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INTERACTIVE

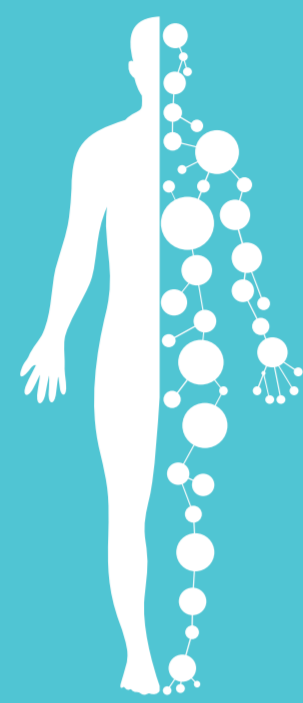
Things Left Unsaid: Important Topics Not Discussed During Systemic Sclerosis Consultations: Impact On Patients And Caregivers

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INTRODUCTION

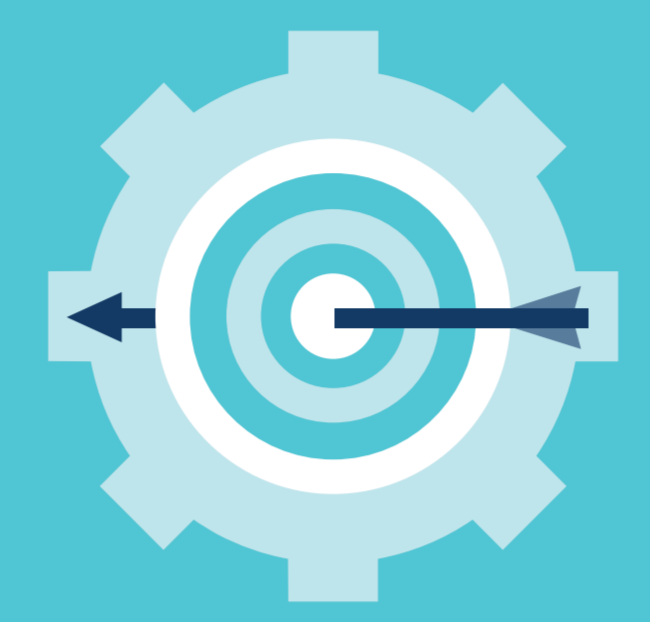
- Brain**
Fatigue / Depression / Anxiety
- Heart**
Heart disease
- Kidney**
Kidney disease
- Skin**
Raynaud's phenomenon / Skin fibrosis / Digital ulcers



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

- SSc, also known as scleroderma, is rare, complicated and unpredictable
- Physicians and nurses may be unsure how best to explain the disease and its treatment
- We explored discussions between healthcare professionals and patients / caregivers regarding SSc-ILD

AIMS



- To explore and identify the information and communication needs of patients with SSc-ILD and their caregivers, and how these needs could be addressed

METHODS



- Conversations between healthcare professionals and patients / caregivers were observed and recorded:
 - 42 physicians
 - 21 patients
 - 16 specialist nurses
 - 5 caregivers
 - 5 countries

RESULTS

TOPICS PATIENTS, CAREGIVERS AND HEALTHCARE PROFESSIONALS ARE MOST LIKELY TO REFRAIN FROM TALKING ABOUT

Unspoken topics were mainly about the future course of the disease

Patient and caregivers' perspective

- Felt afraid to ask physicians and were unsure how to ask
- Wanted a plan for managing the disease (at the time of diagnosis)
- Wanted certainty and predictability
- Needed reassurance that the physician was in control
- Experienced lack of dialogue on future course of disease, which resulted in frustration and fear

Physicians' perspective

- Found these issues difficult to address, particularly in the early stages of the disease
- Tried to avoid such questions for fear of causing distress
- Found difficult to predict what the individual patient's disease course will be
- Found difficult to give a management plan early due to unpredictability of the disease

Nurses' perspective

- Were available and willing to talk but often did not feel adequately informed or knowledgeable
- Saw this as the physician's responsibility

