



Divided By a Common Language: Challenges in Physician–Patient Communication Limit Patient Understanding and Support in Systemic Sclerosis with Interstitial Lung Disease (SSc-ILD)

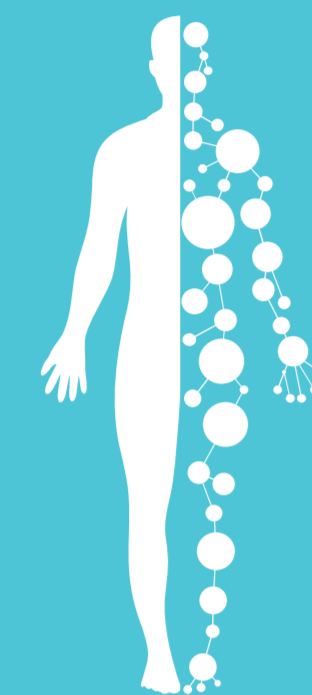


CP Denton,¹ B Laird,² L Moros,³ JL Luna Flores³

¹Royal Free Hospital, London, UK; ²The Research Unit, UK; ³Boehringer Ingelheim, Ingelheim, Germany

INTRODUCTION

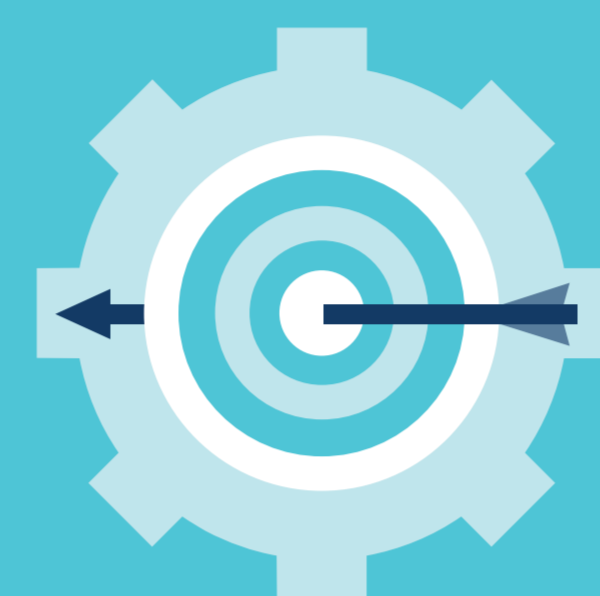
- Brain**
Fatigue / Depression / Anxiety
- Heart**
Heart disease
- Kidney**
Kidney disease
- Skin**
Raynaud's phenomenon / Skin fibrosis / Digital ulcers



- Lungs**
Interstitial lung disease (ILD)
Pulmonary hypertension
- Vascular**
Raynaud's phenomenon
Digital ulcers
Pulmonary hypertension
- Gastrointestinal**
Reflux / Diarrhea
- Nervous system**
Pain

- SSc is a complex and rare condition
- It can be difficult for physicians to explain the disease and its treatment without using complicated medical terms
- Patients are often left feeling uncertain

AIMS



- Observe how physicians and patients with SSc-associated ILD communicate
- Assess mutual understanding and identify information gaps

METHODS



- 23 consultations, directly observed and recorded, were assessed
 - Rheumatologists / pulmonologists and SSc-ILD patients (19 real, 4 actors)
 - 5 countries
- Patients: 34 to 79 years

RESULTS

CONSULTATION PATTERN

During effective consultations

- Patients were first invited to tell their story, and then guided by physicians to provide the necessary clinical information
- Physicians expressed empathy, built rapport and checked patients' understanding

However, in many consultations

- Physicians:
 - Directed the conversation so patients had little opportunity to explain their concerns or ask questions
 - Sometimes asked more than one question at a time, confusing the patient and giving the impression that they were in a hurry
 - Sometimes did not give patients the chance to answer a question

USE AND MEANING OF LANGUAGE

Physicians talking to patients

- Used medical terms when describing complicated points
- Used unemotional and matter-of-fact language
- Used metaphors, which helped to give patients a clear understanding

Patients talking to physicians

- Used functional and factual language, unless the physician demonstrated emotional empathy
- Responded to questions rather than sharing the whole story
- Used medical terms without full understanding (meaning physicians may over-estimate the patient's knowledge)

COGNITIVE MODELS

Patients' understanding of SSc-ILD differed from the medical model of the disease and was often only partly correct

- Physicians and patients had different ways of understanding SSc-ILD
- This affected how patients interpreted information and caused misunderstandings between them and their physicians

DIRECT QUOTES

Demonstrating empathy:

Patient: "Yes, I kind of get, you know, all the symptoms possible".
Doctor: "A little overwhelming, I'm sure, right?"

Regarding the consultation pattern:

"He was talking non stop."
"He had his things to say. He did not stop to listen to what I was saying."
"Sometimes I see him writing in the computer and he asks 'And how have you been?' And he keeps writing."

Demonstrating rapport building:

Doctor: "Do you live by yourself or with family?"
Patient: "I live with my daughter, my seventeen year old."
Doctor: "That's a headache. I'm sorry, I have kids too."
Patient: "Oh my God. I agree, totally. I just can't wait until she's off to college. I mean, I need a vacation."
Doctor: "Okay, uh-oh. I won't tell her you said that."

Regarding the use and meaning of language during the consultations:

"If [doctors] use technical terms, it's beyond me, but a lot of them do that... It used to be like that – I went to lots of doctors and they told me all sorts of things but I didn't know what they meant, but then I found out for myself."
"Of course [the doctor] assumed a lot of knowledge in me, about scleroderma... and also the lung involvement, he also used many specialist terms like fibrosis, lung fibrosis, of course he also wanted a lot of specialist knowledge from me."

Illustrating their understanding of SSc-ILD:

"My body produces too much collagen, it's hard to explain. There are deposits and that is what causes everything to swell, especially the oesophagus, it gets narrower. [The lungs] harden because of the collagen deposits, they get swollen, and this stops them from working properly."
"[The doctor] said it is a congenital disease, it is not because of something I had done or hadn't done to develop this disease, she said that the body itself rejects those cells or something like that..."

CONCLUSIONS



- Communication between patients with SSc-ILD and physicians is sometimes poor, and this could mean:
 - Physicians may not always recommend treatment that is best suited to each patient
 - Patients may have reduced awareness of how best to manage their condition
- These findings are consistent with those from other recent studies¹⁻³
- Consultation success is optimized when physicians:
 - Give patients the opportunity to tell their story
 - Express empathy, build rapport and check understanding
 - Use metaphors to aid patient understanding
- Physicians should develop strategies to facilitate effective communication



References

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