**Nxwisen, ntzarrin or ntzo’lin? Mapping children’s respiratory symptoms among indigenous populations in Guatemala**

Lisa Thompson\(^a,\,*\), Janet Diaz\(^b\), Alisa Jenny\(^a\), Anaite Diaz\(^c\), Nigel Bruce\(^d\), John Balmes\(^a,\,b\)

\(^a\)University of California, Berkeley, CA, USA
\(^b\)University of California, San Francisco, CA, USA
\(^c\)Universidad del Valle, Guatemala
\(^d\)University of Liverpool, UK

Available online 19 June 2007

**Abstract**

Estimating the prevalence of asthma is an epidemiologic challenge, particularly in rural areas of lesser-developed countries characterized by low literacy and poor access to health care. To avoid under or over reporting of symptoms, questionnaires must use terminology familiar to participants and that accurately describes the triad of cough, wheeze and breathlessness characteristic of asthma. In preparation for a large longitudinal cohort study entitled Chronic Respiratory Effects of Early Childhood Exposure to Respirable Particulate Matter (CRECER) that will examine the effects of variable early lifetime woodsmoke exposure on the respiratory health of Mam-speaking children residing in communities in the western highlands of Guatemala, we conducted individual interviews \((n=18)\) and five focus groups \((n=46)\) with indigenous women from 17 of these communities to elicit and define local Mam and Spanish terms for common respiratory symptoms used to describe their own and their children’s respiratory symptoms. Focus group participants were also shown an International Study of Asthma and Allergies in Childhood (ISAAC) video of wheezing children and adults. We developed a conceptual framework that can be used as an efficient model for future studies investigating health and/or disease terminology in isolated communities, an integral step in the development of standardized questionnaires. Among this Mam-speaking population, wheeze was best described as \textit{nxwisen} or \textit{ntzarrin}, “breathing sounds that are heard in the neck but come from the chest.” The variation in understanding of terms between women with and without children with a history of wheeze (such that for those without wheezing children some terms were virtually unrecognized), has important implications for large-scale population surveys within countries and comparative surveys such as ISAAC. It is important to use linguistically and culturally appropriate terminology to describe wheeze in prevalence studies of asthmatic symptoms among relatively isolated communities in lesser-developed countries.

© 2007 Elsevier Ltd. All rights reserved.

**Keywords:** Asthma; Allergies; Survey standardization; ISAAC video; Indigenous populations; Children; Guatemala

---

**Background**

The measurement of the prevalence of asthma and allergic diseases worldwide has evolved significantly over the past several decades. Since 1991,
the International Study of Asthma and Allergies in Childhood (ISAAC) has interviewed over 700,000 children in more than 106 countries to estimate asthma prevalence. A recent review of the findings from the study indicated that factors related to "Westernization" of the environment appear to increase susceptibility to asthma and allergies (Pearce & Douwes, 2006). Among the 13 Latin American study sites participating in ISAAC, prevalence of "wheeze in the past 12 months", as reported by the mothers of 6–7 year olds, ranged from a low of 8.6% in Cuernavaca, Mexico, to a high of 32.1% in Costa Rica (Mallol et al., 2000). There are several limitations to the interpretation of the ISAAC Latin American data: (a) most of the study sites were concentrated in large, mainly urban areas, (b) many of the participating countries have levels of socioeconomic development comparable to industrialized nations and (c) sampling of participants was not representative of the different socioeconomic strata within each country (Anonymous, 1998). To illustrate this, Costa Rica, with the highest asthma prevalence, is ethnically homogeneous (non-indigenous), very "Westernized", and has one of the highest levels of literacy and access to health care in Latin America (Celedon, Soto-Quiros, Silverman, Hanson, & Weiss, 2001).

Few studies have been done in developing countries among the most vulnerable populations, the poor who tend to have low literacy, indigenous groups who may not speak the majority language, and rural, isolated communities who usually lack adequate access to health care (Schwartz, 2004). A PubMed search revealed only one such published study conducted among a rural, indigenous population in Latin America. Among 1058 Guatemalan school children between the ages of 4 and 6 years, the prevalence of wheeze in the last 12 months was reported by their mothers to be 3.3% (Schei et al., 2004). This is much lower than the prevalence of wheezing reported among the more urban and affluent ISAAC participants in other Latin American countries (Mallol et al., 2000). Given the relative absence of epidemiologic studies in rural, poor, indigenous populations in Latin America, one cannot assume that asthma prevalence is increasing at the same pace in lesser-developed countries as in developed countries (Rosado-Pinto & Morais-Almeida, 2004).

Self-reporting questionnaires may lead to under or over reporting of symptoms among populations that do not have regular access to health care. The questions used in epidemiologic studies must use symptom terms with which participants are familiar and which are standardized. In carrying out asthma surveys, it is important to be aware that the term "wheeze" may not be used in other languages, and other terms such as "whistling" or "squeaking" may be the preferred descriptors for noisy breathing (Young, Fitch, Dixon-Woods, Lambert, & Brooke, 2002). In addition, finding the correct word to describe "wheeze" is insufficient; a study conducted among parents of 160 asthmatics revealed that 26% of the parents recognized that their child was "wheezy" solely based on non-auditory signs such as difficulty breathing and appearing sick. Thus, the use of questions that are in locally comprehensible terms and enable ascertainment of other key symptoms of asthma—cough, wheeze and breathlessness—is necessary for the development of an appropriate case definition of asthma (Cane, Ranganathan, & McKenzie, 2000).

