Barriers to nutrition-related chronic disease management in Kaqchikel-speaking communities in Guatemala: an exploratory analysis of cultural and linguistic factors

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Abstract

Barriers to nutrition-related chronic disease management in Kaqchikel-speaking communities in Guatemala: an exploratory analysis of cultural and linguistic factors

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Our Indigenous Maya communities in Guatemala have experienced oppression, exclusion, and racism through ongoing colonization that systemically denies us the right to live happy, healthy lives. The rise of nutrition-related chronic diseases among our communities places us among the few countries facing a double burden of malnutrition, disproportionately impacting Indigenous people in Guatemala. Language has sustained our people through genocide, wars, and illnesses by preserving our knowledge of medicine and survival. It is also central to Indigenous identity, and this study shows it is central to the successful management of nutrition-related chronic conditions. Here, Indigenous Kaqchikel Maya health experts and patients share their insights on the factors that hinder their ability to successfully manage nutrition-related chronic conditions and the impact of language on the health of our people.

Introduction

According to the 2020 World Health Statistics report, non-communicable diseases (NCDs) or chronic diseases such as diabetes, cancer and cardiovascular disease continue to be a major burden worldwide; posing challenges to low and middle-income countries. Approximately 80% of chronic disease deaths now occur in low and middle-income countries (Labarthe & Dunbar, 2011), which signals the need for effective interventions for non-communicable diseases in these parts of the world. In the Latin American and Caribbean region, chronic diseases are estimated to account for over half of the disability-adjusted life years lost (Barreto et al., 2012).

Indigenous peoples in Latin America are especially vulnerable since they often face far worse health outcomes as compared to their non-indigenous counterparts due to historic marginalization (Montenegro & Stephens, 2006); poor outcomes are seen in various areas including large economic gaps, educational achievements and access, life expectancy, and maternal-child health. Guatemala is home to the second biggest percentage of Indigenous peoples in Latin America, where approximately 50% of the population identifies as Maya, Xinca or Garifuna (Ministerio de Salud Pública y Assistencia Social, 2016). Indigenous people in Guatemala face the highest levels of income inequality, living under multidimensional poverty and struggling with historic marginalization (Programa de las Naciones Unidas para el Desarrollo, 2016). The 36-year civil war that killed, displaced, and disappeared approximately 2 million people furthered disadvantaged the Indigenous population, since it is estimated that approximately 83% of the victims of the war were Indigenous Maya (American Association for the Advancement of Science, 1999).

Health outcomes are far worse for Indigenous people in Guatemala than their nonindigenous counterparts. Life expectancy for the indigenous populations is 13 years less,

maternal mortality rates are four times higher and childhood stunting is 50% more prevalent (PAHO, 2007; Ippolito et al., 2017). Malnutrition continues to be on the rise as well as non-communicable disease and mental health disorders (Chary, 2016).

It is generally stated that governmental biomedical health services are accessible in the country, meaning facilities are nearby and consultations are usually free, but the treatment costs tend to be high and the quality poor (Hitziger et al., 2017). Additionally, these facilities tend not to be the first choice for Indigenous peoples seeking healthcare given the reality of discrimination, linguistic barriers, educational differences, and differences in cultural expectations that they face in these settings (Hitziger et al., 2017; Berry, 2008). Further contributing to poor health outcomes is the fact that many of the doctors, nurses and other healthcare practitioners at state-run facilities do not speak any of the Mayan languages, and therefore cannot fully understand the needs nor dissatisfaction of the indigenous communities within which they work (Lawton, 2015).

Guatemala has the highest density of Maya speakers in the world. Although the national census estimates that 40% of Guatemalans speak a Maya language, a more accurate estimate is likely closer to 60%, given that there is often undercounting by government data (Fischer & Brown, 1996; England, 2003). The Kaqchikel Maya people comprise about 8% of the population in Guatemala with some 400,000 speakers. (Merida Ponce et al., 2019) Although Kaqchikel is one of the four most spoken languages in Guatemala, Spanish is the official language of the country and is the language of instruction in school as well as the language that facilitates access to social services (Holmquist & Kahn, 2017).

The linguistic differences between Spanish and Kaqchikel have been recognized by numerous scholars (England, 1991; Holmquist & Kahn, 2017; Balcazar, 2015). This study does

not investigate nor focus on the linguistic components of the language, rather it aims to understand common words, terms and language used in Kaqchikel to describe disease, health, and food in relation to chronic disease management. Nevertheless, it is important to note the linguistic differences between Kaqchikel and Spanish which include significant differences in word order, historical origin, phonology, and morphology (Garcia Matzar et al., 1999; Holmquist & Kahn, 2017). These differences were important to consider in designing this study and the research questions; we designed our study in Kaqchikel and then translated to subsequent languages (Spanish and English) to better capture the community experience.

There is great need for health research that focuses on understanding the unique way that Indigenous Maya communities understand disease in their own language and worldview. Afterall, there is growing recognition that language is not just another barrier to health but rather an essential piece of healthcare delivery to improve health outcomes, especially for Indigenous peoples (Flood & Rohlof, 2018; Ippolito et al.,2017). The rise of chronic disease among the Indigenous population proves a hard challenge to solve, and it begins with focusing on understanding how we, Indigenous Maya people, talk and conceptualize health, diseases, and food and how they are connected.

