

Respiratory disease terminology: Discordance between pulmonologists and patients

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ABSTRACT

Context: A number of local dialects and languages exist in India, which leads to a single disease being addressed by a number of names which may overlap with other disease names also. This creates misunderstanding and is a hindrance to effective patient–doctor communication. **Aims:** The paper aims to find out how effectively the name of the respiratory disease is communicated to the patient. The terminology used by patients to describe their disease was also noted at limited level. **Settings and Design:** The study was conducted in the form of parallel cross-sectional surveys, among pulmonologists and patients. **Methods:** Among the members of the Indian Chest Society and those attending the National Conference on Pulmonary Diseases (NAPCON-2015), 1028 pulmonologists participated in the online survey which was the first part of the study. The term used to address the common respiratory disease was inquired in the survey. To find the response of patients, a questionnaire was given to the patients attending four respiratory disease clinics of a city. They were inquired about the name of respiratory disease they were suffering from. **Results:** Pneumonia was the disease which was communicated with exact terminology by 898 (87.4%) doctors to their patients. In contrast, idiopathic pulmonary fibrosis was communicated with precise terminology by only 171 (16.6%) doctors. Pulmonary tuberculosis was exactly told by 708 (69%), asthma by 731 (71.1%), and chronic obstructive pulmonary disease by 593 (57.7%) doctors. However, only 17.6% of the 1122 patients participating in the survey had a knowledge of the name of disease they were suffering from. **Conclusions:** The exact terminology of the common respiratory diseases is not effectively used by many doctors and most of the patients. The study identifies an important gap in patient–doctor communication, and therefore, highlights the need of effective patient education.

KEY WORDS: Respiratory disease epidemiology, respiratory disease name, respiratory disease survey, respiratory disease terminology

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INTRODUCTION

Disease outcomes may be adversely affected by ineffective doctor–patient communication.^[1] Although the medium of medical education in India is English, local or translated name of most of the diseases is used in communication which varies according to the large number of languages and dialects spoken in the

country. This leads to medical terminologies being lost in the process of translation. Knowledge of the name of disease is the basis of disease understanding. However, the terminology communicated to the patient varies and this disparity leads to many diseases being referred to by same names. For example, bronchial asthma is known by names such as “dama” and “swas.” Similarly, chronic

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obstructive pulmonary disease (COPD) is also known by similar terms “dama” and “swas.” When a patient is asked about his disease, most of the times, he is unable to tell or he may communicate a name representing many diseases. Therefore, disease terminology communicated by a patient during history taking may become unreliable. Knowledge of disease terminology is valuable for the pulmonologists to diagnose the disease on a follow-up visit when earlier prescription is lost. It also saves the consultation time in diagnosis of the disease and repetitive and unwarranted investigations.

Use of proper terminology is also important in research surveys. In the absence of knowledge of standard terminology, the result of questionnaire surveys used in regional languages may also become less accurate. The problem of doctor–patient language discordance has been documented in many countries though the studies were conducted in the patients of nonrespiratory diseases.^[2-4] It has been shown that language discordance is responsible for prolonged hospital stay,^[5] inappropriate medical care,^[6] poor compliance,^[7] and patient dissatisfaction.^[8] Data with regard to the magnitude of the problem of nonuse of exact terminology of the disease are limited in India. This study was planned to assess the accuracy of the disease terminology used by doctors and patients.

METHODS

This was a cross-sectional survey with pulmonologists. Members of Indian Chest Society and registered delegates for NAPCON, Jaipur, 2015 participated in the survey which was conducted from September 05 to November 07, 2015. The participating doctors were chest physicians and resident doctors of chest department. E-mail and text messages were used to contact pulmonologists from all throughout India. The survey was also conducted at a display stall during the conference. Google online survey was used to generate and display the survey form. The link to the online questionnaire was sent to participants through E-mail and text messages. Reminders were also sent with the help of four text message alerts and two E-mails. One thousand and twenty-eight doctors responded to the survey. They were asked what name they communicate to the patient for the five respiratory diseases such as pulmonary tuberculosis (PTB), asthma, COPD, idiopathic pulmonary fibrosis (IPF), and pneumonia.

In the second part of the study, we wanted to know the responses of the patients of same diseases on pilot basis. Therefore, we chose the city with highest number of respondents in the doctors' survey [Table 1]. The pulmonologists who had a busy clinic were identified. Eleven doctors were qualified and they were invited to participate in the study. Four doctors volunteered to participate in the study. The questionnaires were given to consecutive patients of four respiratory diseases attending outpatient clinics of the participating doctors for 15 days. The name of the disease was inquired with the help of

nonleading and descriptive questions. Data were collected from 1122 respiratory disease patients.

