadic attention in FGs, but was important in the questionnaires; sleep may require further iterative investigation to qualify content and relevant language: such as whether sleep is disturbed by breathing or coughing, or if a relationship exists between sleep and worsening symptoms.

In the questionnaires, the concepts suggested by medical experts concurred with patient ratings. This might suggest medical expert influence on experienced patients; or more optimistically, a strikingly empathetic relationship between patient and medical expert.

Finally, *Living with Uncertainty* is a theme that exists across a spectrum of diseases [28,29]. Physician-patient communication impacts many areas of patient health (self-efficacy, education, mental health). Further qualitative work developing protocols for conveying health information and anticipatory guidance may help in allaying patient anxiety and improving CTD-ILD health outcomes. Participants perceived delays in ILD diagnosis as a lost opportunity for earlier treatment and prevention of ILD progression. Although this link has yet to be established, improved medical and patient education is warranted [30,31].

The study design captured comparisons of CTD subtypes; the themes and concepts were congruent across FGs. Though FGs were geographically and culturally diverse, limitations of this study include that participants were English-speaking, thus, the concepts may not be transferable to non-English speaking countries. Though results may be subject to selection bias related to convenience sampling at tertiary referral centres, it is likely that experiences described apply across healthcare center type and should be validated thus.

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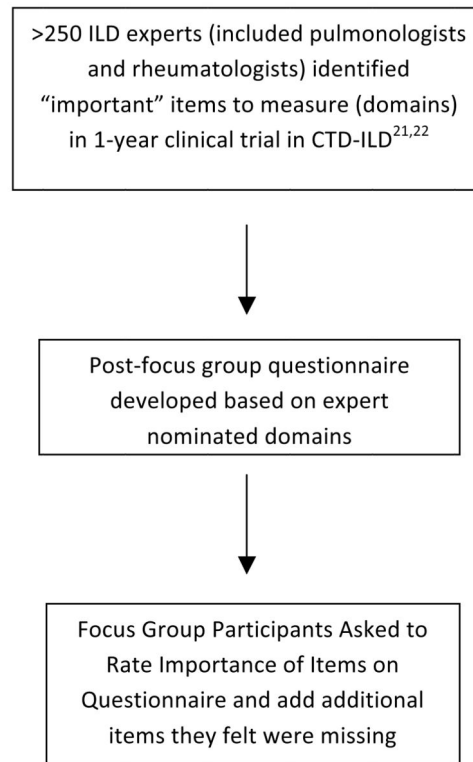
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**KEY MESSAGES**

Patient experiential data generated important insights into CTD-ILD disease and life impact.

Cough and Dyspnea are pervasive in CTD-ILD with language describing dyspnea being unexpectedly unique.

Further content validation for PROM development and communication protocols is required.



**Fig. (1).**  
Post-focus group questionnaire development and implementation.

Patient characteristics of CTD-ILD Focus Groups. Median pulmonary function testing provided as an example of ILD severity.

**Table 1**

Group	CTD Type	Location	N	Gender	Age, in Years Mean (SD)	Race	FVC% Median (Range)	DLCO% Median (Range)	Home O <sub>2</sub> n (%)
1	Various	Winnipeg, MB, Canada	9	8 F, 1 M	53.6 (16.2)	8 C, 1 O			
2	RA	Toronto, ON, Canada	7	7 F, 0 M	64.3 (9.0)	4 C, 2 A, 1 AC			
3	SSc	Baltimore, MD, USA	6	3 F, 3 M	58.2 (9.1)	6 C			
4	IIM	Baltimore, MD, USA	7	4 F, 3 M	52.4 (10.5)	5 C, 2 AA			
5	Various	New Orleans, LA, USA	9	6 F, 3 M	53.8 (15.5)	4 C, 4 AA, 1 H	55 (45–67)	51 (35–59)	3 (33%)
6	SSc	New Orleans, LA, USA	7	5 F, 2 M	54.6 (5.7)	4 AA, 3 C	46 (23–75)	33 (20–69)	2 (29%)

Legend. A: Asian; AA: African American; AC: African/Caribbean; C: Caucasian; F: female; DLCO: Diffusion Capacity of Lung for Carbon Monoxide; FVC: Forced Vital Capacity; H- Hispanic; IIM- idiopathic inflammatory myositis; LA-Louisiana; M- male; MB-Manitoba; MD-Maryland; ON-Ontario; O-Other; RA-rheumatoid arthritis; SSc-systemic sclerosis; SD-standard deviation; USA-United States; Various- various CTD subtypes with ILD.

**Table 2**

Preliminary Themes and Conceptual Framework for Patients' Experiences of Connective Tissue Disease-Related Interstitial Lung Disease (CTD-ILD).