This study therefore aims to bridge the gap in research and writing about nutrition-related chronic disease management and understanding in Guatemala from one of the Maya Indigenous perspectives, Kaqchikel. Through conversations between Kaqchikel researchers and Kaqchikel health experts and community members this study seeks to examine: 1) how health experts and patients understand and talk about health, food, and chronic illness in the Kaqchikel language and 2) the differences and/or similarities between how health experts and patients talk about health, food, and chronic illness.

Methods

This is a qualitative exploratory study that used open-ended interviews to gather information from various stakeholders to better understand how the Kaqchikel community understands and talks about health, food, and chronic illness and the subsequent implications on nutrition-related chronic disease management. The methodology developed for this study incorporated both Kaqchikel Maya linguistic and cultural knowledge and western research methods – an approach closely related to the Two-Eyed Seeing framework developed by Mi'kmaw Elder Albert Marshall, a concept that refers to seeing "from one eye with the strengths of Indigenous knowledges … and from the other eye with the strengths of western knowledges" (Bartlettet al., 2012, p. 335).

The Kaqchikel language was an essential thread woven throughout this study. The research questions and interview guide were developed in Kaqchikel, and most of the interviews were conducted in Kaqchikel, with the option for participants to use the Spanish language if and when they preferred. All interviews were conducted by two main researchers, both Indigenous Kaqchikel Maya women—Ingrid Sub Cuc (Kachikel-Q'eqchi), a public health student at the University of Washington, and her mentor, Magda Sotz (Kaqchikel), a community leader, elder, and linguist. This approach ensured that the research was designed with Kaqchikel community values and identity in mind. The study recruited Kaqchikel Maya health experts and chronic disease patients between March 2021 and June 2021 and data collection was in part done remotely. The University of Washington Institutional Review Board (IRB) determined that this study qualified for exempt status.

Kaqchikel people, language, and territory

There are over half a million Kaqchikel speakers today residing both in Guatemala and abroad. (Merida Ponce et al., 2019). Most of the Kaqchikel population is concentrated in the highlands of the country in the departments of Chimaltenango, Quiche, Guatemala, Sololá, Escuintla and Sacatepéquez (Merida Ponce et al., 2019). All participants for this study identified as Indigenous Maya Kaqchikel. The majority are currently living in Guatemala; one lives abroad in the United States.

Recruitment and Participants

Following exempt approval from the University of Washington Seattle IRB, we recruited 14 participants from which we collected data between March 2021 – July 2021. Using purposive sampling, eight health experts and six chronic disease patients were invited to participate. In this study, we focused on nutrition-related chronic disease among Indigenous communities in Guatemala. Therefore, we recruited health experts from healthcare organizations that provide services on this health issue to predominantly Kaqchikel speaking communities or those that operate a private practice in such a community. Inclusion criteria for health experts included: self-identified as Kaqchikel, currently holds a role at the operational level (doctors, auxiliary nurses, and health educators), trained in Western medical knowledge, possessing expertise in nutrition-related chronic illnesses and currently serving a predominantly Kaqchikel speaking community.

We recruited experts from recognized health organizations such as the Instituto de Salud Incluyente, Wuqu' Kawoq, and western-trained community physicians. Our sample included five experts from Wuqu' Kawoq, a non-profit offering health services in Kaqchikel and K'iche to Indigenous communities in Guatemala which incorporates language, culture, and science in its work. One expert from the Instituto de Salud Incluyente, an initiative led by health professionals

with training in public health, social development, and social medicine also participated. Additionally, we recruited a local family physician in a predominantly Kaqchikel-speaking community, and one Kaqchikel academic whose research includes food, health, and cultural issues among Indigenous communities in Guatemala.

Our patient population were those recommended by the lead researcher in-country, Magda Sotz, and by health experts to assure that our team could speak with thoughtful and open respondents. Inclusion criteria for our patient population included: self-identified as Kaqchikel Maya, spoke Kaqchikel as their first or second language, and currently living with a nutrition-related chronic illness (diabetes and/or hypertension). Patients did not have to attend or seek services at the institutions mentioned to be included. Our patient sample included 6 patients, only one of these received services at Wuqu' Kawoq and the rest received services at either public or private clinics.

The research team contacted all participants via phone or email. There was no direct physical contact with participants in order to follow guidelines laid out by both the Guatemalan government and the United States'Center for Disease Control regarding the COVID-19 pandemic. Interviews via phone and Zoom were possible because both researchers are Kaqchikel-speaking Maya women who understand communication protocols with other Indigenous community members. The participants were informed about the project in their language; they were also informed about virtual interviews due to the pandemic, and they were asked for consent to record their conversations. The ease of both researchers having the ability to speak the colloquial form of the language fluently contributed significantly to building trust with participants.