Creating conditions that are conducive to effective communication by investigators with isolated study populations in poor rural areas is critical for the identification of locally comprehensible terms for questionnaire development. Individual interviews and focus groups are fundamental tools for this purpose. Focus groups allow interaction among participants chosen from the same communities, and the information obtained is enriched through collective recall of experiences. Conversations between individuals as they prompt one another become as important as the comments between the individual and the facilitator. Furthermore, focus groups are an ideal medium for those who might feel reluctant to provide information during individual interviews (Kitzinger, 1994, 1995). Among low-literacy populations, verbal communication becomes a principal method for sharing common experiences. Conversely, some focus group participants may "self-censor" if they feel intimidated by more vocal members and may appear to agree with the majority (when they do not) or refuse to engage in a discussion if they disagree. Thus, conducting individual interviews prior to focus groups provides supplementary information, independent of the "group influence".

Using focus groups with parents of children without asthma, Cane and coworkers (Cane, Pao, & McKenzie, 2001) explored how parents describe terms such as "wheeze" and "breathlessness". After dividing 66 mothers of Bangladeshi, European and Afro-Caribbean descent residing in East London...
into ethnic-specific focus groups, the mothers were asked to view a video of a boy with audible wheeze and cough without being told that the child had asthma. Although none of the women had direct experience with asthma, several women used the word “asthma” as a descriptor. Many of the mothers described what they saw in the video in much more general terms than would be used by a health professional. The authors concluded that, by using this approach, they were able to elicit a broader community understanding of the illness than would have been possible based on individual interviews.

The living environment of the rural poor in lesser-developed countries is characterized by high rates of helminthic, bacterial and viral infections, crowded conditions, high levels of dust and air pollution, poor maternal diet and subsequent low birth weight and low rates of immunization. Studying such populations provides an opportunity to evaluate the effects of these risk factors on asthma prevalence. Moreover, studying the prevalence of asthma among isolated indigenous populations, such as the Mayans (Gomez-Casado et al., 2003), allows one to potentially distinguish the role of environmental factors from genetic factors. In the Western Highlands of Guatemala, the Randomized Exposure Study of Pollution Indoors and Respiratory Effects (RESPIRE) examined the impact of a randomized intervention (an improved plancha chimney stove), as compared to the continued use of an open fire, on acute lower respiratory infections among infants between the ages of 0 and 18 months (Smith, Bruce, & Arana, 2006). Children in RESPIRE were visited weekly by trained fieldworkers and assessed for respiratory illnesses, including wheezing illnesses (Bruce et al., 2007, in press). If they manifested signs of illness, they were referred to study physicians for a complete physical exam. The population in this region of Guatemala is almost entirely Mayan, and nearly 95% of the study households self-identified as such. The majority of the study participants were monolingual Mam speakers. In this mountainous region of Guatemala, there are many local differences in the Mam language, and communities separated even by a short distance might not share the same words for describing illnesses.

A longitudinal study entitled Chronic Respiratory Effects of Early Childhood Exposure to Respirable Particulate Matter (CRECER) of former RESPIRE participants, as well as newly recruited participants, began in February 2006. The goal of CRECER is to examine the effects of variable early lifetime exposure to biomass smoke on the respiratory health of this cohort of young children through ages 7–8 years. The health outcomes of interest include: growth of lung function, as measured by biannual pulmonary function testing; chronic respiratory symptoms, including those consistent with asthma, as measured by fieldworker and biannual clinical assessments; and allergies, as measured by skin prick testing.

Purpose

In this paper, we describe the process used to investigate and validate respiratory terminology in Mam, relating specifically to asthma signs and symptoms, for construction of a respiratory questionnaire that will be used in the CRECER study. The conceptual framework shown in Fig. 1 illustrates the three, chronological phases of this process and is a useful model for future studies investigating health and/or disease terminology in isolated communities, and an integral step of developing standardized questionnaires. Using trained local staff as facilitators, this process is efficient and can be conducted rapidly. Our results also offer important insights into the perceptions, presentation and etiology of respiratory illnesses among the Mam-speaking population in this region.

Methods

Overview

In February 2006, we conducted 18 individual interviews in participants’ homes and five focus groups at the study office in San Lorenzo, Guatemala, with the assistance of experienced local fieldworkers (hired during the RESPIRE study). Five fieldworkers, fluent in Spanish and Mam, and trained in focus group methodology, facilitated the interviews and focus groups. We tape-recorded nine of the individual interviews and four of the focus groups. After each session, written notes and tapes (when available) were reviewed and summarized independently by each of the primary investigators, fluent in written and verbal Spanish (JD and LT); and then together. Working with fieldworkers to aid in translation, any inconsistencies were discussed and terms were categorized. On the final day, a focus group was conducted with the five
fieldworkers to review what had been learned about respiratory symptom terminology in Mam.