Statistical analysis

Frequencies and percentages were calculated for the nominal variables. Sensitivity, specificity, and positive predictive values were calculated for the terms used to refer to the common respiratory diseases.

RESULTS

One thousand and twenty-eight pulmonologists and 1122 patients participated in the parallel cross-sectional surveys. Results of the survey filled by the pulmonologists are given in Figure 1. The terminology lung tuberculosis (TB) was told to the patients by 708 (69%) doctors. Other responses were name in local language by 168 (16.4%), Koch's disease by 73 (7.1%), lung infection by 21 (2.04%), and chronic lung infection by 14 (1.4%) doctors. The common terms used for bronchial asthma by doctors were asthma - 731 (73.1%), name in local language - 103 (10.01%), allergic bronchitis - 64 (6.2%), asthmatic bronchitis - 85 (8.3%), wheezy bronchitis - 11 (1.07%), and other names - 34 (3.3%). For COPD, the common terms used were COPD - 593 (57.7%), smokers bronchitis - 166 (16.1%), name in local language - 146 (14.2%), others - 52 (5.05%), chronic bronchitis - 36 (3.5%), and emphysema - 20 (1.9%). IPF was addressed as lung fibrosis - 406 (39.5%), IPF - 227 (22%), interstitial lung disease (ILD) - 171 (16.6%), lung scarring - 91 (8.8%), name in local language - 98 (9.5%), and others - 35 (3.4%). Pneumonia was termed as pneumonia by 898 (87.4%), name in local language by 51 (5%), respiratory disease by 33 (3.2%), breathing problem by 8 (0.8%), and other names by 38 (3.7%) doctors.

In the second part of the study, 1122 patients participated, 706 males and 416 females. The mean age of the patients was 45.17 ± 20 years. There were 547 patients with asthma, 290 with COPD, 207 with PTB, and 78 with ILD [Table 1]. 23.21% patients with asthma, 0.34% patients

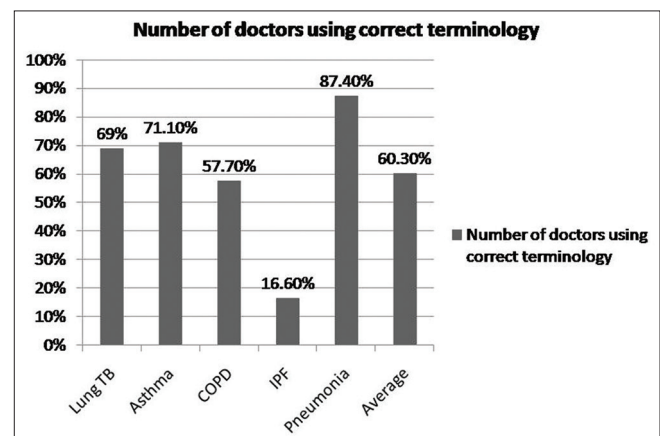


Figure 1: Use of correct terminology to refer the disease name by the doctors to the patients ($n = 1028$)

Table 1: Names of common respiratory diseases used by patients

Diagnosis	Terminology used by patients (%)								
	Asthma	Dama	Swas	Cough	TB	ILD	COPD	Zukam	Others
Asthma (<i>n</i> =547)	127 (23.21)	9 (1.64)	204 (37.3)	120 (22)	1 (0.2)	0	0	32 (5.85)	54 (9.9)
COPD (<i>n</i> =290)	62 (21.4)	17 (5.9)	176 (60.7)	23 (7.93)	1 (0.34)	0	1 (0.34)	3 (1.03)	7 (2.41)
TB (<i>n</i> =207)	3 (1.44)	1 (0.48)	38 (18.35)	48 (23.18)	66 (31.9)	0	0	5 (2.41)	46 (22.22)
ILD (<i>n</i> =78)	17 (21.8)	0	33 (42.3)	17 (21.8)	1 (1.28)	4 (5.12)	0	0	6 (7.7)

COPD: Chronic obstructive pulmonary disease, TB: Tuberculosis, ILD: Interstitial lung disease

with COPD, 31.9% patients with TB, and 5.12% with IPF named their disease correctly. Table 2 shows positive predictive values of various layman terms used to refer these respiratory diseases.