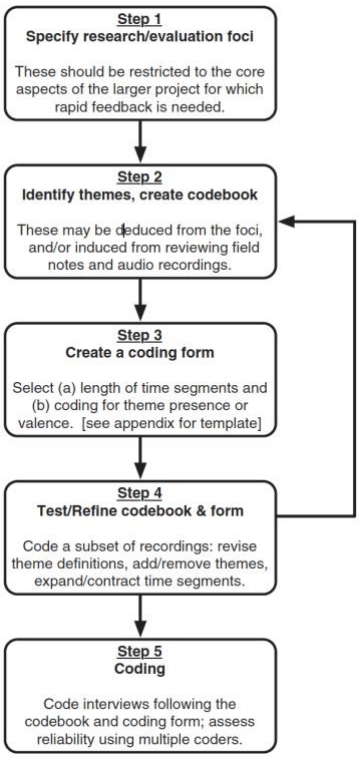
Data Collection

Data were collected through 30–40-minute semi-structured interviews via the Zoom virtual platform or phone calls. The Zoom platform can be an effective qualitative tool for data collection (Archibald et al., 2019). Interviews were conducted by the two main researchers in Kaqchikel. Information about the study was read to the participants in Kaqchikel at the beginning of the interview and before recording. All participants provided verbal consent for the interviews to be recorded. Demographic information collected included: name, linguistic group, location, and profession or role in their households. There was a total of 12 guiding interview questions for health experts and patients touching on three main categories: health/wellbeing, chronic disease/illness, and food/nutrition. Each participant was given an opportunity to share any additional information they wanted at the end of the interview. After each interview, the two researchers debriefed by going over notes, observations, major learnings, and any changes made to the interview questions. Each researcher uploaded their interview packet to a secure Google Drive folder. The interview audios were also uploaded to the Drive and were only made accessible to the research team. All files were assigned a participant ID.

Data Analysis

The Kaqchikel language is mostly preserved orally among its speakers with very few having the opportunity to formally learn how to read and write it (England, 2003). Therefore, the audio recordings of the interviews were not transcribed. Instead, the team used a modified version of the RITA (Neal et al., 2015) – rapid identification of themes through audio recordings – method to conduct the analysis. The data analysis team consisted of the two main researchers. The team followed a modified version of the five steps of RITA outlined by Neal et al. (2015) (see figure 1).

Figure 1. RITA Step by Step Methodology



For the first step, the team was interested in identifying preliminary findings from our purposive sample on two major foci of the linguistic and cultural factors that influence management of nutrition-related chronic illnesses among Indigenous Kaqchikel communities: 1) how health experts and patients understand and talk about health, food, and chronic illness in the Kaqchikel language and 2) the differences and/or similarities between how health experts and patients talk about health, food, and chronic illness.

Step two: the research team did not create initial themes. Instead, we analyzed the data by utilizing questions that informed the two foci listed above on the role of language in managing nutrition-related chronic illnesses. The team did not create a codebook with specific codes because we were interested in learning through the coding process the words and terms used in

Kaqchikel to describe these themes and how they are different or similar for health experts and patients.

Step three: the research team created a coding form organized by rows (questions) and columns (time segments) with an additional column at the end for notes.

Step four: the team tested the form by initially coding in segments of 5 minutes. Coding was done inductively and focused on *in vivo* coding. After a first round of coding the team realized that the time segments were too long. It was decided then to code in segments of 2-3 minutes for each question creating small summaries of the themes that emerged.

Step five: in the final step, the team listened to each interview recording inductively and focusing on in vivo coding. We recoded one by one, question by question, in segments of 2-3 minutes, and made a summary of key codes in the time segment box (column) of how the participants responded as well as specific observations in the notes column, including exact time stamps of key quotes we wished to include in this study.

The research team compared the summary coding documents in three ways: 1) among health experts, 2) among patients and 3) between health experts and patients. First, we compared each health expert interview to each other and identified how similar/ different the responses were, and how similar/ different were the terms being used in Kaqchikel for concepts of interest. We also drew preliminary key themes emerging from the interviews with health experts. Second, we followed the same process for patient interviews. Finally, we compared the findings between health experts and patients looking for overarching themes and differences between the two groups. The research team did not identify themes at the beginning of our analysis; that step was part of the final product. We identified a set of initial themes and exemplary quotes from

Kaqchikel health experts and patients presented below that can be used to inform future research in this area of interest.

Results

Three overarching themes emerged from the interviews conducted with Kaqchikel health experts and patients with implications for the linguistic and cultural factors that influence management of nutrition-related chronic illnesses among Indigenous Kaqchikel communities. The themes are presented in the table below:

Table 1.1 Major Themes from Kaqchikel Health Experts and Patients

1.	The concept of health is understood as something more complex and collective than the western definition by both health experts and patients.
2.	Indigenous people's relationship and history with food is one shaped by colonization, war, trauma, and poverty.
3.	Kaqchikel language is essential to the health and happiness of our people.

Additionally, we identified one important difference among experts and patients pertaining to disease and its management.

Table 1.2 Differences between Kaqchikel Health Experts and Patients

1.	Experts believe that nutrition-related chronic illnesses are due to behavioural and dietary lifestyles, while patients believe their illnesses are brought about by emotions or past traumas.

Theme 1: The concept of health is understood as something more complex and collective than the western definition by both health experts and patients.

Most health experts provided a baseline definition of health that is similar to the one laid out by the World Health Organization: "a state of complete physical, mental and social well-being" (WHO, 2006). Additionally, they expanded on this definition to include concepts such as spirituality and good relationships with family, community, and nature as essential to good

health. Although all health experts interviewed were trained in western medical systems, they understand and respect their patients' descriptions of disease and health which often include concepts that are not recognized by western medicine but are well known in Indigenous Kaqchikel communities.

