The Experience of Managing Type II Diabetes Among Indigenous Maya in the Western Highlands of Guatemala

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With assistance from the Hospitalito Atitlan, the primary referral hospital in the region, I conducted semi-structured interviews with a purposive sample of 41 people with diabetes. Patients were recruited from diabetes clubs at different health centers and a private clinic. I wanted to take a look at the experience of diagnosis, access to treatment, and management of type II diabetes among Tz’utujil and Kaqchiquel Maya in order to try to understand the factors that contribute to their experience.

There are key features in diet, history, and gender roles that with further evaluation could reveal an explanatory model for the factors associated with managing type II diabetes among indigenous Maya. The population of the lake region incorporates ethnic medicine with biomedical treatment, so that there is not just one solution for managing type II diabetes. While most of the people interviewed were receptive to medication from their health care providers, there was division among those who preferred herbal remedies and those who preferred taking both medication and herbal remedies. Cost was identified as a major barrier in attempting lifestyle change. Patients expressed a sense of distrust toward their health care providers that caused them to withhold information about their lifestyle change attempts and medication adherence. Overall, the experience of managing type II diabetes among indigenous Maya is one that is filled with hardship, loneliness, and alienation.

Keywords
type II diabetes, chronic illness, biomedicine, natural remedies, health transition, post-colonialism

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THE EXPERIENCE OF MANAGING TYPE II DIABETES AMONG INDIGENOUS MAYA IN THE WESTERN HIGHLANDS OF GUATEMALA

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Type II diabetes is a chronic condition that has impacted many populations around the world. Diabetes is a chronic illness that causes one’s blood sugar levels to rise above normal, which can lead to serious health problems, such as nerve damage and loss of eyesight (“Type 2 Diabetes,” ADA, 2018). Among people of all ages, 2015 data indicate that an estimated 30.3 million people – or 9.4% of the U.S. population – have diabetes (National Diabetes Statistics Report, 2017). In the last 34 years, the number of people affected with diabetes worldwide has risen from 108 million to 422 million (World Health Organization [WHO], 2017). The global prevalence of diabetes among adults over 18 years of age has almost doubled from 4.7% to 8.5% in the last 34 years (WHO, 2017).

Diabetes, once attributed to wealthy nations, is increasingly and disproportionately impacting low- and middle-income countries (Pacheco, 2015, 1). In developing nations, people between the age of 35 and 64 are the most frequently affected, which makes the years lived with disability (YLD) and disability-adjusted life years (DALY) a heavier burden relative to other countries (Boutayeb, 2005, 193). Guatemala has entered what is known as the fourth epidemiological transition characterized by the coexistence of suffering from the underdevelopment of noncommunicable and degenerative diseases, sometimes known as “diseases of civilization,” along with the reemergence of the importance of infectious diseases like HIV (Becerril-Montekio and Lopez-Davila, 2011, 199). These diseases include diabetes and are thought to be a product, in part, of modern day lifestyles. However, while biological processes play a role in the onset and spread of type II diabetes, social and cultural processes are significant components in the “change in quality and quantity of energy consumed (diet) and energy expended (physical activity)” (Ferzacca, 2012, 412). As a result, this has led to scholarly

Introduction:
consideration of the relationship between culture and diabetes. The purpose of the study is to
depend on the topic of type II diabetes.
Literature Review:

Santiago Atitlan is a small town situated next to Lake Atitlan which sits between two volcanoes: Volcan Toliman and Volcan Atitlan. The vast majority of the population is indigenous, and the primary language spoken is Tz’utujil. Few people speak Spanish, and even fewer can read and write in Spanish. The indigenous Maya of the lake region are a population with a history full of violence and discrimination. “For nearly five centuries, the Tz’utujil Maya have experience repeated cycles of conquest: first by imperial Spain, in 1524, and later by international and local capitalism, as well as state terror during the Guatemala Civil War from the 1960s to the 1990s” (Nagata, Smith, Barg, Guidera & Bream, 2011, 10). Colonialism, natural disasters, and local and foreign powers are all forces that have contributed to the current state of struggle among the people surrounding the lake region. These are forces that still have influence through the government and its different aspects, including healthcare. In my analysis, I will describe how the legacy of government response to colonialism, natural disasters, and local and national politics has continued to marginalize these communities.