Themes and Subthemes	Concepts	Participant Quotes
<b>Biophysiologic Sphere</b>		
Cough	Frequently-reported symptom Symptom with impact on important life areas Participants able to describe triggers and qualities Symptom often triggered by inspiration	"First thing in the morning I cough. Or when I talk on the telephone...I cough when I walk. I would have to sit down and get a hold of myself." "I don't sleep at night. I sleep maybe a half an hour and then I'm up because all of a sudden... I'm coughing, you know."
Difficulty Breathing (Dyspnea)	Frequently described experience Symptom with impact on important life areas Experience predominantly described contextually Use of specified vocabulary for this symptom was rare Vocabulary was largely unique among participants Terminology often reflected the ability to inspire	"...(my kids) need to read a book before they go to bed or even during the day because sometimes they'll come back from school and go to the library... she likes for me to read the book... but I can't read all the words." "Basically when you're bending over, whether you're drying off or washing yourself, if you're over, and it doesn't have to be for a long period of time and you go to stand up and all the sudden you're panting." "You know what I mean, my grandson or nieces or something will holler you know, come on, run. I said it don't look like it but I am running. Again when it comes to the breathing aspect of it, you've just got to stop"
<b>Psycho-Social Sphere</b>		
Living with Uncertainty 1 Healthcare Provider Communication 2 Health and Disability	Unpredictability of immediate changes in health status Poor predictability of prognosis and life expectancy Lack of confidence in life-planning Inadequate information at time of diagnosis and self-management Associated with anxiety Associated with heightened attention to the present time	"I went 4 times to the Emergency, and they keep telling me, oh it was pneumonia. They did tell me it's pneumonia and they gave medication for pneumonia. Antibiotics didn't work." "I'm home with a 4 year old. I teach him, I said if mom ever fall down, call 911." "...yes, I do live with the fear that either the lungs or some other problem, major problem is gonna happen.. and in that, because of that I do live more fully, as much as I can... So I kind of take each day and live it to the fullest.. and you know, do as much as we can."
Struggle Over Self-Identify	Maintenance of autonomy (physical and decision-making) Preserving self-identity in face of changing ability	"I mean, I already have a friend checking into disability. I'm like I refuse, I got a handicap that upsets me. " "So we rode around the neighborhood and it was flat and downhill coming back, grandma, are you sure you don't need to rest? No. Going uphill it was killing me!... I was a half a block from the house and I said oh I'm fine, I'm fine. I would not let on. " "And then I gave up my coaching of soccer because I couldn't, well I couldn't yell at them. I couldn't run with them. I couldn't walk the field without ( <i>imitates hard breathing</i> ). 'Okay, guys, go run around - I'm just gonna sit here for a minute' -you know." "I would like, I always have... to iron every single piece of clothing.. I can't do it.. I bought a steam cleaner. I steam my shirts."
Self-Efficacy 1 Symptom Management 2 Engagement of Assistance 3 Seeking Knowledge	Self-management of symptoms Pacing activities Reorganization of physical space Developing mental health strategies Selective engagement of assistance from family and friends Value of communication with others who have CTD-ILD	"It looks like my house is a bit unkempt but ( <i>the pots and pans</i> ) are stacked up nicely and they are clean, they're ready to go, but that means that I don't have to bend over to pull that out and I can make a meal, I can do something by myself, you know, and my husband he's afraid to leave me alone sometimes, you know, so I'm good with that and I have a new dishwasher...I don't have to bend over. Yea, you do that, you make modifications and you know life goes on merrily." "...normally I could, you know, clean the house in a day. Now I take my time and I have to pace myself. You know, I may be able to do the master bedroom today and forget the rest."

**Table 3**

Post focus group questionnaire results from 31 participants in response to the question ‘*On a scale from 1 to 7, how much do you care about the following items as they relate to your lungs?*’, with ‘not applicable’ as a possible choice. ‘Important’ was defined as a rating of 4–7 (moderately to extremely important) on a Likert scale of 1–7.