**Subject recruitment**

The local field supervisor (AD), and fieldworkers visited homes in 17 of the 23 communities that are enrolled in CRECER and invited mothers with at least one child under the age of 4 years to participate in an hour-long individual interview or focus group. As outlined in Fig. 2, we recruited mothers into three groups: (1) mothers who had children who had a history of wheeze in the previous study, RESPIRE (defined as at least one wheezing episode identified by a fieldworker at a home visit and confirmed by a study physician during the 18 months of surveillance), (2) mothers who had children with no history of wheeze and who were formerly enrolled in RESPIRE and (3) mothers who had children for whom we had no information about past wheeze history and who did NOT participate in RESPIRE (non-RESPIRE), but resided in the same communities as RESPIRE participants. By grouping the women as such, we targeted mothers who represented a range of experience with asthma. Our rationale for selecting
mothers who did not participate in RESPIRE was to find a group that was not influenced by the weekly surveillance visits by fieldworkers and was thus not overly familiar with terms introduced by past researchers. The goal was to elicit a broader community understanding of the illness. The respiratory health status for any of the 64 participating mothers was not known prior to the study. To compensate them for their time, the women were given a set of plastic bowls. The project was approved by the Committee for the Protection of Human Subjects at the University of California, Berkeley, and by the Universidad del Valle in Guatemala City. Either written or oral-informed consent was obtained for all participants.

**Phase I: individual interviews**

On the first day, we conducted 18 individual interviews (six from each group) from seven communities. One fieldworker facilitated the interview in Mam, a second fieldworker took notes in Spanish, a third fieldworker took notes in Mam and a fourth fieldworker simultaneously translated the conversation into Spanish for the study investigators (JD or LT). See Table 1 for the list of open-ended questions. Prompts were used to assist the women in describing the events of interest. To elicit a broad understanding of respiratory symptoms, we asked the mothers to describe any symptom that they themselves or their children had experienced. We conducted the individual interviews prior to focus group sessions to identify themes and terms that might arise during subsequent focus groups.

**Phase II: focus groups with participants**

Over the next 3 days, a total of 46 women from 15 communities participated in five respiratory focus groups (two with mothers of RESPIRE children with a history of wheeze, two with mothers of RESPIRE children with no history of wheeze and one with mothers of non-RESPIRE children). One fieldworker facilitated the focus group in Mam, a second fieldworker simultaneously translated the conversation into Spanish for the primary investigators (JD and LT), a third fieldworker transcribed the conversation in Spanish and a fourth fieldworker wrote down Mam words with the Spanish translations for all signs and symptoms that came up in the conversation.

During the first part of each focus group session, the facilitator asked the open-ended questions shown in Table 1. An additional question was asked of women who suffered respiratory symptoms...
to assess the impact of symptoms on activities of daily living. During the second part of the focus group session, we showed a minute-long video clip created by the ISAAC study investigators (http://isaac.auckland.ac.nz/Phasethr/Video.html) of children and adults with active wheeze (nocturnal and exercise induced). Participants were then asked questions shown in Table 2 that were modified from a previous study (Cane et al., 2001). The goal of using the video was to allow participants to view the symptoms, free of any descriptive terms for “asthma” or “wheeze” from the researchers and then permit them to supply their own terms, thus reducing bias imposed by the researchers (Cane & McKenzie, 2001) (see Fig. 3).

Phase III: focus group with fieldworkers

On the final day, we conducted a focus group with the five fieldworkers and their supervisor (who was present at all focus group sessions). The purpose of this focus group was to clarify terms that were generated in the participant focus groups. The ISAAC video clips were shown again. Study investigators (JD and LT) administered open and directed questions (see Table 3).

Subsequently, we reviewed all the Mam terms that described specific respiratory signs and symptoms. One fieldworker read the Mam word or phrase out loud, and the other fieldworkers translated the terms into Spanish. If more than one Mam word was noted for the same symptom, or more than one symptom for the same Mam word, the most common term was identified by group consensus. This was a challenging task, as Mam has only recently been taught as a written language in area schools. Only three of the fieldworkers, who

<table>
<thead>
<tr>
<th>Table 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Open-ended questions asked to women participating in focus groups after video</td>
</tr>
<tr>
<td>1. “What do you think about what you just saw?”</td>
</tr>
<tr>
<td>2. “How would you describe the difficulties this child has?”</td>
</tr>
<tr>
<td>3. “Have you met children with similar difficulties? If yes, what was the difficulty called?”</td>
</tr>
<tr>
<td>4. “Have any of your children ever had this problem? If yes, what was the difficulty called?”</td>
</tr>
<tr>
<td>5. “Have you ever had this problem? If yes, what was the difficulty called?”</td>
</tr>
<tr>
<td>6. “What do you think causes this difficulty?”</td>
</tr>
<tr>
<td>7. “Do you think this affects the child in any way? How?”</td>
</tr>
</tbody>
</table>

Fig. 3. Two focus group participants viewing the ISAAC video, three fieldworkers in background.
were trained as teachers, could write Mam, and there were inconsistencies in spelling agreement among the three. All five of the fieldworkers can read Mam, although some are more proficient than others.