Most of the literature on type II diabetes addresses the obstacles patients face when seeking treatment, whether it be the distance from one’s home to the clinic or the high price of medication, and little research has been done on the experience of managing diabetes and the experience of taking medication among minority or low socioeconomic groups. A study on health perceptions among American Indians with type II diabetes found a strong correlation between personal control and health perceptions. American Indians who described themselves as feeling more in control of their illness had better perceptions of their health (Patel, Davila, Patel, & Norman, 2014, 37). The more control a patient was perceived to have, the less concern there was regarding their health. Another study on diabetes self-management among Australians from
a low socioeconomic background revealed that the experience of managing type II diabetes was an emotionally, physically, and socially challenging one, and the main themes that arose from patient narratives included “the work in managing diabetes,” diabetes as a silent killer, and “access to resources and services” (Carolan, Holman, & Ferrari, 2014, 1014). Participants in the study were uncertain and “fearful of what additional complications they might face in the future” (Carolan et al., 2014, 1015). Distress, disbelief, and a feeling of unfairness at the time of diagnosis were common reactions among patients, and the new level of personal responsibility required for diabetes care gave rise to feelings of loneliness and isolation (Carolan et al., 2014, 1015). There was difficulty transitioning into a routine form of care.

Another study looked at type II diabetes among African Americans in Chicago and focused on their experience with type II diabetes medication. This article was recently published in 2017, and it also noticed the lack of literature surrounding the discussion of the experience of managing type II diabetes. While medicinal practices and beliefs have been documented, there is hardly any literature that focuses on the experience of taking diabetes medication (Bockwoldt, Staffileno, Coke, Hamilton, Fogg, Calvin, & Quinn, 2017, 363). Cost and access are among the most addressed issues in literature on adherence to diabetes medication, but not on adapting to treatment (Bockwoldt et al., 2017, 364). Participants often had a negative perception of their type II diabetes diagnosis and medication, and these strong negative reactions affected medication adherence significantly (Bockwoldt et al., 2017, 366). There is a connection with the way in which the person receives and perceives their diagnosis and medication adherence.

However, the experience with managing type II diabetes can also direct the conversation of chronic illness toward tensions in various aspects of the patients’ lives, such as the transfer of responsibility from doctors to patients, the use of biomedical technology to discipline
personhood, and the transformation of the body into a “pharmaceutical normal” (Langdridge, 2016). In this case, the pharmaceutical normal refers to a compliant patient who is willing to take the medication prescribed without question, a form of biological citizenship a person of “ill-health” is expected to follow. Concepts like Adele Clarke’s biomedicalization, Adriana Petryna’s biological citizenship, and Nancy Scheper-Hughes and Margaret Lock’s look at the transformation of health in biomedicine contribute to components of the overall experience with diabetes (Clarke, 2003; Petryna, 2013; Scheper-Hughes and Lock, 1990).

Clarke’s thesis on biomedicalization describes “…the increasingly complex, multisited, multidirectional processes of biomedicalization, both extended and reconstituted through the new social forms of highly technoscientific biomedicine” (Clarke, 2003, 161). There are five key processes described within biomedicalization: “Economics: The U.S. Biomedical TechnoService Complex, Inc.; the focus on health, risk, and surveillance; the technoscientization of biomedicine; the transformations of information and the production and distribution of knowledge; and the transformations of bodies and identities” (Clarke, 2003, 161). Biomedicalization is a key term in understanding the processes involved in shaping the identity of a person when transitioning from a healthy person to a patient with diabetes.

Biological citizenship is “…a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it” (Petryna, 2013, 68). Biological citizenship is in essence the reward received for the degree of injury suffered. Biological citizenship is often used by the government through the health care system in order to dictate the kind of patient a person has to be when diagnosed with a chronic illness. This goes hand in hand with Nancy Scheper-Hughes and Margaret Locks’ description of health and ill health. “Health is increasingly viewed in the United
States as an achieved rather than ascribed status, and each individual is expected to “work hard” at being strong, fit, and healthy. Conversely, ill health is no longer viewed as accidental, a mere quirk of nature, but rather is attributed to the individual’s failure to live right, to eat well, no exercise, and so forth” (Lock and Scheper-Hughes, 1990, 494). Health is individualized in biomedicine, and this transition of health responsibility to the patient affects the way people are able to manage type II diabetes in their context.