THE 'WHITE COAT BARRIER' BETWEEN DOCTORS AND PATIENTS

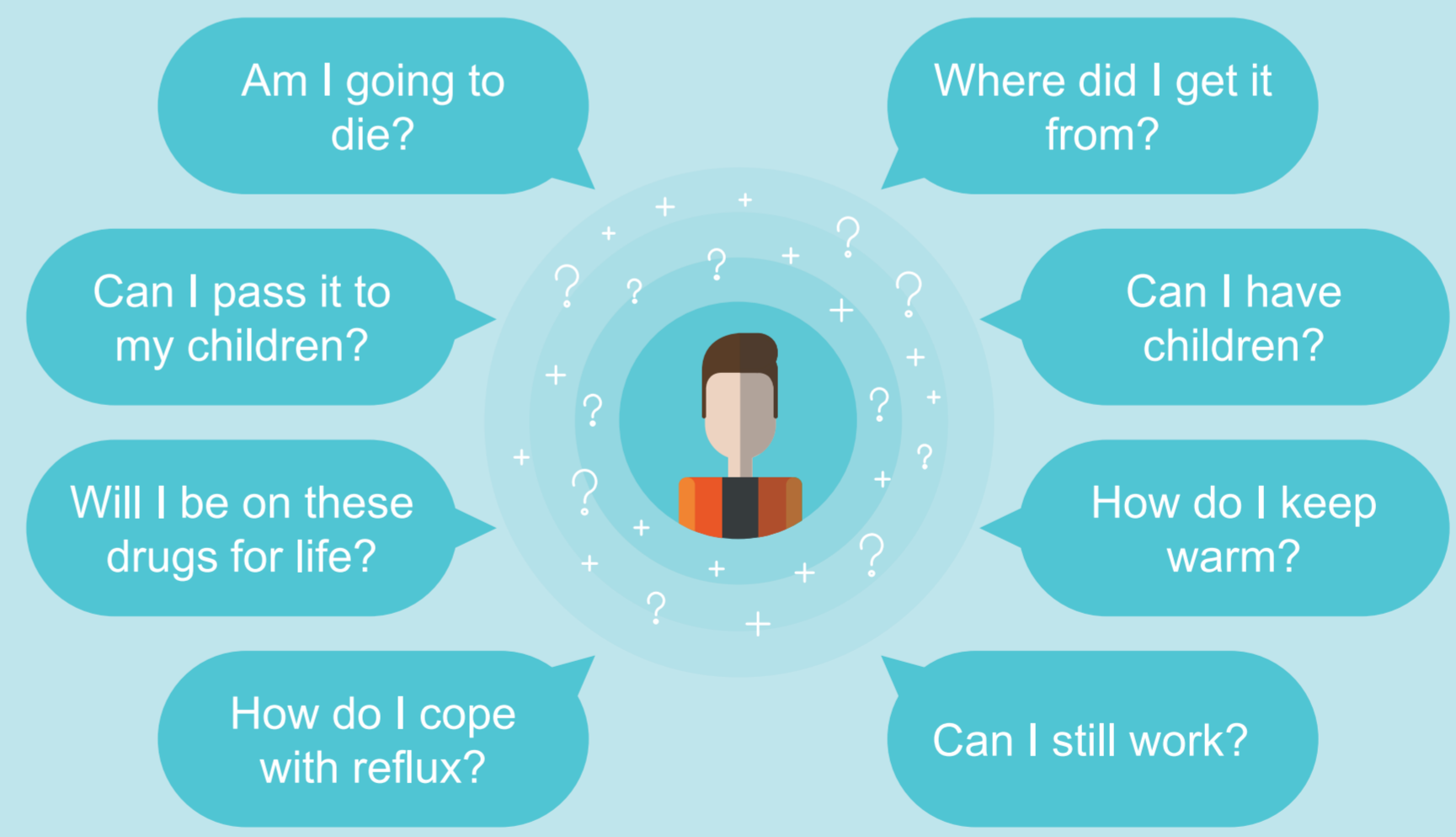
Patients sometimes felt too intimidated or embarrassed to ask about:

- Work
- Eating and drinking
- Exercise
- Pregnancy and children
- Intimacy and sexuality
- Altered appearance
- Holidays

