

Illuminating the Patient Perspective: What Healthcare Professionals Should Know About Living With Nontuberculous Mycobacterial Lung Disease

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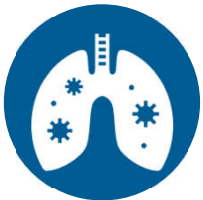
Survey Purpose and Methods



- Information is lacking on the experience of patients living with nontuberculous mycobacterial (NTM) lung disease



- A survey was offered to adult patients in partnership with the patient advocacy group NTM Info & Research in September 2021



- Survey focused on key NTM lung disease clinical characteristics:
 - Qualification and ranking of symptoms
 - Healthcare provider usage for care
 - How care could be improved
 - Impact of COVID-19 on care

Survey Results: Patient Characteristics



Among
97
respondents,
91.8%
were female and
mean age was
62 yr



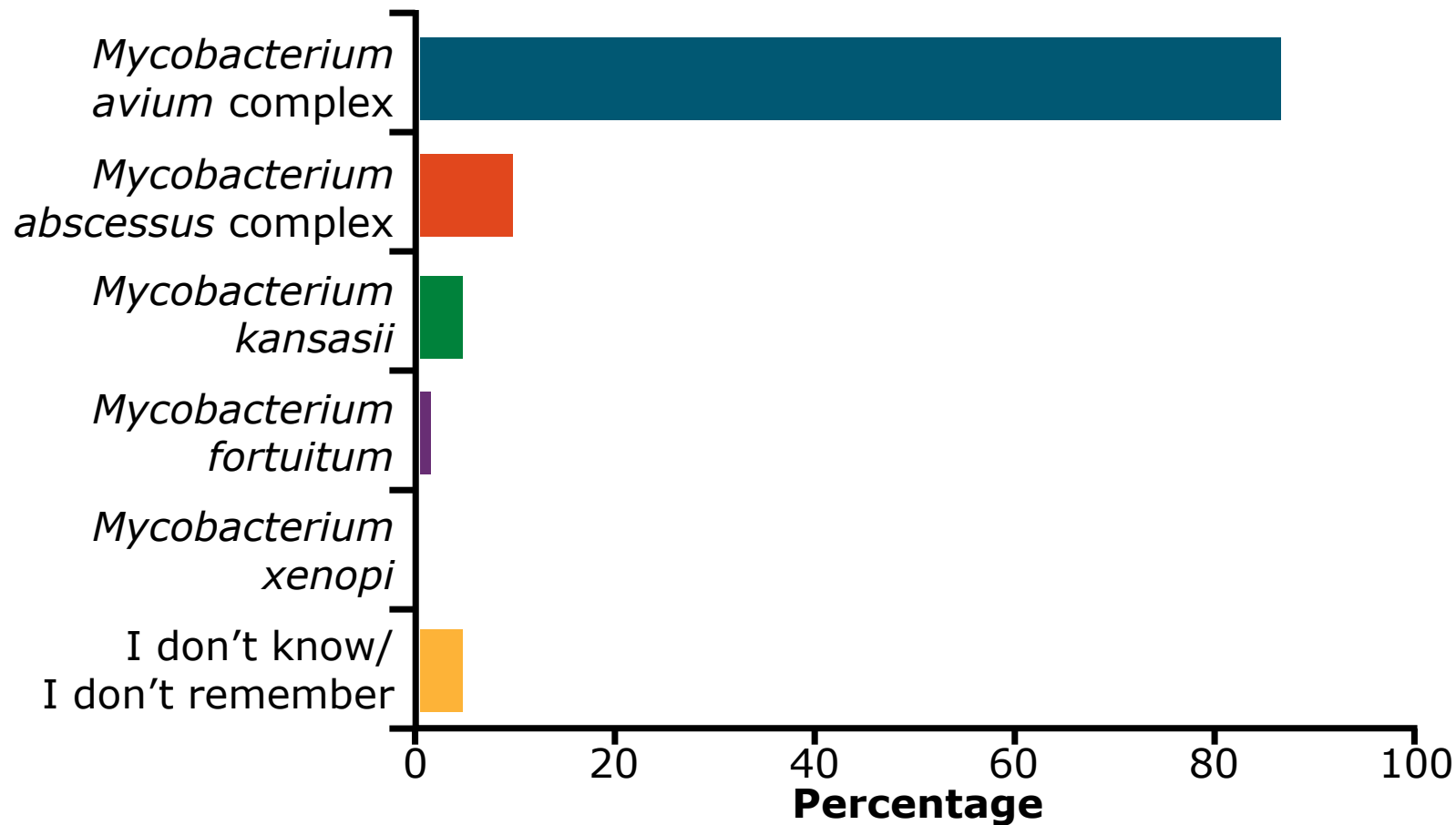
Of those who
responded,
96.5%
(57/59) received
care from a
specialist, with
30.5%
(18/59) accessing
care from a
respiratory therapist