Furthermore, Scheper-Hughes and Lock take a look at the community and government with the three bodies: the individual, the social, and the politic. “At the first and perhaps most self-evident level is the individual body, understood in the phenomenological sense of lived experience of the body-self. We may assume reasonably that all people share at least some intuitive sense of the embodied self as existing apart from other individual bodies” (Lock and Scheper-Hughes, 1990, 483). This idea of the individual person is pretty unique to Western medicine and culture since it shifts away from the collective structure that is often found in other cultures. At the second level of the body, Scheper-Hughes and Lock also describe how the body is used to represent certain images about society. “At the second level of analysis is the social body, referring to the representation uses of the body as a natural symbol with which to think about nature, society, and culture” (Lock and Scheper-Hughes, 1990, 483). In a broader view of the body, Scheper-Hughes and Lock acknowledge the role of the government in the regulation of bodies in several contexts. “At the third level of analysis is the body politic, referring to the regulation, surveillance, and control of bodies” (Lock and Scheper-Hughes, 1990, 483). In this case, I would be taking a look at the government’s role in regulating the body in the context of health and medicine.
Through an analysis motivated by the concept of biological citizenship, illness identity, body perceptions along with biomedicalization, I look to bring new understandings on the process of diagnosis and treatment for type II diabetes and the relationship between the individual experience and broader sociopolitical processes around the lake region in rural Guatemala in order to present the current situation of indigenous Maya in managing type II diabetes.

Maize and Diet

One of the key features of indigenous Maya culture is corn as a staple diet item, but it should be limited in the diet because of its effects on glycemic control. Breakfast often includes a cup of *atol de elote*, a corn based drink, or *mosh*, an oatmeal drink with milk and sugar along with a piece of sweet bread. People on the street sell fresh homemade corn tortillas on the streets at any hour at an affordable price. They are cheap, and they fill an empty stomach. It is difficult to imagine having a meal without tortillas, and this is why being told to cut corn from their diet is an impossibility.

It is interesting to notice that while corn has been a part of their diet for hundreds of years, type II diabetes is a recent development for this population. “[M]aize is the central cultural object that represents a Maya connection to the land” (Huff, 2006, 79). More specifically, the indigenous Maya of the Lake Atitlan region have a “relationship to the land, lake, and mountains” that “is central to daily existence” (Huff, 2006, 79). The cycle of maize production and consumption represents family and community life, demonstrating strong ties between maize and social relationships (Huff, 2006, 79). Maize is linked to spiritual, cultural, and social activities, and this makes it the all-encompassing “substance of life” (Huff, 2006, 81). The *Popol Vub*, a text often described as the “bible” of the Mayas of highland Guatemala, explains that
maize is the primary staple for the people of Mesoamerica, and it is the material from which humans are formed, and it is the main source of nourishment for humans (Huff, 2006, 84).

One of the reasons type II diabetes has emerged fairly recently is that the quantities of food consumed have changed. One of the nurses from Hospitalito Atitlan mentioned that a person consumes an average of 30 tortillas a day. The amount of corn consumed overall in a day is more than needed. Another contributing factor to the change in diet among indigenous Maya is the influx of processed foods and substances, such as Coca-Cola and Pepsi that are largely a product of “Coca colonization,” a term synonymous to cultural imperialism (Nagata, Barg, Valeggia & Bream, 2011, 298). The transition to market-based economies in Latin America has led to increased availability of calorie-dense but nutrient-poor processed foods (Nagata et al, 2011, 298). While most Tz’utujil Maya in Santiago Atitlan know that Coca-Cola is harmful, about a third of the respondents believed Coca Cola to be a healthy product due its medicinal value and refreshing qualities (Nagata et al., 2011, 306). Soft-drink companies such as Pepsi target small shops and offer to paint the shops for free if a certain amount of cases is sold (Nagata et al., 2011, 308). The licuado, smoothie, trend has also caught on, and there are all kinds of licuados made with fresh fruit, scoops of baby formula, and sugar. The people of the Atitlan region have been introduced to processed foods from other countries without being informed of the consequences from consuming the products.

In addition, lifestyles are different, and people may be getting less exercise. Tuk tuks, or small taxis, are becoming increasingly popular because they are cheap and convenient. However, this means that people spend less time walking. Diabetes pamphlets distributed at diabetes clubs encourage people to reduce the use of tuk tuks and to walk more. Lifestyles also change when it comes to marriage. Unmarried women of the region may lead more sedentary lifestyles since
there is no need for the daily labor and work a married woman must do when she has a husband and children to care for (Nagata, 2008, 14).