Results

Phase I: individual interviews

All 18 mothers participating in the individual interviews reported a similar number of cough-related symptoms when describing their own illnesses. As expected, the RESPIRE mothers with a child with a history of wheeze reported an average of 5.3 child respiratory symptoms, which is twice the amount reported in the other two groups (see Table 4). Three mothers used the terms nloqin, ntzo’lin and nxwisen to describe respiratory sounds. In contrast, among RESPIRE mothers with a child with no history of wheeze, only one mother mentioned the term nloqin to describe her child’s respiratory sounds. Similarly, among mothers with a non-RESPIRE child, one woman used the term ntzo’lin and one woman used the term nloqin to describe the respiratory sounds their children make. Two of the women stated that they did not know how to describe what they saw or heard.

We observed a very rich interview with a RESPIRE mother who had a 6-year-old girl with a history of a wheeze. She described how her child had episodes of frequent cough with phlegm (“xlo’q") with a respiratory sound described as nloqin that comes from her neck. When she gets this cough, she requires effort to breathe (“nqub’ maqli kyxew") and her throat screams (“nqa’ajtitqul”), although the translating fieldworker stated that this was not synonymous with the Spanish term, silbido, which is used to describe wheeze. The little girl’s voice changes (“sjumin nyolin") and this change was described “like when you are on the phone and you hear noises”. When she walks she cannot breathe (“mina nxewin wen”), when she sleeps she suffocates (“n maq set txew") and upon arising she has a moist cough (“tzjo’l ak’iyin”). The mother believed that these symptoms were caused by the cold, rainy weather. Interestingly, the mother did not use the term “asthma” once or provide any other medical terminology to describe this illness event, despite having paid a number of visits to RESPIRE doctors and the local health center for care of her daughter.

Table 3
Open and directed questions asked to fieldworkers

1. “What were your impressions of the focus groups? How do you think they went?”
2. “Do you think the respiratory terms were clarified or is there still some confusion?”
3. “Can you explain to us the difference between the Spanish terms pillido and silbido?”
4. “Which word would you use to describe the respiratory sounds presented in the video?”
5. “Are the following Mam words the same: ntzarrin, nsorren and nsirren?”
6. “Are the following Mam words the same: ntzarrin, nxwisen?”
7. “Will people understand it if we say, “nxwisen which you hear from the neck but comes from the chest?”
8. “What does the Mam word ntzo’lin mean?”

*Pillido is described as a high-pitched sound like a chicken “peeping” and is probably derived from the verb piar, to chirp. Silbido is a whistling sound, from the verb silbar, to whistle. Both have been used to describe noisy breathing.

Table 4
Average number of cough-related symptoms reported during individual interviews

<table>
<thead>
<tr>
<th>Cough-related symptoms</th>
<th>Women enrolled in RESPIRE</th>
<th>Women not in RESPIRE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Children with wheezing</td>
<td>Children with no wheezing</td>
</tr>
<tr>
<td></td>
<td>history</td>
<td>history</td>
</tr>
<tr>
<td>Among themselves</td>
<td>2.6</td>
<td>2.5</td>
</tr>
<tr>
<td>Among their children</td>
<td>5.3</td>
<td>2</td>
</tr>
</tbody>
</table>
wheeze discussed the difference between dry and moist cough, but then went on to spend most of the time discussing rubella, pertussis and varicella. The other group described a more diffuse list of children’s respiratory illnesses, which included a discussion of acute gastrointestinal symptoms. Finally, in the focus group conducted with mothers of non-RESPIRE children they stated, “this is the same illness that all children get” referring to the common cold, or chon’wi in Mam.

When asked to discuss their own respiratory illnesses, women in the five groups used similar descriptive terms for cough, breathlessness and noisy breathing, as they used to describe their children’s symptoms, with the distinction that they described a wider range of non-respiratory symptoms including sore throat, itchy throat, head ache, fatigue, chest pain, dizziness and body ache. The mothers did not use any descriptive terms for pain or discomfort when discussing their children’s respiratory illnesses. When mothers described their children’s symptoms they discussed what they saw and heard (objective signs), but not what the children felt (subjective complaints). Among the mothers of non-RESPIRE children, there was much discussion about the open fires causing irritative respiratory symptoms. One woman stated, “when you blow on the fire, you get a lot of dry cough and an itchy throat which makes you want to vomit. When you go outside and breathe air, the cough goes away”.

Part 2: responses after viewing the ISAAC video

After viewing the video clips, several women commented that the people in the video “looked like they were going to die” and they “need a lot of strength to cough”. One woman said that a boy who presented in the film with exercise-induced asthma “was dying from the breathing problem; this is what happens when you run a lot”. When asked to name the illness, women in three focus groups used the medical term in Spanish for whooping cough, and those in two focus groups used the medical term in Spanish for pneumonia. However, the Mam term chon’wi or “cold” was mentioned at least once in every session. There was no mention of “asthma” as an illness term during any of the focus groups.

Aside from these diagnostic terms, women limited their descriptions to the type of noisy breathing, cough or breathing pattern demonstrated in the video. During the focus groups with RESPIRE mothers with a child with a history of wheeze, 11 of the 17 women stated that their children had presented with some of the symptoms that they saw on the video, but their children had never been so severely ill. One of the women exclaimed, “maybe in another part people get that sick, but not here”. Nxwisen was the term most commonly used by the women to describe the wheezing sounds they viewed and heard in the ISAAC video.

