

USE OF ASTHMA TERMINOLOGY BY XHOSA-SPEAKING PATIENTS IN SOUTH AFRICA – HOW IT AFFECTS ASTHMA-CONTROL QUESTIONNAIRES AND QUESTIONNAIRE-BASED EPIDEMIOLOGICAL STUDIES

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ABSTRACT

Background. Language and cultural differences between Xhosa-speaking patients and English-speaking health-care providers have been documented as factors causing miscommunication in the South African setting. Large epidemiological studies on asthma prevalence utilise questionnaires rather than direct assessment of asthma. Studies may be conducted in English with respondents not perfectly familiar with this language, or may utilise questionnaires that have been translated into a local language. Respiratory medical terminology may not be equivalently understood between the two groups. This may affect the validity of questionnaire-based assessment of the prevalence of asthma and wheezing.

Objectives. To describe differences in the definitions of common respiratory medical terminology by patients and doctors.

Design. In-depth, semi-structured interviews were conducted with three speech communities: 8 English-speaking doctors, and 33 Xhosa-speaking parents, with an education level of grade 12 or less and recruited from two areas in a paediatric teaching hospital, the short-stay ward and the allergy clinic. Definitions were elicited for common respiratory terminology in both Xhosa and English. Differences in the definitions of terminology were identified.

Results. Terminology is used differently by Xhosa-speaking patients and English-speaking doctors. Most Xhosa words were not part of the doctors' vocabulary, and some common English words were not part of the parents' vocabulary. Where words were part of the vocabulary of both groups, significant differences existed in the definitions, with many clinically significant discordances being apparent. For example, the word *asthma* is not used exclusively for a medical diagnosis of asthma. Words for asthma symptoms were also poorly understood by respondents, with the words *wheeze*, *shortness of breath* and *tight chest* being defined by only a minority of respondents in ways concordant with medical practitioners. This may lead to difficulties in communication and either falsely raise or decrease the prevalence of questionnaire-based assessments of wheezing and asthma, depending on the composition of the group interviewed and the language of the questionnaire.

INTRODUCTION

Medical terminology is not equivalently understood by doctors and lay people, with asthma terminology often being used imprecisely by English-speaking lay people.^{1,2} Communication problems and imprecise use of medical terminology may be more marked where providers and patients differ from each other in first language and culture. Words such as *wheezing* and (self-diagnosed) *asthma* are often used in questionnaire-based surveys of asthma prevalence. The word *wheeze* is poorly understood by patients whose first language is not English and patients from deprived communities.³ Concerns about the validity of using *wheezing* or *whistling in the chest* as a surrogate term for asthma were raised in the report on the results of the International Study of Asthma and Allergies in Childhood (ISAAC) 1.⁴ In addition the prevalence of 'asthma' in these surveys indicates either the levels of perceived or diagnosed asthma, neither of which may correlate with the prevalence of asthma were it to be measured rigorously in epidemiological surveys.⁵ Where asthma surveys are translated into other languages, they are ostensibly validated by translation into the target language and then (blinded) back-translation into English. Usually this is performed by medical professionals or language experts, rather than ordinary members of the speech community that they target.

In ISAAC 1, the prevalence of asthma on written questionnaires is higher in English-speaking countries than in countries using other languages. Additionally, a lower prevalence for wheezing is obtained when subjects are prompted by video scenes depicting wheezing rather than prompted by written questionnaires.⁴ The authors note a high prevalence in Spanish- and Portuguese-speaking countries in South America as well as variations in prevalence within language groups, citing this as evidence that language bias is minimal, but do not take into account that different factors (notably the degree of familiarity with medical terminology among different communities) may cause either non-recognition of a term (falsely decreasing recognition), or the term being used non-specifically (falsely increasing recognition).

