

Symptom burden among patients reporting nontuberculous mycobacteria (NTM): Findings from the COPD Foundation Survey

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BACKGROUND

The burden of symptoms that patients with nontuberculous mycobacterial lung disease (NTMLD) or infection can experience remains underreported. These data may contribute to design future investigations of individuals diagnosed with NTM infection or disease.

OBJECTIVE

To determine the proportion of NTMLD patients with NTMLD who reported symptoms and quality of life impairments. We also sought to determine the proportion of patients reported being troubled by these symptoms or impairments.

METHODS

The COPD Foundation developed the website BronchandNTM360social based on their COPD360 social community. The “Burden of NTM Survey” was developed by the COPD Foundation and posted on the website from September 12, 2016 through January 11, 2017. Respondents were limited to those patients reporting that they had been diagnosed with NTMLD. The survey participants were asked about experiencing twelve symptoms during the past two weeks including cough, cough up blood/phlegm/mucous, fatigue or lack of energy, sleep problems, feelings of sadness or depression related to illness, difficulty in walking 500 meters without stopping, difficulty in interacting with others, difficulty with sensitivity to cold or heat, difficulty with fever, chills, or night sweats, and experiencing body pain. The survey participants were also asked about taking any medication to treat their NTMLD, their age group, gender, residence, duration of living with NTMLD, and experiencing selected comorbidities.

The analysis was carried out using SAS 9.4. Descriptive statistics of the study sample as well as the rank-based nonparametric tests were used to assess whether there were differences in the number of self-reported symptoms among gender and age groups. Moreover, the differences among four U.S. regions were examined for those patients who resided in the U.S. Two-sided p-values ≤ 0.05 were considered statistically significant.

RESULTS

Data were available from 266 individuals reporting an NTMLD diagnosis. The majority (n=250, 95.06%) of respondents were aged 50 or older, of female gender (n=244, 93.1%), had an on-going NTM lung infection (n=190, 73.9%), were living with NTMLD for more than 5 years (n=142, 55.7%).

The proportion of respondents reporting symptoms and being troubled often (at least 6 days in the prior 14 days) by these symptoms is shown in Table 1.

Table 1. The burden of the self-reported symptoms.

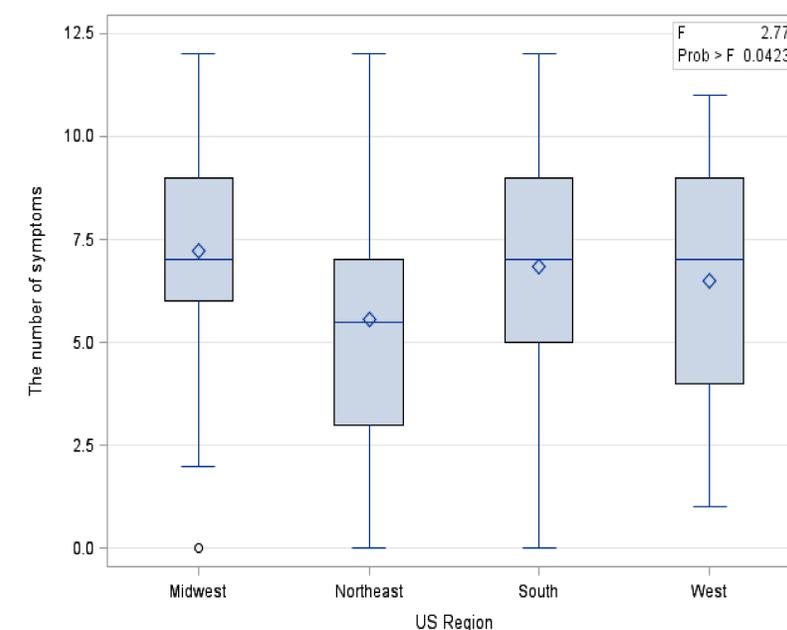
# Responded	Symptom during the past 2 weeks	Reporting Any	Troubled Often or Daily
		(% of those who responded)	
251	Cough	80.9	61.0
252	Cough up blood, phlegm, mucous	59.5	45.2
250	Shortness of breath, wheezing or other breathing difficulties	68.8	51.2
249	Fatigue or Lack of Energy	81.1	60.6
247	Loss of appetite	34.8	23.9
246	Sleep problems	61.4	45.9
246	Feelings of sadness or depression related to the illness	55.3	31.3
247	Difficulty in walking 500 meters without stopping	40.5	32.0
245	Difficulty in interacting with others	39.6	26.1
242	Difficulty with sensitivity to cold or heat	64.1	41.3
245	Difficulty with fever, chills, or night sweats	37.6	22.4
243	Experiencing pain in body	49.4	37.0

The Kruskal-Wallis H test indicated that there were no statistically significant differences between the medians of the number of self-reported symptoms neither between women and men ($\chi^2 = 1.4436$, $p = 0.2296$) nor between two age groups of less than or equal/more than 50 years old ($\chi^2 = 2.9870$, $p = 0.0839$).

For the subsample of the U.S. patients only (n=235), statistically significant differences ($\chi^2 = 8.7104$, $p = 0.0334$) among the medians of the number of self-reported symptoms were observed among four U.S. regions representing the place of residence.

Also, those patients who were from the Midwest had reported a higher mean number of symptoms ($\mu = 7.1$), followed by patients from the South region ($\mu = 6.8$), the West ($\mu = 6.5$), and finally from the Northeast region ($\mu = 5.5$).

Figure 1. Distribution of the number of self-reported symptoms by the region of residence in the U.S.



CONCLUSION

The findings of this study suggest that there were no significant gender or age differences in the medians for number of self-reported symptoms, whereas statistically significant differences were observed among the U.S. patients from different geographical regions. The symptom burden among patients is high, with many patients reporting symptoms that bother them frequently.

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