Women were asked to describe the factors that might precipitate respiratory symptoms. Dust and smoke, two pulmonary irritants that are ubiquitous in their indoor and outdoor environments, were mentioned frequently. Both sun and cold weather (typical of the summer season, and coinciding with the viral influenza season) were also described as making a cough worse. If cough was due to cold weather, then using the temascal (traditional sauna bath) was said to help. On the other hand, if cough was due to sunny weather, the hot temperature in the temascal would make the cough worse. This belief in hot-cold humoral balance is common in this region, and among many Latin American populations (Foster, 1987; Saenz de Tejada, 1999). Taking inadequate care of children—“mal cuidado”—and not vaccinating children were cited in one focus group as causes of respiratory illness. Older age was also mentioned as a cause of cough and difficulty breathing, which was described by one woman as “something we get when we sleep in a smoky kitchen since we were little; we get phlegm and the neck gets tight”.

Phase III: fieldworker focus groups—clarifying Mam terminology for noisy breathing

As the primary goal of the study was to ascertain locally comprehensible terms to describe respiratory symptoms, specifically the triad associated with asthma—wheeze, cough, breathlessness—we present our data as a compilation of the individual interviews and focus groups in Tables 5–7. The terms that are in bold print were selected by group consensus during the focus group with the field workers and are the recommended terms for use in the CRECER questionnaires. During the remainder of this section, we discuss in more detail the linguistic work that took place during our last focus group that enabled us to better understand some of the potentially complex Mam terms for respiratory signs and symptoms. Although this work may seem Mam-language specific, there are general concepts
## Table 5
Mam terminology to describe noisy breathing

<table>
<thead>
<tr>
<th>Mam</th>
<th>Spanish</th>
<th>English</th>
<th>Associated Cough</th>
<th>Comments/Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Upper airway sounds (Not wheeze):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ntzo’lin</td>
<td>Pillido</td>
<td>Whistling in the throat</td>
<td>Dry cough</td>
<td></td>
</tr>
<tr>
<td>Lower airway sounds:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nlogin</td>
<td>Hervor</td>
<td>Boiling chest or throat</td>
<td>Moist cough</td>
<td>Described as rattling sound in upper-mid chest due to phlegm</td>
</tr>
<tr>
<td>Wheeze:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nxwisen (ttzi’ tk’uj: chest)</td>
<td>Silvido</td>
<td>Wheeze</td>
<td>Dry cough</td>
<td>Same as ntzarrin but more commonly used. Can be in throat (only) or heard in throat but comes from the chest</td>
</tr>
<tr>
<td>Ntzarrin (Also called nsorren or nsirren)</td>
<td>Silvido</td>
<td>Wheeze</td>
<td>Dry cough</td>
<td>Best descriptor for wheeze, but less commonly used</td>
</tr>
<tr>
<td>Nxut’in</td>
<td>Silvido</td>
<td>Wheeze</td>
<td>Dry cough</td>
<td>Not common</td>
</tr>
<tr>
<td>Ntzisjen</td>
<td>Silvido</td>
<td>Wheeze</td>
<td>Dry cough</td>
<td>Not common</td>
</tr>
<tr>
<td>Nxub’en</td>
<td>Silvido</td>
<td>Wheeze</td>
<td>No</td>
<td>Not common</td>
</tr>
<tr>
<td>Ntzo’lin</td>
<td>Pillido</td>
<td>Whistling in the throat</td>
<td>Dry cough</td>
<td></td>
</tr>
</tbody>
</table>

## Table 6
Mam terminology for cough and phlegm

<table>
<thead>
<tr>
<th>Mam</th>
<th>Spanish</th>
<th>English</th>
<th>Comments/Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tzjo’l; Tqul; Tzo’q</td>
<td>Tos</td>
<td>Cough</td>
<td>Tqul also means neck</td>
</tr>
<tr>
<td>Tzjo’l b’unin;</td>
<td>Tos suave</td>
<td>Mild cough</td>
<td>Tzjo’l b’unin is more commonly used.</td>
</tr>
<tr>
<td>Tzjo’l ak’iyin</td>
<td>Tos húmeda</td>
<td>Moist cough</td>
<td></td>
</tr>
<tr>
<td>Tzjo’l tzaj</td>
<td>Tos secu</td>
<td>Dry cough</td>
<td></td>
</tr>
<tr>
<td>Tzjo’l tsuk’e xlo’q</td>
<td>Tos, sacando flemas</td>
<td>Cough, bringing up phlegm</td>
<td></td>
</tr>
<tr>
<td>Ntzaj kopaj toj; Njatz t’aqpaq toj; Tzq’aj sjo’l; Njatz t’aqpaj</td>
<td>Sacar flema</td>
<td>Bring up phlegm</td>
<td>Does not indicate whether there is cough or not</td>
</tr>
<tr>
<td>Tzjo’l chq’al</td>
<td>Tosiendo a cada poco</td>
<td>Frequent cough</td>
<td></td>
</tr>
<tr>
<td>Tzjo’l mani’tz</td>
<td>Tos fuerte</td>
<td>Strong cough</td>
<td>Only two communities used this term</td>
</tr>
<tr>
<td>Nzojen</td>
<td>Mucha tos</td>
<td>Lots of cough</td>
<td>Xlo’q is most common, flem is derivative of Spanish, plut not frequently used</td>
</tr>
<tr>
<td>Xlo’q or Flem or Plut</td>
<td>Flema</td>
<td>Phlegm</td>
<td></td>
</tr>
</tbody>
</table>