Gender Roles

The indigenous Maya of this region are a conservative population. Women are expected to wear their traditional garments, keeping their shoulders and knees covered, whereas it is acceptable for men to wear Western style clothing, though many do wear their traditional clothing when in town. Machismo is also strong aspect of this region. It is acceptable, and often expected, for a woman to assist with household chores in preparation for running a household after marriage. The role of the woman is to care for the children and the home while the men occupy public spaces and provide economically for the family (Wehr, Chary, Webb & Rohloff, 2014, 100). When women work, they are expected to fulfill certain roles. Women are thought to be better suited for harvesting delicate crops because they have more nimble hands, and they are believed to be doing what should come natural to them from working at home (Fischer & Benson, 2006, 85). While women embody traditional elements of their culture, they are also monitored by men and older women who discipline them if they violate the norms (Wehr, Chary, Webb & Rohloff, 2014, 100). Women are usually criticized by their community and extended families if they violate traditional authority structures and gender roles (Wehr, Chary, Web & Rohloff, 2014, 100). Gender relations research in Latin America involves many narratives of unhappy marriages and explanations for male behavior (Ehlers, 1991, 1). These relationships and roles women and men are expected to fulfill influence the experience of managing type II diabetes.
The health system in Guatemala is composed of a public sector and a private sector. My focus was on the public sector, which involves the Ministry of Public Health and Social Assistance (MSPAS), which focuses on 70% of the population, the Guatemalan Institute of Social Security (IGSS), which offers coverage for less than 17.45% of the population, and Military Health, which offer coverage for the armed forces and police including their families at less than 0.5% of the population (Becerril-Montekio, et. al., 2011, 200). While the intentions of the *Modelo Incluyente de Salud* (MIS) are conveyed in a way that demonstrates concern toward providing healthcare to the whole population, only a select few actually have access to coverage. There were forces larger than the individual at play in providing limited access to healthcare resources.

For further background information, I interviewed a doctor in charge of a health center in Santiago Atitlan who also works at the Ministry of Public Health. He explained that the *Modelo Incluyente de Salud* was a new program that was recently introduced by the Ministry of Public Health in Guatemala. This program includes three levels of attention. The first one is at the community level, where you would find the *Puestos de Salud*, or small health program centers mainly run by nurses. The second level corresponds to the clinical level, such as the *Centro de Salud*, or health centers run by doctors and nurses. General tax is the source of funding for the Ministry of Public Health and the Ministry of Public Health provides funding for the *Centros de Salud* (Becerril-Montekio, et.al., 2011, 198). At the third level is where you find regional hospitals where patients can receive specialized attention. Below is a chart that shows the sources of funding for healthcare institutions in the public health sector in Guatemala (Figure 1).
Figure 1: Chart demonstrating the sources of funding for the public health sector in Guatemala (after Becerril-Montekio & Lopez-Davila, 2011).
MIS is a model that strengthens attention at the community level, also referred to as the first level of attention. More specifically, MIS functions through four perspectives: the right to health, interculturalidad, gender, and the environment. In order to address these four aspects, MIS has divided attention at the individual level called Programa Individual de Salud, or PIAS; attention at the family level called Programa Familiar de Salud, or PFAS; and attention at the community level called Programa Comunitario de Salud, or PCOS. However, the core of MIS is self-care, a concept that aligns closely with the biomedical definition of health in a community where health is not defined individually.
Research Method:

Through discussion and dialogue with the Hospitalito staff, a purposive sample of the population, Kaqchiquel and Tz’utujil, was recruited from diabetes clubs and a private clinic in Santiago Atitlan to participate in semi-structured interviews since those who attended have been formally diagnosed with type II diabetes. For the purpose of the investigation, the patients had to be 18 years or older and formally diagnosed with type II diabetes. Patients were provided a description of the goal and purpose of the research and the steps of the interview process. My research question was what is their experience with diagnosis, treatment, and management of type II diabetes. Before each interview, the patient was informed that the interview would be recorded and transcribed. After the transcription, the recordings would be erased in order to maintain patient privacy. Patients were asked for their consent to be recorded. The recordings were initiated only after receiving the patient’s verbal consent. Patients were asked their age before moving on to the rest of the interview questions. Patients were informed that if at any moment they had to leave or felt uncomfortable, they could leave.