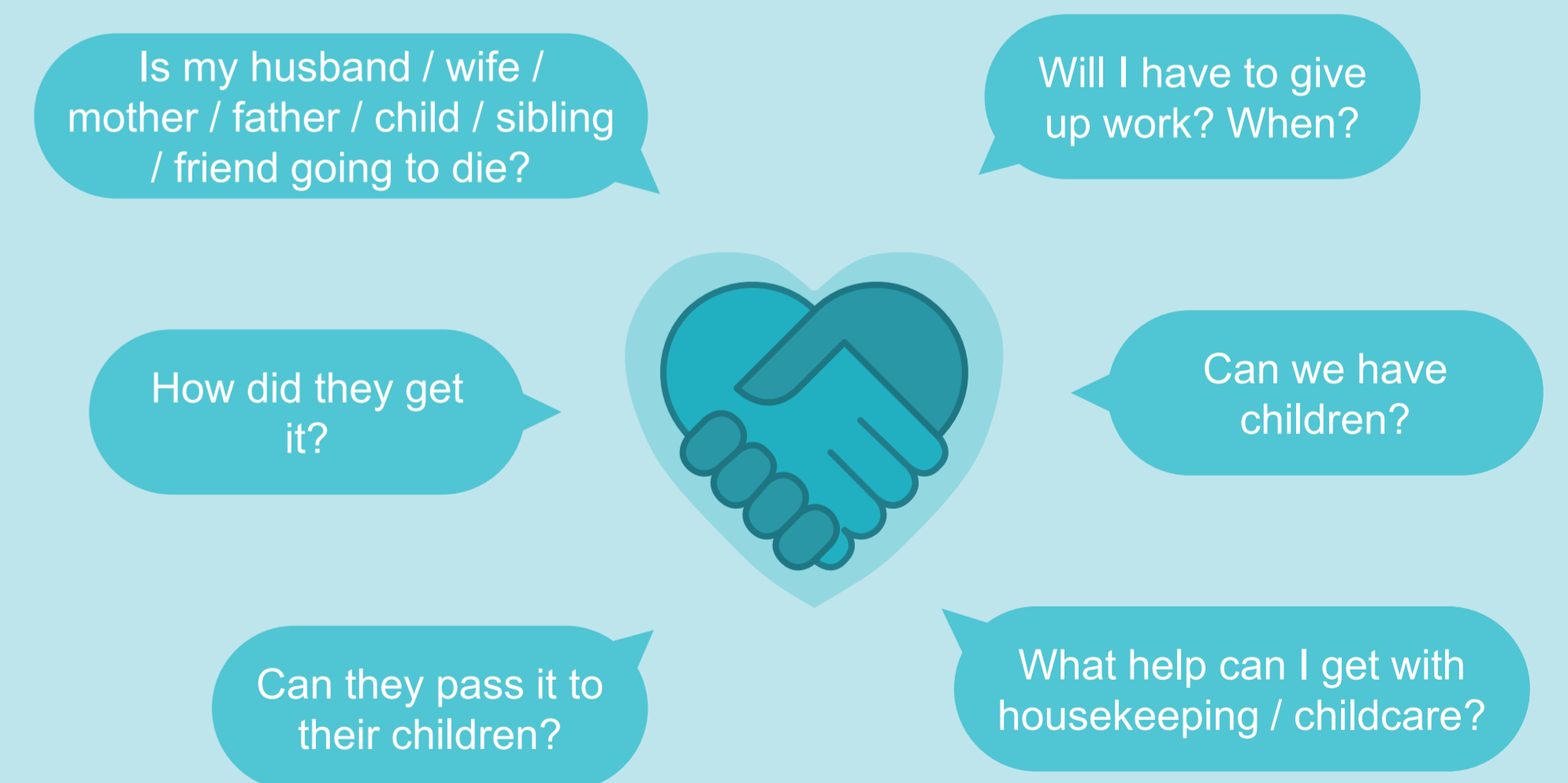


Members of the healthcare team can help break down barriers, but they need enough disease knowledge

KEY PATIENT QUESTIONS



KEY CAREGIVER QUESTIONS



CONCLUSIONS

- Death and disease course are important topics which are not very often discussed, but are the most relevant for patients with SSc-ILD and their care team
- This creates uncertainty about the future and leaves patients less equipped to manage their disease

- Physicians and nurses could help patients / caregivers by proactively raising these difficult issues

- If healthcare professionals use a team-based approach, communications may improve



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