## Table 7
Mam terminology for difficulty breathing

<table>
<thead>
<tr>
<th>Mam</th>
<th>Spanish</th>
<th>English</th>
<th>Comments/description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Njaw txew</td>
<td>Respiraciones rápidas</td>
<td>Rapid Respiration</td>
<td>Interpreted as shortness of breath</td>
</tr>
<tr>
<td>Nmaq set txew</td>
<td>Se tapa su respiración en el pecho</td>
<td>Breathing is obstructed in the chest</td>
<td>Could be interpreted as nasal obstruction</td>
</tr>
<tr>
<td>ttzi’ tk’uj’</td>
<td>Mina nxe’win wen</td>
<td>No respira bien</td>
<td>Used when referring to exercise but also used generally</td>
</tr>
<tr>
<td>Nqub’ maqli txew; Mi njatz txew</td>
<td>Le cuesta respirar</td>
<td>It takes a lot to breathe</td>
<td>Interpreted as breathlessness</td>
</tr>
<tr>
<td>Nji’q’bin ttzi’ tk’u’j’</td>
<td>Se ahoga en el pecho</td>
<td>S/he is suffocating in the chest</td>
<td>Interpreted as chest pressure</td>
</tr>
<tr>
<td>Njit’et ttzi’ tk’u’j’</td>
<td>Apretada del pecho</td>
<td>Chest tightness</td>
<td>See explanation below</td>
</tr>
<tr>
<td>Tzaj nxiy toj il tuka</td>
<td>Momentos fuertes</td>
<td>Asthma attacks</td>
<td></td>
</tr>
</tbody>
</table>
that can be applicable to other researchers faced with similar linguistic challenges when working with isolated communities with an oral language tradition.

**Mam terminology for noisy breathing**

**Nxwisen and ntzarrin**

*Nxwisen* was the term most commonly used by the mothers to describe the wheezing sounds they viewed and heard in the ISAAC video. The women described *nxwisen* as breathing sounds that were heard at the neck, but come from problems in the chest. Many women used hand gestures pointing to their necks and then to their chests to clarify this point and to clearly distinguish this term from *ntzarrin*, which was also heard at the neck but did not come from the chest. In fact, there was only one other noisy breathing term that all the women described as being over the chest area, *nloqin*, which could be comparable to “chest rattling” and this term was not used to describe the sounds heard in the video. *Nxwisen* was associated with difficulty breathing and a dry cough. The cough was dry because phlegm was trapped in the chest.

*Ntzarrin* was used much less often by study participants to describe what was shown on the ISAAC video. In fact, only one fieldworker had heard the term *Ntzarrin* prior to the focus groups. Despite this, the field workers concluded by consensus that *Ntzarrin* was synonymous with *Nxwisen*. One woman described *Ntzarrin* as “the most troublesome” sign. *Ntzarrin* was commonly associated with shortness of breath, requiring “lots of force to breathe out” (“con fuerza se saca el aire”), with “a neck that screams” (“grita su pescuezo”), a tight neck (“apretado del pescuezo”) and a whistling throat after exercise (“después de ejercicio silba el pescuezo”). In Spanish, *ntzarrin* is referred to as *silbido*, which was the preferred Spanish term to describe the respiratory sounds in the ISAAC video. Thus, despite its less frequent use, *ntzarrin* appears to be the most specific term to describe wheeze, but at the expense of lower sensitivity; in other words, it would not be understood by all community members.

*Nloqin*

As mentioned above, *Nloqin* was used to describe a sound that was heard in the neck, but did not come from the lungs; study participants would not use this term to describe the respiratory sound presented in the ISAAC video. Most study participants and field workers agreed that *ntzo’lin* is a sound in the throat that may come from running too much and is associated with a strong dry cough, when phlegm gets stuck in the chest or throat, or a tight feeling in the throat. However, one of the focus groups thought that *ntzo’lin* was the same as *nxwisen* and *nxub’en* and several participants in this group seemed to think that *ntzo’lin* might come from the chest (pointing to front and back of the upper body). This raised some concern about the actual meaning of this term, but group consensus with the field workers clarified that it was not synonymous with wheeze. In Spanish, the preferred term is “pillido” which might be generally described as the peeping sound a chick makes, although there is no exact term in the English language.

**Mam terminology for cough and phlegm**

Table 6 lists the many different ways to describe cough, by type (dry or moist), by strength or frequency or by presence of phlegm. The three terms for cough are interchangeable and vary by community with *tzjo’l b’unin* being the most common. Given that *tqul* is also “pescuezo” or “neck”, it is advisable to avoid this term when discussing wheeze. None of these terms describe whether cough is dry or productive of phlegm. *Tzjo’l b’unin* (“mild cough”) is seen as a “good” cough since it is productive of sputum. *Tzjo’l tzqij* (“dry cough”) is most worrisome and was most frequently mentioned in conjunction with *nxwisen* as well as *ntzo’lin*.