Question	Item important (Number of Ratings 4–7/Number Responses)	Mean Rating	Median Rating
<b>SYMPTOMS</b>			
How much you cough?	73% (22/30)	5.0	4.9
How much phlegm you cough up?	72% (22/31)	5.5	4.9
How short of breath you are?	91% (28/31)	6.5	6.0
How much fatigue you feel/tired you are?	86% (27/31)	6.0	5.7
How well you sleep?	90% (28/31)	6.0	5.7
How much heartburn you have?	52% (16/31)	4.0	4.1
How well you eat?	97% (30/31)	5.0	5.2
How much the symptoms from your autoimmune disease bother you (e.g. Joints, Muscle Weakness, Tight Skin, Dry Eyes/Mouth)?	94% (29/31)	6.0	5.9
How much medical problems, other than your autoimmune or lung disease, bother you (e.g. diabetes, blood pressure)?	65% (20/31)	4.5	4.4
<b>MENTAL HEALTH/CONCEPTS OF WELL-BEING</b>			
How depressed you feel?	67% (21/31)	5.0	4.5
How much anxiety you feel?	67% (21/31)	6.0	4.8
How much anger you feel?	58% (18/31)	4.0	4.1
How fulfilled you feel?	86% (27/31)	6.0	5.4
How much you enjoy life?	97% (30/31)	6.5	6.2
How much vitality (energy) you have?	97% (30/31)	6.0	5.8
How disabled you feel?	69% (20/29)	6.0	5.0
<b>CONCEPTS OF CARING</b>			
How well you are able to care for yourself?	100% (29/29)	7.0	6.3
How well you are able to care for others?	90% (26/29)	6.0	5.5
How well you are able to care for your surroundings?	93% (27/29)	6.0	5.4
<b>CONCEPTS OF FAMILY/SOCIAL PARTICIPATION</b>			
How able you are to interact with family?	95% (28/29)	6.0	5.9
How able you are to interact with friends?	97% (26/27)	6.0	6.0
How much you engage with your community?	87% (27/31)	5.0	4.8
How able you are able to do hobbies?	97% (30/31)	5.5	5.5
How able you are to be physically intimate?	77% (23/31)	5.0	4.9
<b>CONCEPTS OF WORK PERFORMANCE</b>			
How much time you are able to spend at work? (presenteeism)	61% (19/31)	5.0	4.3
How many sick days you need to take from work? (absenteeism)	55% (17/31)	5.0	4.5
How well you perform at work? (productivity)	68% (21/31)	6.0	5.1



Question	Item important (Number of Ratings 4–7/Number Responses)	Mean Rating	Median Rating
The amount of time you feel sick at work	58% (18/31)	6.0	4.7
<b>CONCEPTS OF HEALTHCARE ACCESS</b>			
How much are your health care costs?	84% (26/31)	6.0	5.5
How easy it is to get appointments with your doctor/lung specialist?	90% (28/31)/90% (28/31)	6.0/6.0	5.4/5.5
How easy it is to get your medications?	87% (27/31)	6.0	5.8
<b>CONCEPTS RELATED TO MEDICATIONS</b>			
How much steroid do you need?	65% (20/31)	6.0	5.5
How many other (non-steroid) medications for your lungs do you take?	84% (26/31)	5.0	4.5
How many meds for other med problems?	81% (25/31)	6.0	5.6
<b>CONCEPTS RELATED TO INCREASED UTILISATION</b>			
How often you need to go to the emergency room?	65% (20/31)	6.0	5.2
How often you are in hospital?	68% (21/31)	5.0	4.6
How much oxygen you need?	52% (16/31)	5.0	4.8
How often you need to see the lung specialist?	81% (25/31)	6.0	5.5
<b>CONCEPTS RELATED TO DIAGNOSTIC STUDIES</b>			
How well your doctor says you are doing?	96% (28/29)	6.5	6.1
How good the results of your chest xray or chest scan are?	100% (31/31)	7.0	6.3
How good the results of your breathing tests (PFTs) are?	97% (30/31)	7.0	6.2
How good the result of your lab tests are?	100% (31/31)	7.0	6.2
How good the results of your heart tests are?	97% (30/31)	7.0	6.3

**Table 4**

Items of the post focus group questionnaire most important to patients with CTD-ILD – results of the cluster analysis. ‘Important’ was defined as a rating of 4–7 (moderately to extremely important) on a Likert scale of 1–7.

Precipitated Items in Order of Descending Importance	Item important (Number of Ratings 4–7/Number Responses)	Median	Mean
How Good Results of Your Chest Xray or CT Scan Are	100% (31/31)	7.0	6.3
How Well You Are Able to Care For Yourself	100% (29/29)	7.0	6.3
How Good Results of Your Blood Tests Are	100% (31/31)	7.0	6.2
How Good Results the Results of Tests For Your Heart Are	97% (30/31)	7.0	6.3
How Good Results of Your Breathing Tests Are	97% (30/31)	7.0	6.2
How Much You Are Enjoying Life	97% (30/31)	6.5	6.2
How Well Your Doctor Says You Are Doing	96% (28/29)	6.5	6.1
How Short of Breath You Are	91% (28/31)	6.5	6.0
How Much Your Health Care Costs	84% (26/31)	6.0	5.5
How Often You Need Your Lung Specialist	81% (25/31)	6.0	5.5