For example, one expert (HealthExpert_01) gave her perspective on the importance of listening to her patients and respecting their worldview as best practice when her patients seek medical care for an illness that might not be recognized by western medicine:

> *"…Janila' K'atzinel ri kamelanïk, chuwäq ri b'anob'äl ruma man Itzel ta, janila' ütz, niqamol ta qi' niqak'uqub'a ta ruk'u'x ri yawa' ke ri. Taq nikib'ij ka chi qe xink'waj rik'in ri ixöq xb'än pe ri raq'on. Ütz k'a ri, tutz'eta' na ri ixöq k'a, tub'ana' pe raq'om, xa xe tab'ana' utzil taya' chi re ri ri ruya' aq'om wi k'o jun ruk'ayewal tak'ama' pe, majun achike ta ri'. Po pa juley chïk taq aq'omab'äl jay. Taq jun winäq nutzijoj chi xuk'waj rik'in jun ixöq ruma aq'omanïk, k'o chaponïk, majun ütz ta naxëx, ruma ri aq'omanïk, ruma k'a ri majun nikiya' kik'uqub'ab'äl k'u'x pa taq aq'omab'äl jay, ruma k'a ri aq'omanïk rik'in jun ixöq re' jun peraj richin ri maya' nimab'äl k'u'x o ri b'anob'äl, chike na rub'i' nikiya' kan ja wi öj ke re', ninnimaj chi öj k'ïy ri öj maya' winaqi' e qawinaq, stape man konojel ta nikib'ij chi e maya' winaqi', xa junan ri qaxe'el ja ri ri' k'atzinel ri kamelanïk chi qawäch, wi naläx ta jun ruwäch junamil richin ta ütz nib'iyin apo ri qak'aslem." (HealthExpert_01)*

> *" …respect is important in those cases [seeking care for illness not recognized by western medicine] because it isn't bad and actually it is good and necessary for establishing trust with the patient. So when they say – yeah, I went to see her [traditional medicine woman] and she gave us medicine – that is fine, she can keep making the medicine but also incorporate what I am giving you and if things get bad please bring them to me…it doesn't matter but when they disclose this information to other health providers they are shamed, they are criticized and that doesn't build trust with the provider. So, this is part of our spirituality, our ways of being …or whatever we want to call it. And that is who we are- most of us are Indigenous people, even if we don't self-identify as Indigenous, we have common roots and beliefs and it's important to acknowledge that and create a link with our work so that things work well." (HealthExpert_01)*

HealthExpert_01 elaborates on the importance of validating and recognizing health beliefs in Indigenous communities because they are rooted in ancestral wisdom, knowledge, and identity. Even so, not all health experts know or incorporate ancestral definitions of health as part of their

practice. Another health expert highlighted the complexity of what it means to be healthy according to our ancestors:

> *"e k'o oxi' ruwäch, nikib'ij rije'. oxi' ruk'aslen, oxi' ruwäch niqab'ij chi richin. ri nab'ey cha, ri nab'ey awäch, ja ri ri' ruwäch aq'ij, ja ri ak'amon pe, ja ri awuchuq'a, ruq'ij ri tikb'äl ri ik' ri ch'umilal, ak'amon peja …Ri jun chïk awäch cha, ja ri ri qab'aqil, aj ri ri' qach'akul, ja ri ri' qawi', qawäch, ja ri' ri qonojel röj, ri k'o modo niqachäp, ja ri jun chïk ruwäch… Ri jun chïk nikib'ij ri qati't qamama', ja ri ri' qak'aslem niqab'än kik'in konojel ri qawinaq …" (Healthexpert_02)*

> *"There are three ways we understand health, according to our ancestors. First, is our destiny, what were born to do and what we need to fulfill… Second, is our physical health, our bones, our muscles, our hair, our eyesight, everything we can touch…third is the relationships, as our ancestors described it, relationships with our community and our family." (Healthexpert_02)*

HealthExpert_02 further elaborates that as a medical practitioner he keeps this in mind when approaching Indigenous patients and thinking about public health initiatives effecting Indigenous peoples and communities.

Similarly, patients recognized health not simply as the absence of sickness but also as eating foods that come from the earth, being physically strong, using medicinal plants as our grandparents (ancestors) did and having eyes that express joy – meaning one lives a life full of happiness which is evident in the eyes. Only one patient named exercise as a source of good health. While other patients did not use the word "ejercicio" (exercise) in their definition, they did attribute good health with the ability to perform hard physical work. For example, one patient shared with us some characteristics of a person who is healthy:

> *"Majun, ri rupaläj nuk'üt, rupanta k'a ri', ütz ütz titzu'un y runaq ruwäch chuqa' yekikot, e… kan nitz'e'en niqab'ij röj chi manjun ruyab'il ruma, jantape nisamäj, stape ya rij chïk po k'a k'o na ruchuq'a' che nisamäj, y majun natz'ët ta wi k'o nich'ito' ta rik'in ri raqän. Ruma e k'o ri yeq'axon ri b'aqil manjun, y niwa' ütz niwa' ütz, y chuqa' e…k'in jub'a' ruchajin ri' ütz ri' ruma manäq ruyab'il." (Patient_01)*

> *"…you can see it in their face, they seem really well, their eyes are full of joy… here we say that they do not have an illness because they can work… they still have strength to work… you don't see them complaining about their feet because their bones hurt – their*

> *bones are healthy. They eat well, eat really well… maybe they take good care of themselves and that's why they are not sick… they eat a lot of ichaj (greens)." (Patient_01)*

Both health experts and patients recognized the importance of joy as a statement of good health. This is important to highlight, given that emotions continue to surge as measures or influencers of good or bad health among Kaqchikel community members.

Theme 2: Indigenous people's relationship and history with food is one shaped by colonization, war, trauma, and poverty.