**Mam terminology for difficulty breathing**

Table 7 shows the different terms that were used to describe breathing difficulties experienced during respiratory illness, such as breathlessness or chest tightness, symptoms that would be experienced
during an asthma episode. The concept of an “asthma attack” was unfamiliar to the participants and could not be translated into Spanish or Mam, as they understood “ataque” in Spanish as “con- vulsions”. To facilitate the understanding of a severe asthma episode or asthma attack, as shown in the ISAAC video, the terms used by the participants and the fieldworkers were “tzaj nxiy toj il tuka” (as back translated from Mam into Spanish means “momentos fuertes”; in English “strong moments”).

Discussion

This is the first comprehensive analysis of Mam language terminology collected from 64 indigenous Mayan women from 17 communities in the western highlands of Guatemala to describe respiratory signs and symptoms, emphasizing those consistent with asthma—cough, wheeze and breathlessness. We designed a conceptual framework that consisted of three chronological phases: individual interviews, focus groups with study participants and focus groups with local fieldworkers. In Phases 2 and 3, a minute-long video clip created by the ISAAC investigators was used. This approach allowed the participants to view the symptoms, free of any descriptive terms for “asthma” or “wheeze” from the researchers and then permitted the participants to supply their own terms, thus decreasing researcher-imposed bias (Cane & McKenzie, 2001). By using local fieldworkers trained in this methodology, our framework was carried out efficiently and effective-ly. A major research tool employed in CRECER is a respiratory questionnaire that is to be adminis- tered to the mothers in the local Mam language. Although these women were not familiar with the medical term “asthma”, we concluded that women of this area identified the local Mam words, nxwisen or ntzarrin, breathing sounds that were “heard over the neck but come from the chest,” to best describe “wheeze”.

As with many languages, slight variations in pronunciation and tone can change the meaning of words and ultimately affect diagnostic terms. To capture this intra-cultural variability, we recruited members from 17 communities to participate in the focus groups and individual interviews. An earlier (unpublished) study by Saenz de Tejada conducted in a nearby region in 2002 (which sampled women from four communities) did not identify a specific term for wheeze. The women in Saenz de Tejada’s study referred to noisy breathing in the throat as in tzirum, which is probably related to the term identified in this study as ntzarrin or nsirren. In loglon toj tqul was described as “boiling in throat”, similar to the word nloqin described in this study as boiling or rattling, usually attributed to phlegm in the chest and/or throat. In Saenz de Tejada’s study, only one word (tqul) was identified as the descriptor for cough, which was also the word they used to describe phlegm, throat and neck. In our study, the word tqul was also used for cough, but was used less often, and is less specific, than the word tzjo’l which is the preferred term. A potential weakness of our study is that the terms described herein may only be applicable to these communities, and even other communities in western Guatemala may use different terms. Conversely, an important finding of this research is that these local variations in understanding and use of terms have direct implications for standardization within population surveys, and particularly for comparative studies. Thus, we conclude that comprehensive linguistic work that captures intra-cultural variability in isolated communities requires participants from as many different communities as feasible to appropriately represent the study population.

Many studies have reported that the general population employs a broader language to describe health and illness than the medical community, which limits definitions to specific, proscribed terms (Cane et al., 2001). Agreement among rural, coastal Guatemalans about specific symptoms caused by asthma has been found to be lower than for other Latino groups in Mexico and immigrant Latino populations in the US, and many of the reported “asthma” symptoms overlapped with symptoms commonly seen in upper respiratory infections (Pachter et al., 2002). Our study participants used many Mam terms to describe their own and their children’s respiratory problems, which we categorized into three groups: noisy breathing (eight descriptive terms), types of cough (nine terms) and difficulty with breathing (eight terms). For example, phase I of our study provided many Mam terms for noisy breathing but none that we were able to discriminate as being closely related to wheeze. Although we had made an effort to recruit some women who had a child with a history of wheeze, these interviews, albeit rich in discussion, did not provide us with a Mam term for wheeze. During phase II of our study, we found it essential to use the ISAAC video clips to discern the local word(s)
that were most synonymous for wheeze. The video clips offered visual and auditory presentations of wheezing episodes without language cues and women were then able to verbally describe what they had just seen and heard in their local Mam language, with no researcher introduced bias. Finally, in phase III, by group consensus, it was clear that two words, *nxwisen* (more commonly used) and *ntzarrin*, most closely described the term wheeze. We concluded that in this population, both words be used in the CRECER questionnaire when referring to wheeze. While the conceptual framework is presented as a unidirectional approach, feedback loops could be introduced at any stage of the process. Had there not been consensus during the fieldworker focus group, the phase II step might have been reinitiated. The product of phase III is the final feedback loop: a standardized questionnaire to be used during individual interviews with CRECER participants.

Prior to our study, we had anticipated using the standardized phrase from the ISAAC questionnaire, “wheeze or whistling in the chest,” in the CRECER questionnaire. From data collected in phases I and II, our main concern was that nearly all the women reported that most of the terms used to describe noisy breathing (seven out of eight) were heard at the neck, and this included the words for wheeze, *nxwisen* and *ntzarrin*. Phase III gave us the opportunity to work on the standardization of this phrase. We learned that the direct translation into Mam language of the ISAAC phrase, “*nxwisen* and *ntzarrin* in the chest,” would confuse local women because these sounds were heard over the neck. This did not connect with our modern biomedical framework, in which wheezing clearly originates in the chest but made some sense because without a stethoscope the wheezing can potentially be heard just over the neck. To avoid a confusing phrase or confusing *nxwisen* or *ntzarrin* with the *ntzo’lin* (the other noise heard at the neck), the women and fieldworkers suggested that the emphasis be placed on these words as “heard at the neck but coming from the chest”. Furthermore, the fieldworkers suggested that to standardize this phrase, non-verbal cues should be used when administering the questionnaire. Specifically, the person administering the questionnaire would point at his/her neck then chest while asking this phrase. We concluded that standardizing a questionnaire in isolated communities, such as this one, requires careful attention to not only the intra-cultural variability of specific terms, but also to how they are used, and non-verbal cues may be helpful.