Although many studies show concordance between written and video questionnaires,⁶⁻¹⁰ these are usually conducted in homogeneous populations with good socio-economic and educational backgrounds. In addition, studies looking not only at concordance, but using statistical measures, show only limited agreement between these modalities; a lower reported prevalence rate documented with the video questionnaire was not explained by differences between the two

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groups in language use, culture or literacy.^{11,12} In patients both with and without asthma, one-third to one-half of those who answered positively to written questions regarding *wheezing*, *current wheeze*, *wheeze on exercise* and *nocturnal wheeze* responded negatively to the corresponding scene in the video questionnaire. Pizzichini *et al.*¹¹ went on to calculate the measures of agreement in previously published studies and showed low agreement despite the reported good concordance between the two groups. Other studies have reported that the proportion of positive answers to the written questionnaire was higher than that obtained with the video questionnaire both in children of the same language^{7,9,11} and in children from different countries.^{7,13,14}

Validation has not been performed in many African settings. In an ISAAC study on eczema in Ethiopia, the conclusion was that the ISAAC questionnaire did not perform well.¹⁵ An ISAAC-based study¹⁶ in Maputo, Mozambique, utilised questionnaires in Portuguese, Ronga and Xangana. The authors cast doubt on the accuracy of translation of the Portuguese version of *wheeze*, *hay fever* and *eczema* and the Ronga translation of *eczema*.

In the South African results of both ISAAC 1 and ISAAC 3, the prevalence of wheezing is approximately double in questionnaire-based assessments versus video-based assessments (ISAAC 1: 16.0% vs 6.4%; ISAAC 3: 20.3% vs 11.2%).¹⁷ This difference is more marked than that found in many other countries. This suggests that the word *wheeze* may be used imprecisely by many respondents, falsely increasing the estimation of *wheeze* on written questionnaires. In South Africa, surveys are often undertaken in multiple languages. An asthma control test and a childhood asthma control test, both validated in English, have been translated into Afrikaans, Sesotho, isiXhosa and isiZulu. Research for ISAAC in South Africa was undertaken and recorded in four languages, English, Afrikaans, Xhosa and Northern Sotho.¹⁷ Differences were found between language groups (personal communication – Rodney Ehrlich), raising concerns as to whether language serves as a proxy for differences in class, ethnicity or social circumstances or whether language differences and different use of medical terminology affect the quality of the data.

Studies conducted in English have shown that parents' perceptions of the word *wheezing* differs from that of health care professionals. Cane *et al.*¹⁸ found that according to parents, *wheezing* was not restricted to an abnormal sound made by their children's chests. Only 36% of parents defined *wheeze* as a sound alone, of whom 11% mentioned 'whistling'. The others included features like difficulty in breathing, being unwell or a cough and 26% recorded only non-auditory responses. In a Swedish study comparing clinically diagnosed asthma with parental assessment of children's asthma in an ISAAC questionnaire,¹⁹ the written questionnaire identified only 54% of the children with a medical history of asthma and 40% of the children claimed by their parents to be asthmatic had no medical record of asthma. The conclusion, rather strangely, was that the ISAAC-based questionnaire (4.4%) provided an acceptable estimation of the prevalence of asthma by medical record (4.9%) although only half of the individual patients identified in this manner are the same as those diagnosed clinically!

In South Africa, the public health sector services patients mostly from lower socio-economic groups. At many hospitals staff communicate mainly in English or Afrikaans, while many patients speak Xhosa (or other African languages) as their first language. At Red Cross

War Memorial Children's Hospital, a paediatric teaching hospital in Cape Town, language issues are closely followed by socio-economic issues as major access barriers to good care for Xhosa-speaking patients and parents.²⁰ In a recent study only 6% of doctor-patient interviews were conducted partly or wholly in the patient's home language and of the remainder less than one-quarter were conducted with the aid of an interpreter.²¹

We report further on a linguistic study on the language used in this setting,^{22,23} In this study significant differences in the use of terminology between doctors and patients are demonstrated.

Methodology

The methodology of contrastive linguistic analysis used in this study has recently been fully described.²³ Briefly, semi-structured interviews were conducted with subjects in three groups: 8 English-speaking doctors; 17 Xhosa-speaking parents whose children were admitted to the short-stay ward for chest disease; and 16 Xhosa-speaking parents of children attending the allergy clinic for asthma. Respondents' definitions of medical and lay persons' respiratory terminology in both English and Xhosa were elicited. English-speaking doctors and Xhosa-speaking parents all defined the same list of terms in both languages.

The proportion of respondents in each group who were unable to attempt any definition of a particular word was used as a measure of how familiar each group is with the word. Differences in this measure were visible for words that were not part of the doctors' or parents' lexicons. The definition of each term was compared between the three groups to ascertain if they were being used similarly by different groups.

This article focuses on those terms relevant to the care of Xhosa-speaking asthmatics or terms used in asthma-monitoring questionnaires and epidemiological studies. The words chosen are listed in Table I.