Both experts and patients highlighted the eating habits of their parents or grandparents (ancestors) as examples of health and habits that lead to a person being strong, happy, and taking preventative measures against disease and illnesses. However, health experts and patients alike acknowledge the history of poverty, displacement due to the war and economic hardships that forced their parents and grandparents (ancestors) to be resourceful with food, a legacy that continues for many patients today. One expert shared with us the difficulty of recommending healthy diets to patients when the patients may have very little to eat in the first place or have difficulty obtaining healthy foods:

> *"Pues si yojch'on chi rij ri comunidad. E… rije' k'o yeb'e pa taq juyu' nikikanuj taq kichaj o nikikanuj kibrocoli, k'o tal de que nikimol jun ti jub'a'. pero e… man jantape ta, nikimol porque ya yojch'o'n chi rij a nivel general, ri man jantape ta chuqa' nikimol konojel entonces con eso pues. Por ejemplo: taq nikitäj jun kisaqmolo' yin ruya'on apo kwenta de que k'o familias e ocho miembros, jun ejemplo entonces rije' nikib'än jun o ka'i' taq saqmolo' rik'in ke'en, chin como que ya nik'oje' más kichin ri e ch'aqa, y ya más nikib'än rik'in ri xkoya' nikiq'ut ronojel, entonces e… ja jun forma ri k'o chïk ch'aqa chïk familias pues ri nikib'än chïk xe ri xkoya' nikiq'ut y casi que xa xe jujun kiway nikitijla'. Entonces e… en lo personal pues k'ayiw jub'a' nuna'on porque ninwajo' ta ke nijalatäj chuqa' re re' pero manäq qa-posibilidad richin yeqato' ta richin yeqajäl." (HealthExpert_04)*

> *"Well, if we're talking about small rural communities. People there sometimes go up to the mountains to gather ichaj [leafy greens] or they get broccoli, so they gather what they can. But what they gather isn't enough, because if we talk about what they need and what they can gather, it isn't enough. For example: when they eat an egg, I have noticed*

> *that there are families of eight, just to give you an example, who between them prepare one or two eggs with corn masa [corn meal] just so that there is more to eat, and then they add a little bit of tomato sauce, so that is a way that big families make more out of very little and some even mix the egg with just the tomato sauce and generally they just have one tortilla each. So personally…personally one feels sadness [grief] because one wishes they could change this reality for them, but we cannot, there are no possibilities of helping them." (HealthExpert_04)*

Patients often receive recommendations to eat better, healthier foods from their healthcare providers and recognize healthy foods that their ancestors ate yet find it difficult to connect those two concepts to one another. Although many patients understand what their parents and grandparents ate to be healthy, they also recognize the poverty their ancestors lived in. One patient shared with nostalgia the differences she sees in the foods her children consume today compared to those consumed by her parents and grandparents:

> *"Ri qati't ri qamama' rije' puramente natural xewa' je', tal vez xkitïj ki-caldo rije' niqab'ij chi ke, pero tal vez hasta cada quince, o hasta cada mes. Pero wakamin, wakamin, más lo que k'o jun chïk xtinb'ij apo, por ejemplo ri ingrediente, lo que son sazonador, consomé ronojel ri', rïn majun nib'än ta consumir ri'. Pero ri nu-familia rïn majun xink'üt ri' chi kiwäch, pero rije' nikik'ama' … ri fideos ri sopas… nikib'ij chi re, nikib'än preparar. Wakamin como que ri ak'wala' manäq ta qak'utun pe chi kiwäch ri natäj a hierbita, a-chilmolito con pepita, como que manäq ak'utun chi kiwäch ri ak'wala' nikib'än wakamin. Ja ri ru-diferencia, porque ri qati't qamama', me recuerdo nutzijoj mi-difunta mamá rija' xk'ïy pe en la pobreza, ¿Achike comida nikib'än entonces? Nuk'ilij jun oxi' o kaji' ri chaqij ik y nib'an qa jun xti' chilmolito y ri tortilla… nub'ij ri numama', ja nuke'ej podrido, lo que es röj wakamin niqaya' chi ke ri awäj niqab'ij chi re, ja ri q'aynäq ta k'a ri', ja ok ri' xkib'än consumir qate' qatata'. y rije' majun yab'il ta tal vez niqaxaj ta ri yab'il como ri situación wakamin, jun ak'wal k'a ri naläx ya ruk'amon pe lo que es la diabetes ¿Por qué? Porque pa rukik'el ri te'ej k'o pe, o pa rukik'el rutata' k'o wi." (Patient_06)*

> *"our grandparents [ancestors]ate very naturally, they ate their caldo [stew] every two week or once a month. But today… what we see a lot today…for example…these ingredients that we use to flavor food like the seasonings, beef/chicken bouillon – I don't consume it but my family – even though I didn't teach them that .. they go and buy those soups… those instant soups and prepare them. Children today behave as if we didn't teach them how to eat ichaj [leafy greens] or dried squash seeds with traditional tomato sauce. Because our grandparents[ancestros] ate well… I remember what my mother told me… she grew up in a lot of poverty…what did she eat? They use to toast 3 or 4 chiles and back then they would make their tortillas out of the corn that we would consider rotten today (the corn that we throw away so easy today) but they didn't get as sick as*

> *we do today…they didn't have many of the sicknesses that we see today.. . today children are born with diabetes because the mother has it in their blood or the father has it in his blood." (Patient_06)*

Indigenous patients and health experts find themselves in a difficult space when managing nutrition-related chronic diseases. On one hand, both recognize the growing access and targeting by fast food and cheap food companies towards their communities while at the same time carrying the legacy of poverty and starvation of their parents and grandparents. Neither option is sustainable nor desirable, but consumption of fast and cheap foods is a rapidly growing trend among Indigenous people.