The women had strong perceptions of which respiratory symptoms were “good” or “bad”. For example, nearly all the women believed a dry cough was worse than a wet cough because the production of phlegm was seen as a positive sign. Because a wet cough is perceived not to be a serious condition, this suggests that chronic bronchitis that is not associated with breathing difficulties is accepted as a “fact of life”. The women attributed respiratory symptoms to either an infectious process (lack of proper vaccination, whooping cough, pneumonia or a common cold) or an environmental exposures (dust and smoke). They appear to have a basic understanding of respiratory irritants, such as dust and smoke. As most of these women were participants in RESPIRE, which focused on the impact of reducing exposures to indoor air pollution on the respiratory health of women and children, this is not surprising. One of the mothers stated that with the open fire, she had “lots of cough”, but with the improved vented-chimney stove, her cough has disappeared.

In our conceptual framework, the individual interviews and focus group sessions were complimentary tools used to gain knowledge of terms for respiratory symptoms in the local Mam language and to develop a standardized questionnaire. Experienced fieldworkers who were members of the local communities, spoke Mam as their first language and were known to the participants, enhanced the effectiveness of these tools. We conducted the individual interviews prior to focus group sessions to identify themes and terms that might arise during subsequent focus groups and to minimize group interference. The focus groups allowed for the benefits of group interaction, disagreement and discussion. While nearly all of the women were active discussants, younger women tended to be more reserved with their opinions and looked for guidance from older women and most women were shy about mimicking the noisy breathing sounds. Although the women had never seen video clips of asthmatic episodes before, these clips were well received. After seeing the video clips, one woman commented, “who knows what they are going to ask us now!” which was followed by laughter among the participants. The most successful sessions occurred when the facilitator kept up with the flow of conversation, other fieldworkers did not try to interject/interrupt, participants spoke one
at a time, and appropriate time was given for participants to respond.

Our findings emphasize the importance of exploring local terms for respiratory symptoms in preparation for conducting an epidemiologic study, especially in communities that have low-literacy levels, poor access to health care and a language without a long written tradition. The knowledge gained will be applied to the development of the respiratory questionnaire that will be used in the CRECER study to assess symptoms of asthma and allergies. The current linguistic work will undoubtedly improve the accuracy of the respiratory questionnaire, and allow an improved estimation of the prevalence of asthma and allergies in this rural, indigenous population with exposures to high levels of indoor air pollution. Furthermore, lessons learned from our work are relevant to other studies of chronic respiratory illness symptoms among populations in rural areas of developing countries, particularly, women and children who experience the majority of the substantial burden of disease attributable to indoor air pollution from solid fuels (Smith, Mehta, & Feuz, 2004).

Conclusion

The prevalence of asthma and allergies in indigenous children from rural areas of lesser-developed countries and the association with exposure to indoor air pollution are unknown. CRECER, a longitudinal study currently being conducted in the Western Highlands of Guatemala, will attempt to fill these gaps in knowledge using respiratory questionnaires, allergy skin-prick testing and lung-function testing. The respiratory questionnaire will be administered in the local Mam language. Using a conceptual framework which consisted of three chronological phases—individual interviews, focus groups with study participants and focus groups with field workers—and the use of the ISAAC video clips, we found that the words that best describe wheeze for our population are nxwisen and ntzarrin, which can be translated as “wheeze that is heard in the neck but comes from the chest.”

We conclude that in order to minimize errors in under or over reporting of wheeze among any population, it is imperative to assess the variations in usage and understanding among mothers who have children with, and without, wheeze and to use culturally appropriate lay terms when developing questionnaires or using standardized respiratory surveys such as ISAAC.

Acknowledgments

The work reported here is part of a 15-year set of projects in highland Guatemala led by Kirk R. Smith, which attempts to understand environmental determinants of maternal and child health. These projects involve multiple investigators, medical personnel, students, field staff and others from several different disciplines and nations working in close collaboration. The limit of six authors, as required by this journal, thus does not reflect the true complexity of this long-term, interdisciplinary international research effort. We would like to thank Julian Crane, MD, for his suggestion to use the ISAAC video, and in Guatemala, fieldworker supervisor, Gilberto Davila and the fieldworkers, Expedita Ramirez, Aura Morales, Domitila Velasquez, Vicente Tema and Micaela Isidro for their hard work and dedication. We appreciate the assistance and cooperation of the Guatemala Ministry of Health. We especially appreciate the patience of our interviewees and focus group participants. The project described was supported by Grant number 2R01ES010178 from the National Institute of Environmental Health Sciences, NIH. Additional funding for the RESPIRE project described in the text was provided by the World Health Organization, Geneva and the AC Griffin Family Trust.

References


Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. Sociology of Health & Illness, 16(1), 103–121.