**COVID-19 did not
significantly
impact care in
53.5%**
(31/58) but nearly
one third (**31.0%**;
18/58) said that the
pandemic made
care **more difficult**

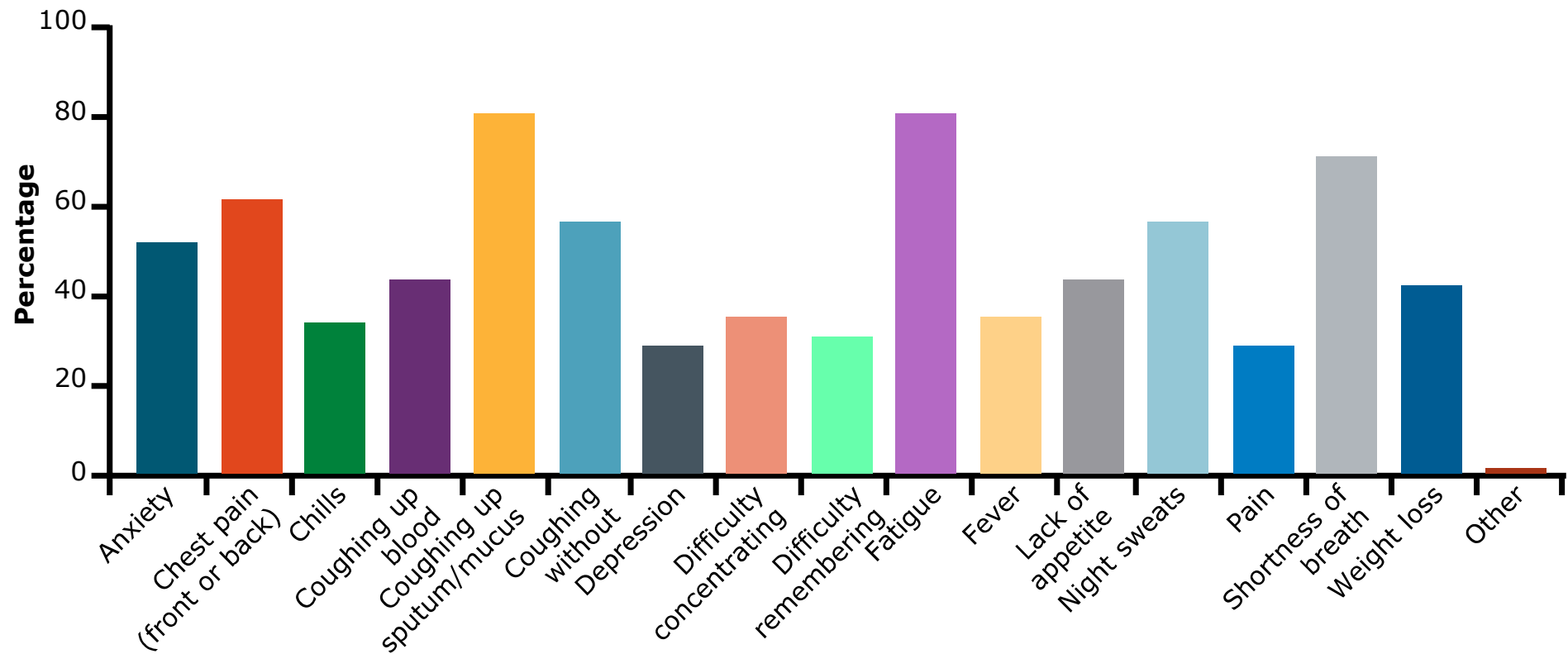
Survey Results: Mycobacterial Characteristics

- 86.9% infected with *Mycobacterium avium* complex



Survey Results: Symptoms

- Coughing up sputum and mucus (81.7%) and fatigue (80.0%) most frequently reported symptoms
 - **Fatigue** ranked **most bothersome** symptom followed closely by coughing



Survey Results: Patient Desires for Care Improvements

- Earlier diagnosis of NTM lung disease
 - *"I should have been investigated and diagnosed 8 years ago."*
 - Better education of general practitioners
- Sooner evaluation by specialists
 - *"Finding knowledgeable doctor who can diagnose and treat this disease is a maze until you are lucky enough to find the right one."*
- Shorter, better-tolerated treatment courses
 - *"More options than a 12- to 18-month course of antibiotics."*
- More patient and provider education about the disease and treatments
 - *"More educational awareness of the symptoms and impact and seriousness of NTM by both physicians and employers."*

Survey Conclusions and Clinical Implications

- In a largely North American cohort of female respondents older than 60 yr of age with NTM lung disease, *Mycobacterium avium* complex infection is the most common self-reported pathogen, and antibiotic use is frequent
- Cough and fatigue are the most frequently reported and most bothersome symptoms
- Respondents would like to be diagnosed sooner, have access to more efficacious and shorter treatment courses, and be provided more information
- Understanding the patient's perspective is key to being better informed about the experiences of patients with NTM lung disease