Table I. List of words and phrases assessed in terms of groups' ability to give a definition

Asthma
Wheeze
Tight chest
Shortness of breath
Coughing
Isifuba
Ukukhohlela
Iphika
Ukutswina
Ukuminxana

Results

Differences were found in the frequency with which the three groups attempted any definition of the words at all. English-speaking doctors were unable to attempt any definition of the words *iphika* (shortness of breath), *ukutswina* (to wheeze) and *ukuminxana* (to have a tight chest) as they are not part of the doctors' vocabulary.

Xhosa-speaking parents (from the short-stay ward and the allergy clinic) were unable to attempt any definition of the English word *wheeze* which was not part of either parent group's vocabulary. Parents from the short-stay ward were not able to attempt any definition

of the English phrase *tight chest* but patients from the allergy clinic were familiar with the phrase and attempted its definition.

Both doctors and parents were able to offer a definition for the words *asthma/i-esma*, *coughing*, *isifuba* (chest), *shortness of breath* and *ukukhohlela* (to cough); however significant differences existed in the range of definitions. These differences are discussed below.

DISCUSSION

Isifuba

The word *isifuba* had three different senses when used by parents. Most literally it describes the anatomical chest. Secondly, it describes a constellation of signs and symptoms signifying chest disease, such as difficulty in breathing. Finally, it may be used loosely as a disease name for any chest illness with these signs or symptoms, which may or may not correlate with a medical diagnosis of asthma.

The following interviews were conducted in isiXhosa and then translated into English. In order to ascertain the meaning of terminology from context, the target word was not translated from the original and is in bold type.

Interview example 1

...**isifuba** differs, there is **isifuba se-esma** and there is **isifuba seTB**.

Interview example 2

Q: Is **isifuba** the same in everyone?

A: It's not the same because there's one of **ukuminxana** 'tight chest' and there's one that isn't.

Q: Which one isn't?

A: He is able to breathe, he doesn't get closed completely. Others get closed completely and can't breathe.

Q: So does he get closed?

A: Yes, he gets closed completely.

Q: So, **izifuba** (the plural form of *isifuba*) differ according to being closed?

A: Yes.

Doctors should not use the word *isifuba* as a disease name for parents as it does not convey any more meaning than 'a chest disease'. In particular, *isifuba* should never be used as a synonym for a medical diagnosis of asthma. In order to explain more fully the nature of the disease that the patient has, a specific medical term such as *asthma* or *pneumonia* should be appended to the word *isifuba*.

Asthma/i-esma

The word *asthma/i-esma* was defined by different parents in many different ways. Only a minority defined *asthma* in similar terms to what doctors consider necessary symptoms for a diagnosis of medical asthma. These parents defined *asthma/i-esma* as 'a disease of the chest/lungs with a closed chest causing difficulty breathing, wheezing and coughing, treated with pumps or oxygen and caused by heredity.' Other parents defined *asthma/i-esma* in ways that are not compatible with a medical diagnosis of asthma, showing that they are using it to refer to other chest diseases/symptoms. These parents are probably aware that some people use the word *isifuba* to refer to asthma (the medical diagnosis). But because they are unaware that *asthma*

is a specific chest disease they are 'back-translating' *asthma/i-esma* to mean what they define as *isifuba*, i.e. a non-specific constellation of chest symptoms and signs, rather than a specific illness.

Interview example 3

This mother is using the word *isifuba* as a generic sign of chest disease, similar to tight chest or respiratory difficulty. She feels *asthma* means the same thing and that her child therefore has *asthma*. In fact he has pneumonia.

In Groote Schuur they tried to explain to me what causes **isifuba**. They said, sometimes *isifuba* is caused by HIV, **isifuba** varies in children so I asked them to do an HIV test and the results came back negative. They discovered that she has **asthma** and that was it, they later said she has **pneumonia** and then they said **asthma** again...we Xhosa-speaking people refer to it as **isifuba** and doctors say it is **asthma**.

Q: Sisi, are you saying that **isifuba** is the same thing as **asthma**?

A: Yes, in my own opinion. I say my child has **isifuba**, that's how it has been referred since I grew up. They mean that a person's chest gets closed. When I came here they were using the word **asthma**, an English word.