It is important to approach nutrition-related chronic disease management with and understanding of the history of and ongoing efforts of colonialism against Indigenous peoples in Guatemala. One health expert shared with us the importance of viewing the current alarming rates of malnutrition and nutrition-related chronic illnesses as an accumulation of policies that have denied Indigenous communities' access to food and land the last 500 hundred years. Our expert said:

> " … Y ri jun chïk chuqa' e… digamos ri qa, la desnutrición niqab'ij chi re', porque ja ri causa ja ri k'o ruxe'el pero jampela yab'il, la qetaman chi la digamos histórico pues como más de 500 años. – Y röj, ruma öj nata' jun digamos como jun pueblo e mita chïk, si no que röj oj nïm, ¿Achike ruma? Entonces Porque jampe la desnutrición más de 500 años desnutridos manäq ütz yojwa'" *(HealthExpert_02)*

> *"malnutrition…as we very well know, is the cause, the root of so many of the illnesses we see. We know, we know very well that it is historic right…for over 500 years.. for 500 years…we are not a people of short stature or that doesn't grow this is rather due to the malnutrition we have lived through…we have never eaten well that is why…" (HealthExpert_02)*

Recognizing the legacy and ongoing efforts of colonialism and the role it plays in understanding nutrition among Indigenous Kaqchikel communities does not negate the role that more recent trends of excess availability and marketing of poor-quality foods have played. Ancestral wisdom

of nutritious foods persists with our parents and grandparents and should be a resource that inform policies and initiatives for the management of nutrition-related chronic diseases.

Theme 3: Kaqchikel language is essential to the health and happiness of our people.

Most health experts and patients recognize not only the importance of providing services in Kaqchikel but of having a provider that respects, honors, and validates the use of our language. Health experts shared the reactions of gratitude and relief their patients have when they are spoken to in Kaqchikel.

> *"achi'el xinb'ij chawe. Ri Janila' k'atzinel, chwe rïn richin ye'into' ri winaqi'. Chuwäch ri oken chi re ri aq'omanïk wachoch, k'o rutzijol chuwäch ri xan, yatinwaq'omaj pa qach'ab'äl, chuqa' pa kaxlan ch'ab'äl, jantape ke ri nub'ij ruxan wachoch, ri winaqi' ütz nikak'axaj ruma nikib'ij: To wawe xkech'on pe chwe, rïn wetaman ütz ri qach'ab'äl, man ïn achi'el ta ri nikitijoj ki' niketamaj jun maya' ch'ab'äl, loman yetzijon majun k'ïy ta ketaman, k'o b'ey napon pa kijolom, k'o b'ey majun, po nukaqchikel janila' tz'aqät, achi'el ri yetzijon wawe…" (Healthexpert_03)*

> *"as I was explaining to you. It [Kaqchikel] is very useful to me, it allows me to help my community. I have a sign outside my clinic, it says: I can provide services in our language [Kaqchikel], and in Spanish. With just that, people get excited because they often say – here they will value and hear me – I am a native speaker, others learn the language but their understanding [of culture] is limited, there is much they don't understand or they use words we don't use, I speak like our people speak …" (Healthexpert_03)*

Although some patients expressed that some words are easier said in Spanish like "diabetico" "pastilla" "capsula" "presion" or "dolor" other shared that communicating the complexity of their symptoms and concerns was easier in Kaqchikel with phrases like:

- "ri b'is xer yak pa ru nuyab'il" – "it was sadness/grief that kickstarted my symptoms and illness"
- "nuwi' xer chapapa…nu pachij rupam nuwi" – "it started with headaches…it felt like my head was being split from the inside"

- “ma nu rayij ta atix nuba’n cha nurusrin ri wuchulej chin wach” – “I lost all desire to do anything I could see my surroundings/environment spinning around me”

Patients expressed being unable to provide that level of detail to a provider who does not speak their language and agreed that meeting with a provider that speaks their language would likely be a different experience. More so, patients expressed sadness at the thought of their elders or other community members who cannot speak Spanish. Most patients stated having at least “basic” ability to use Spanish, yet all acknowledge that medical terminology is difficult even for those who speak Spanish. For example, one patient said:

> *“Ri español k’o ri qa-niqab’än niq’ax pa qawi’y yojch’o’n utzil, pero k’o qach’alal manäq qitzij yech’on español pero yatzijon rik’in jun medico jun chïk rutzijonïk nub’än rija’, ahora si indígena ta, ri medico entonces ri medico nub’än nitzijon awik’in rik’in ri idioma o sea qa-idioma peja’ pero ja taq manäq, to ja ri nib’anun chi ke ri winäq, ri winäq nikib’ij xu majun chike ta nub’ij pe chwe, porque ri medico tal vez nub’ij pero manäq napon ta pa awi’de que ¿Achike ruchapon rub’ixkil chawe?, ja ri ri obstáculo nintz’ët rïn y ninwak’axaj rïn ri winäq manäq nikikanuj ta ri médico.” (Patient_02)*

> *“Spanish is something some of us understand, a little, but there are a lot of our people [Kaqchikel] that do not speak it [Spanish] maybe they speak it but a doctor uses a lot of big words or explains with a lot of details and that we do not understand. Now if the doctor is one of us [Indigenous Kaqchikel] then they do speak to you in our language [Kaqchikel]. But if not that is why we hear our people say – the doctor didn’t say anything – the doctor might’ve said something but we might have not understood them … it’s a misunderstanding.” (Patient_02)*

Although most health experts in this study speak Spanish and Kaqchikel, a skill they often use with their patients, most patients in this study did not interact with a provider that spoke Kaqchikel. Only one patient received services at one of the organizations mentioned in this study and the patient said that sometimes her services were in Spanish and sometimes in Kaqchikel.

