

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

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INTRODUCTION

- Systemic sclerosis (SSc) is a complex and rare condition.
- It can be difficult for a physician to explain prognosis and treatment options without complicated medical terms, making it hard for patients to understand.
- As a result, patients can feel uncertain about their future, or the best treatment options available to them.

AIM

- To observe how physicians and patients with SSc-associated interstitial lung disease (SSc-ILD) communicate with each other.
- To assess mutual understanding and identify information gaps and needs.

METHODS

- Twenty-three, 20-minute consultations between physicians (rheumatologists, pulmonologists) and patients with SSc-ILD (19 real, 4 actors) across 6 countries: Germany, Italy, Japan, Spain, UK and USA.
- Patients ranged from 34 to 79 years of age, and duration of disease between 1 to 29 years.
- Consultations were directly observed and video/audio recorded.
- ILD associated with SSc (limited/diffuse cutaneous involvement) of all severities, with a range of other organ involvement, was represented.
- None of the patients or physicians were known to one another.
- Consultations were analysed using linguistic techniques based on interactional sociolinguistic discourse analysis to determine:
 - The pattern and meaning of communication;
 - Whether the needs of both participants were met;
 - The level of understanding between participants.

RESULTS

- Analysis found that factors inhibiting effective physician-patient communication fell into three main categories:



1. CONSULTATION PATTERN

- During effective consultations, patients were invited to tell their story, then guided by physicians as they gathered clinical information.
- These physicians used techniques to check and demonstrate understanding, express empathy and build rapport.

Direct quotes demonstrating empathy:

“Patient: Yes, I kind of get, you know, all the symptoms possible.
Physician: A little overwhelming, I’m sure, right?”

Direct quotes demonstrating rapport building:

“Physician: Do you live by yourself or with family?
Patient: I live with my daughter, my seventeen year old.
Physician: 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.
Physician: Okay, uh-oh. I won’t tell her you said that.”

However, in many consultations:

- Physicians solicited the patient’s story, but quickly diverted the course to extract clinical information.
- Physicians sometimes asked more than one question at a time, confusing the patient and giving the impression that they were in a hurry.
- Physicians sometimes asked a series of questions, then answered them on behalf of the patient.
- In some cases, physicians reordered the sequence of a patient’s story as the consultation proceeded to fit their knowledge of SSc.
- Even patients who had been diagnosed for many years had a limited understanding of the disease process and how their symptoms fitted together.
- In many consultations, patients were given little opportunity to explain their concerns or ask questions.

Direct patient quotes 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.”



2. USE AND MEANING OF LANGUAGE

Physicians talking to patients

- Physicians typically tried to use plain language to describe complex concepts, but often started using medical terms when the description became more complicated (e.g. if asked to explain what SSc is and how it fits together).
- Physicians’ language tended to be unemotional, matter-of-fact, lacking imagery and metaphor.
- When metaphors were used, it helped to give patients a clearer understanding of the issue being discussed.

Patients talking to physicians

- Patients’ language tended to be functional and factual, unless the physician demonstrated emotional empathy (this elicited more emotional language from the patient).
- Overall, patients’ tone was physician-led, influenced by the questions they asked and the way they asked them.
- The focus was on providing information that the physician was seeking, rather than sharing their whole story.
- Patients often used medical terms without fully understanding them.
- As a result, physicians incorrectly assumed that the patient knew more than they actually did.

Direct patient quotes regarding the use and meaning of language during the consultations:



“If [physicians] 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 physician] 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.”



3. COGNITIVE MODELS

- Patients’ understanding of what SSc-ILD is differed from the medical model of the disease.
- Patients’ beliefs about causes, symptoms and transmissibility were often only partly correct or based upon misconceptions.
- Physicians and patients had different ways of understanding SSc-ILD, based on their knowledge, experiences, expectations and beliefs.
- This affected what information patients shared and how they interpreted information provided by physicians.
- Differences in cognitive models between patients and physicians were responsible for misunderstandings.



“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 physician] 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 challenges between patients and physicians limit bidirectional understanding of SSc-ILD and the patient experience, which could mean:**
 - Both parties missing important information.
 - Patients being less aware of self-help management approaches.
- These findings are consistent with those from recent studies in France² and Canada³, as well the results of a 2016 systematic review published in the Journal of Rheumatology.⁴**
 - Patients expect physicians to be knowledgeable about their condition, but also human and attentive. More attention should be paid to improve patient-physician relationships.²⁻⁴
- As demonstrated by the consultations in this study, consultation success is optimised when physicians:**
 - Give patients the opportunity to tell their story.
 - Use techniques to check and demonstrate understanding, then express empathy and build rapport.
 - Use metaphors to aid patient understanding.
 - [On muscle affected by SSc] “It’s like wood.”
 - [The lower lungs are] darker alleys, with constriction and small spaces, and instead of a balloon that you can push on, there are just more rigid walls, with some very narrow areas.”
- Strategies should be developed with physicians to facilitate effective communication and increase patient understanding and support.**

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Acknowledgments

This study was supported by Boehringer Ingelheim. The authors acknowledge and thank all the participants involved. Medical writing assistance was provided by Hamell Communications, UK, and was sponsored by Boehringer Ingelheim.

Printed at 9th European Conference on Rare Disease & Orphan Products, 10–12 May 2018 in Vienna, Austria