Interview example 4

Another mother was asked to define *asthma*. She is unaware of any of the features of *asthma* but believes it is a synonym for *isifuba*:

... I've heard of **asthma**. I remember when... another woman... asked what was wrong with the child. I told her she has **isifuba**. She asked whether it was **asthma** and I said yes. That's when I deduced that it's **asthma**.

Q: How would you describe **asthma**? What happens to a person with **asthma**, what is it?

A: I don't know what it is.

Interview example 5

The following mother is using *isifuba* and *asthma* interchangeably, and seems to be referring to a medical diagnosis of asthma:

Q: So what is **isifuba**?

A: One closes up with difficulty in breathing properly. The air cannot pass through properly. The only thing that would help in order to breathe properly would be oxygen.

Q: What about **asthma**?

A: **Asthma** is **isifuba**.

Q: How different is **asthma** from **isifuba**?

A: They are not different.

Q: So are you saying **asthma** is therefore an English term for **isifuba**?

A: Yes, it is an English term.

During history-taking, a Xhosa-speaker who uses the word *esma*, may or may not be describing 'medical' asthma. Therefore further interrogation is necessary to see if this is medical asthma or simply a sobriquet for a generic chest disease. Further questions should ascertain whether a doctor or nurse has ever used the word *asthma*, whether the symptoms are recurrent and whether they are reversible with asthma pumps or nebulisers. In addition, a medical diagnosis of asthma

will need full explanation and counselling. To ensure that Xhosa-speaking patients are aware that a specific medical diagnosis of asthma is being made, that is a form or subtype of generic chest diseases (*isifuba*), the phrase *isifuba se-esma* (the chest disease that is called asthma) should preferably be used when we counsel patients in Xhosa about asthma.

Difficulty breathing: tight chest, shortness of breath, ukuminxana, iphika

English words signifying breathing difficulty were variably understood by Xhosa parents. Only 44% of parents from the short-stay ward and 42% of those from the allergy clinic defined *shortness of breath* as 'difficult or fast breathing with exertion or illness'. In addition, parents from the short-stay ward were unable to attempt any definition of *tight chest*. Xhosa parents from the allergy clinic fared better, with 67% defining *tight chest* as 'difficulty breathing due to a closed chest.' They cite the Xhosa word *ukuminxana* as a synonym.

Eighty per cent of doctors defined *shortness of breath* as 'a feeling of struggling to breathe.' They cite two possible meanings of the phrase *tight chest*. Sixty-three per cent used it to refer to 'a feeling of struggling to breathe due to airway obstruction' and 38% as 'a (visible) sign of airway obstruction.'

Doctors were unable to offer any definition of the word *ukuminxana*, and only 25% defined *iphika* as 'a feeling of struggling to breathe.'

Seventy-one per cent of parents from the short-stay ward defined *ukuminxana* as difficulty breathing due to a closed chest when one has *isifuba*. One hundred per cent of parents from the allergy clinic defined *ukuminxana* as 'difficulty breathing due to a closed chest' and many offered the synonym of *tight chest* in English. Seventy-five per cent of parents from the short-stay ward defined *iphika* as 'difficult or fast breathing with exertion or illness'. Eighty-seven per cent of parents from the allergy clinic gave the same definition and many added that the English equivalent is *short breath*.

In summary, therefore, the Xhosa word *ukuminxana* (literally 'to narrow by coming together') best represented to Xhosa parents what doctors mean by respiratory difficulty or *tight chest*. Some parents from the allergy clinic were aware of both words (*ukuminxana* and *tight chest*) and cited them as equivalents in the other language. The Xhosa word *iphika* may be an acceptable substitute as it was uniformly understood by parents. However, this word can also be used to refer to someone who has no respiratory illness and is simply 'short of breath' or 'has a stitch' from exertion, whereas *ukuminxana* is never a feature of well people.

Wheeze/ukutswina

All doctors defined *wheezing* as 'a sound made by the chest with asthma or airway obstruction.' Eighty-three per cent of parents from the short-stay ward were unable to offer any definition at all. In addition, 64% of parents from the allergy clinic were unable to define the word. Only 29% of patients from the allergy clinic defined *wheezing* as 'the whistling noise in the chest when one has difficulty breathing.'

This surprising result means that the word *wheeze* must be considered medical jargon that will usually not be understood by Xhosa-speaking parents.