Understanding of illnesses in Indigenous Kaqchikel communities

One stark difference among health experts and patients was the concept of disease development. Specifically, how these nutrition-related chronic diseases such as diabetes and

hypertension emerge in their own lives. Most health experts attributed the rise of nutrition-related chronic diseases among indigenous communities to poor diet and lack of exercise. Although two experts mentioned that these nutrition-related diseases (diabetes and hypertension) have always existed in our communities. There is agreement among health experts that poor dietary choices, due to the increase accessibility of highly processed/fast foods, and the decrease in physical activity have contributed to the rise of these diseases. For example, one expert when asked what has contributed to the rise of diseases such as diabetes and hypertension in our communities mentioned the following:

> *"Según ri wetamab'äl rïn wakamin es de que e…röj niqatïj como k'ïy cosas como niqab'ij chi re chatarras, peja entonces ja ri niqab'ij chi re' ri grasas saturadas ronojel riri', rumak ri ri' nijote' qa-colesterol falta de actividad fisica, junam rik'in ri presión, por ejemplo e… ya niqatïj k'ïy atz'am, man niqab'än ta ejercicios y ri qa-dieta man balanceada ta peja kamin. Y si niqaya' pa kwenta' ronojel ri niqatïj e… xjalatäj , achi'el antes yewa' como que más natural peja pero wakamin ronojel ya quimico peja y k'o k'ïy atz'am o azúcar o k'ïy grasa saturada rik'in ruma k'a ri yojrub'än afectar." (HealthExpert_07)*

> *"Well, from what I know now, we consume a lot of cheap, highly processed foods right and saturated fats and that is why our cholesterol goes up. Also, the lack of exercise that has to do with our blood pressure. Also, that we do not drink a lot of water, we eat a lot of salt, we don't exercise. Also, if we are being honest a lot of what we ate before has changed because in the past they [our grandparents/ancestors] ate... how do you say it…much more natural? But now, everything has chemicals, has a lot of salt or sugar, a lot of saturated fats in everything and that eventually affects us." (HeatlhExpert_07)*

Most patients on the other hand attributed their diabetes and hypertension or other chronic illness to emotions. Although some acknowledge the role of fast foods and fried foods as contributing to the rise of these illnesses in their communities, most identified emotions as the root of their own illness.

> *"Man niqab'än ta kwenta' qi' tal niqatïj qa deplano que ja ri' nib'anun y k'o chuqa' yekib'ij ruma desesperación , yab'ison dice que nitok la yab'il la chawe', k'ïy cosas achi'el chupan ri tiempo re' xoqila' jun tiempo tan dificiles, niqab'än ri xtaq qasamaj majun chïk yojtoj ta, y majun chïk chi yeb'e ta y chi ri nipe desesperación, porque e k'o*

> *a familia y chuke naya' chi ke, y ke ri y como manäq chïk öj kow ta, ja nitok la yab'il la chawe." (Patient_04)*
>
> *"There are some things that we eat that aren't very good for us and I suppose those affect us but there are a lot of people who say that it is also because of desperation, that if one is very sad or grieving that is why the sickness enters our lives. There are a lot of things, like these times when we are living in very difficult times when one works but one is not paid for that, you can go into desperation because you have a family and what are you supposed to feed them? And if one is not very strong then the sickness enters easily into our lives." (Patient_04)*

Another patient said:

> "*Rub'anikïl ¿Cómo es que taq ntok re jun enfermedad re'? No se cómo Ahike rub'anikil ri ki-situacion ri winäq taq kik'owisam pe kiq'asam pe, ri iwïr kab'ijïr kan ri e jampe ri e k'o ri diabetes chi ke, por mi parte ri nu-salud rïn pues xinwil, puramente ri jun susto, que fue en mi niñez, y rïn pa siwan nink'ama' nuya' taq xinqatïj en tiempo de verano, y nuxib'in wi' chi kiwäch kumätz, y xinxib'ij wi' pa violencia y chi ri petenäq ru-proceso. Y como ri kik' xa jun ok tiempo ri fuerte nub'än , y de luego como que niqab'ij chi re' ri kik' nerb'ana' agotar ri', nerb'ana' agotar ri', y es por eso que ntok pe diabetes." (Patient_06)*
>
> *"How does this sickness begin? I don't know how or what has happened in people lives yesterday, a few weeks ago or years ago. But in my case, what affected me was fear, fear in my childhood when I had to go down to the ravine to look for foods that we would eat during the summer, I got scared by snakes and also, I got really scared during the violence [war] and like that it has been a long process and since the blood is only strong at certain times in life and then it weakens. It weakens and that is why diabetes starts." (Patient_06)*

Although health experts in this study expressed being open to patients' perspectives and their beliefs about their disease that is not the case for most healthcare providers specially those operating in the public health sector. Numerous barriers have yet to be overcome to achieve true intercultural medical partnerships between the government ran health structure (mostly informed by western medical practices) and the Maya medical system (informed by ancestral knowledge) (Hitziger et al., 2017).