DISCUSSION

Our study revealed that 60.3% pulmonologists told the exact terminology of the disease to their patients [Figure 1]. However, around 39.7% communicated name of the disease in nonstandard terminology or in local language. It is debatable whether to use exact terminology of the disease or to use translated or patient-friendly version of the name of disease. A doctor translates his knowledge, which was acquired in English, in local dialect to explain it properly to the patients. This process of translation has many fallacies and exact terminology of the disease may be changed. When the name of the disease is not effectively communicated, it causes ambiguity for a new doctor who treats the patient for the first time, especially if the doctor's understanding of the local terminology is also vague.

Only 17.6% patients communicated the exact terminology of the disease in our study [Table 2]. Knowledge of proper disease terminology forms the basis of understanding on the part of patient and is needed to ensure regular compliance to treatment to avoid often fatal complications.

In many surveys carried out for estimation of disease burden in the country, local name of diseases were used. In ISAAC^[9] and INSEARCH^[10] studies, word dama was used. Our study, however, showed the term “dama” had positive predictive values of only 33.3% for the disease asthma. “Swas” was the most common term used, but it had poor predictive values for either of the disease [Table 2]. Even use of term asthma is not specific to asthma because 21% of COPD and 22% of ILD patients described their disease as asthma. On the other hand, the terms asthma, COPD, TB, and ILD had high positive predictive values and specificity to diagnose the respective disease. Thus, these specific terms should be used in routine practice while referring to respiratory diseases; this practice will, in turn, improve the sensitivity of these terms. Subsequently, with a good sensitivity and specificity, these terms may be used in epidemiological surveys thereby avoiding under-diagnosis of these diseases.

Probably, people of India have been changing fast to adopt medical terminology during last decade. The patients

Table 2: Sensitivity, specificity, and positive predictive values for various terminologies used to refer common respiratory diseases

Term for disease	Sensitivity	Specificity	Positive predictive values
Asthma versus asthma	23.2	85.7	60.8
COPD versus COPD	0.3	100	100
TB versus TB	31.9	99.7	95.7
ILD versus ILD	5.1	100	100
Dama versus Asthma	1.6	96.9	33.3
Dama versus COPD	5.9	98.8	62.9
Dama versus TB	0.5	97.2	3.7
Swas versus asthma	37.3	57	45.2
Swas versus COPD	60.7	66.9	39
Swas versus TB	18.3	54.9	8.4
Swas versus ILD	42.3	59.9	7.3

COPD: Chronic obstructive pulmonary disease, TB: Tuberculosis, ILD: Interstitial lung disease

have started calling their disease asthma instead of dama or swas. In view of these results, use of translated disease terminology in Hindi in questionnaires of surveys should be discouraged. If used simultaneously, medical terminology should also be written in the parenthesis. These results may have limited value because the patient sample was from one city of Rajasthan only. However, it emphasizes the need to carry out a bigger study and to take countrywide data.

The problem of not knowing or using the correct disease terminology has been found in many studies. The term “wheeze” was interpreted differently by African-American adolescents and caregivers.^[11] Thus, use of such terms may cause misunderstanding. Our previous study of hospitalized patients also identified the lack of knowledge among patients about the disease they were suffering from.^[12]

A study conducted in Spain found that only 38% of the respiratory disease patients could identify the disease they were suffering from.^[13] Furthermore, a study conducted on 165 patients of COPD and asthma in the Netherlands found that 65% patients with asthma and 70% patients with COPD could correctly identify the disease.^[14]

Use of standard name of disease may be a step toward better understanding of the disease and help in overcoming barriers of patient–doctor communication. The name of a person or a place is never translated and it remains same and uniform worldwide. The ultimate goal is to implement the use of terminology as per the International

Statistical Classification of Diseases and Related Health Problems-10.^[15] It will lead to better communication between doctor and patient, and therefore, a better cost effective treatment. It will also enhance more effective communication over the telephone. It will also improve accuracy of questionnaire surveys.

Strengths and limitations

A limitation of the study was that the patient base was from limited centers (four) in one city only although the respiratory disease survey covered doctors from all throughout India. However, the number of patients ($n = 1122$) and doctors ($n = 1028$) participating in the survey were large, which was also the strength of the study. Another limitation is that the education and socioeconomic background of the participating patients were not known. Hence, the correlation between unawareness of disease terminology with both the factors was missed out. This was, however, a small pilot study and it may provide basis for the future large and multicenter studies; taking into account all these factors.

CONCLUSIONS

It is concluded that a communication gap exists between pulmonologists and patients regarding use and understanding of the terminology of the disease. The positive predictive values of the terms asthma, COPD, TB, and ILD are high. It is thus imperative to communicate the proper name of the disease and to motivate patients to use the exact name of disease during communication. The patient should be educated about the proper name during regular visits and through patient education programs as well.

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Conflicts of interest

There are no conflicts of interest.

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