Doctors were unable to offer any definition of the word *ukutswina*. Eighty-one per cent of parents from the allergy clinic and 80% of parents from the short-stay

ward defined *ukutswina* as 'the hii-hii noise in the chest when the chest is closed or one has difficulty breathing.' Therefore *ukutswina* is the Xhosa equivalent of the word *wheeze*. This does not mean that Xhosa-speaking lay people understand and use the word in the same way as doctors, rather that Xhosa speakers understand the word *ukutswina* in much the same way that English-speaking lay people understand the word *wheeze*.

Interview example 6

When it attacks him he can't even talk... he will **tswina** like a cat... It makes very low sounds.

Interview example 7

The problem that he had before I brought him here is that I would not sleep because of his chest (**isifuba**) and you would think that I am sleeping with a cat because of the noise made by his chest...The other day, my friend told me that she could not sleep over at my place because of the level of noise that my child made...because his chest wheezes (**isifuba siyatswina**).

CONCLUSION

Respiratory medical terminology is used differently by Xhosa-speaking parents and English-speaking doctors. Further differences are evident between those parents whose children attend the allergy clinic and those whose children were admitted to the short-stay ward for chest diseases.

Asthma/i-esma is not used specifically to refer to medical asthma. This may be because of meaning transfer during back-translation from the Xhosa word *isifuba* which has a major sense of 'any generic chest disease' but is sometimes used to refer to medical asthma. The word *isifuba* should be avoided as a disease name. If used by a patient, the word *asthma/i-esma* should be explored further to determine whether it refers to any generic chest disease or symptoms, or to a specific chest disease. If a Xhosa speaker claims to have *asthma*, this chest disease may or may not be compatible with a medical diagnosis of asthma. If the word *asthma* is used during education of a patient about asthma, full explanation will be needed, and it may be useful to refer to *isifuba se-esma* to ensure that it is understood that a specific medical diagnosis of asthma is being made, that is a subtype of generic chest diseases. Self-reported asthma on questionnaires may overestimate the prevalence of medically diagnosed asthma as a result of imprecision in the use of the term.

The English word *wheeze* was not recognised by 83% of parents of general patients and 64% of asthma parents. Only 29% of asthma parents defined *wheeze* in a way concordant with the medical definition of the word. Therefore the English word *wheeze* will not be understood by the majority of Xhosa-speaking patients. Epidemiological questionnaires performed by partially multilingual Xhosa speakers in English (using the word *wheeze*) will record falsely low prevalence of wheeze. The Xhosa word *tswina* may be used as a lay equivalent but is less specific than a medical definition of wheeze, as it includes other noises heard from the chest. It is not used, however to refer to other abnormalities such as visible, rather than audible, signs of respiratory difficulty. Questionnaires completed in Xhosa (using the word *tswina*) will falsely overestimate the prevalence of medically defined wheeze.

Most parents of general patients had never heard the words *tight chest* (79%) and *shortness of breath* (56%) and only 44% of this group defined *shortness of breath* in a sense similar to definitions used by medical practitioners. Xhosa parents from the allergy clinic group fared better, with 67% defining *tight chest* as 'difficulty breathing due to a closed chest' and citing the Xhosa word *ukuminxana* as a synonym. The phrase *shortness of breath* was defined by 42% in a sense similar to medical practitioners' definitions, but a further 42% of parents were unable to define it at all. The Xhosa equivalents *ukuminxana* 'tight chest' and *iphika* 'shortness of breath' were understood by all patients' parents, but few doctors.

If established questionnaires are to be utilised in large epidemiological studies on asthma prevalence in South Africa in non-English-speaking populations, such questionnaires will require more than simple translation and back-translation by professionals to be reliable as a measure of medically defined asthma. Questionnaires will need to be specially formulated and validity verified for sample populations before widespread use. This conclusion may well be applicable to other questionnaire-based studies on prevalence of other diseases in South Africa.

Further research should be performed to ascertain the use of terminology in other official languages by lay people (who may be first-language or second-language speakers). This should include the Afrikaans 'equivalents' of terminology used in control tests and questionnaires, such as the word *asma* used for asthma and *fluit* (whistle) used for wheeze, and the equivalents in Zulu, seSotho and other languages. Another methodology would be to perform studies comparing physician-diagnosed asthma with written questionnaires identifying asthma, or parents' offering wheezing as a presenting complaint in children with acute chest diseases with doctors' auscultatory findings.

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