Limitations

There were several limitations to this study. First, our sample was relatively small and although our team recruited a diverse and wide range of health experts and patients our sample was still mostly concentrated to one region of Kaqchikel speakers. Second, our data collection was all done remotely via zoom or phone call due to the COVID19 pandemic. Although we experienced no technological problems, we know we would have built better trust with participants had these conversations happened in person between Indigenous researchers and participants following cultural norms and protocols. Third, the Kaqchikel language has several variations depending on the region where it is spoken. Although one of the researchers spoke the variation most of our participants spoke, it may still be possible to have missed something. Finally, our findings may not be generalizable to other indigenous communities around the world, but they do contribute to a growing body of research on the need to bring Indigenous languages at the forefront of healthcare programs, delivery, and policy.

Discussion

It would be impossible to talk about Indigenous Maya languages without acknowledging the long history that has suppressed them and worked to systemically erase them. Speaking a Maya language is widely considered a central piece if not the most important piece of Indigenous identity in Guatemala (England, 2003). Nevertheless, hundreds of years of racism and hate towards Maya language speakers in Guatemala has inevitably internalized the belief that speaking our languages deem us inferior therefore they should be forgotten (Montejo, 2005).

This was particularly striking during our interviews in this study. Both researchers who conducted the interviews are Indigenous Kaqchikel Maya women who have had the privilege of studying their language and have learned to write it, read it, and reclaim its value. All health

experts were educated in western systems as well and expressed similar pride and value in our language and the need for it in healthcare – it is worth mentioning that five out of our eight health experts work for an NGO that focuses on language restoration. Most patients when asked about having a provider that speaks their language affirmed that they did speak Spanish ranging from "basic" to "very good" and could most of the time communicate with their providers. Being asked if having access to services in their languages would be better for them most responded with *"I can speak Spanish"* or *"I don't speak full Kaqchikel, I mix it with Spanish so speaking fully in Kaqchikel would be hard."* We learned from this process that asking Indigenous patients if it would easier for them to have a Kaqchikel speaking provider contributes to the marginalization and shame they have been made to feel for not speaking Spanish. It was not until the end of the interviews when participants were asked to share anything they wished that most, health experts and patients, expressed gratitude for having the opportunity to share their thoughts and ideas in Kaqchikel.

The themes that emerged from this study were not surprising findings to us as Indigenous Maya women working in public health. Health experts and patients alike recognized that as Indigenous peoples we have our own understanding of health that is rooted in community. Health experts spoke of the important role family play in helping a patient manage their nutrition-related chronic condition. Family members participate as both translators and economic and emotional supporters; they also help monitor medication uptake and preparing healthy meals. Most patients supplement their medications or rely solely on medicinal plants for their disease management. This knowledge is obtained through conversations with other patients in their communities—elders, traditional healers, and family members. These examples contrast with the westernized hegemonic biomedical approach (Menendez 2020), taken by the

Guatemalan public health system for the management of nutrition-related chronic diseases. Furthermore, this westernized hegemonic model ignores the Maya medicine model from which Indigenous patients draw extensive support and knowledge.

The malnutrition rates among our Indigenous communities in Guatemala are staggering. Guatemala has the highest percentage of chronically malnourished children (over 50%) in Latin America and the fourth highest in the world, impacting predominately the Indigenous population (UNICEF, 2007). Furthermore, the double burden of malnutrition, which refers to both the existence of under-nutrition and obesity, which is increasing in Guatemala (Ramirez-Zea et al., 2014). Although much of this problem is attributed to changes in diet and physical activity along with high rates of poverty, little mention is made of the historic and ongoing colonialism that burdens Indigenous communities.

Health experts and patients that we spoke to in this study recognized the role of the lack of access to land for sustainable food sources, trauma from the war and increased access to cheap, highly processed foods as key components to the increase of nutrition-related chronic diseases in their communities. We echo the thoughts of one of the health experts we interviewed that Maya people's relationship with food is intertwined with the history of starvation, poverty, discrimination, and racism over the last 500 years.

The findings in this study highlight the need to integrate Maya languages in the health system to improve health outcomes of Indigenous peoples in Guatemala. Yet, we must underscore that these efforts should parallel efforts to educate providers, researchers, organizations, etc. on the history of Indigenous peoples. Particularly, the historic and ongoing colonialism that is connected to nutrition and access to healthy foods and land. Additionally, this education must extend to Indigenous patients as well. Indigenous Maya people have their own

journey in coming to terms with and understanding their identity, language, spirituality, and worldview. Most have been denied the opportunity to talk or learn about the historic injustices that contribute to their lack of access and representation in various spaces including healthcare.

Conclusion

Our historically starved community will continue to consume highly processed, nutrient poor foods at the same time that we distance ourselves from ancestral foods such as *ichaj* (variety of leafy greens) to survive in a society that continuously denigrates our identity, way of being and thinking. It is therefore the duty and responsibility of healthcare leaders, experts, and academics to be the leaders in changing these dynamics by intentionally integrating Indigenous perspectives in public health efforts.

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