My list of questions, originally asked in Spanish, included:

- Could you describe the moment you were first diagnosed with type II diabetes?
  - How did you feel when you were told you had diabetes?
  - How old were you when you were first diagnosed?
  - Have you been hospitalized due to your condition?
    - If so, how did you feel when you were hospitalized? How did you feel when you went back home after being hospitalized?
- How did you consider your state of health before being diagnosed? In what way?
- How did you consider your state of health when you were diagnosed? In what way?
- How do you consider your state of health now? In what way?
- Have you ever felt any confusion about your state of health since being diagnosed with diabetes?
- Could you talk to me about symptoms you felt before seeing a doctor and being diagnosed with diabetes?
  - What motivated you to seek help from a doctor?
  - Did you feel something out of the ordinary?
- How has your lifestyle changed with diabetes?
Are there things you could do before that you feel you can’t now due to diabetes?
- How do you feel about your future with diabetes?
- What have you done to manage your diabetes?
  - Have you sought alternative (to the pills)?
- Do you take medicine now for your diabetes?
  - What memories or thoughts surge when you see/take/think (about) the medicine?

The questions were related to the patient’s experience with their diagnosis and treatment of type II diabetes. I conducted a total of 41 semi-structured interviews in towns around the lake region, including Santiago Atitlan, Panajachel, Agua Escondida, San Pablo, Godinez, San Lucas Toliman, Las Canoas San Andres, and Santa Clara.
Results:

There were some key themes that arose in several interviews, such as comfort and discomfort with natural remedies and/or pills (metformin/glyburide) and difficulty in accessing diabetes medication before switching over to the diabetes clubs. There were three categories of treatment that patients followed: those who took only pills (metformin/glyburide), those who took both pills and natural remedies, and those who only took natural remedies. There were mixed thoughts on diabetes being a curable or incurable disease since some patients thought diabetes was something that could come and go whereas others knew that it was for life. Responses on their perceptions on their state of health before, during, and after diagnosis varied; however, the overall experience managing type II diabetes is one filled with hardships related to feelings of alienation, loneliness, and hopeless indifference. In my analysis, I address the political and economic forces that have shaped the current situation of a person managing type II diabetes in the lake region community.
Analysis:

To analyze the interviews, I used a qualitative analysis program called NVivo in order to determine recurring themes throughout patient narratives. I made six nodes, or categories, in order to code patient narratives. The following codes were created: alternative diabetes treatments, feelings about pills, obstacles in getting better, state of health before diagnosis, state of health when diagnosed, and state of health after diagnosis. I then did a synonym and specialization word frequency query (WFQ) in order to find the words most used when describing the situation under each node theme. After this, I did a text frequency query (TFQ) search in order to create a word tree to see the terms throughout the general narrative. This was key in determining whether the term had meaning outside of its context, or its node group. The terms highlighted reflect the terms that came up most in the WFQ. All search, queries, and nodes were run on NVivo under a Spanish language setting of the program.

There were many variations when it came to patients’ health perceptions during diagnosis and after diagnosis; however, the overall experience managing type II diabetes is one filled with hardships related to feelings of alienation, loneliness, and concerns of lack of means. The frustration and distress expressed with their diagnosis could stem from their recognition of the lack of support they will receive from the government in managing a chronic illness that requires routine intervention. Before diagnosis, patients generally had a similar perception of their state of health. They considered themselves normal. God and family were common themes among people who described a more positive outlook regarding their illness. People who mentioned living close to their families or receiving support from their families and friends did not get very upset when they received the news of their diagnosis. However, themes of frustration, depression, and denial were common among narratives of patients who did not expect the results
of the diagnosis. “I felt desperate, very desperate, and I told my children that I wanted to die. I didn’t want to suffer anymore” (Female, 6 July 2017, transcript). The themes were reminiscent of Carolan’s study with low socioeconomic Australians with type II diabetes, in which distress and disbelief were common reactions when it came a diagnosis they were not expecting (Carolan et al., 2014, 1015). There was a sense of unfairness at the time of diagnosis. Some patients had gone to the doctor for something else, and they left with a diagnosis of type II diabetes, an illness with no cure, and this felt unfair to the patients.

Patients mentioned the desire to return to normal, which is reminiscent of Langdridge’s autoethnography on the recovery from a heart attack: “Talk of… when we might be able to leave and return to work became code for asking when—if ever—we would return to normal… I felt he knew, like me, that it was likely that neither of us would ever feel quite the same again.” (Langdridge, 2017, 1391). Patients expressed a loss of normality after diagnosis.

How did you feel when you were diagnosed with diabetes?
Well, I felt sad. Very sad because one feels that they are no longer normal like the other people… I couldn’t swallow my food. I was always tired, I couldn’t walk. I felt terrible.
(Female, 6 July 2017, Transcript)

How did you feel in the moment you were diagnosed?
Eh, well, my self-esteem dropped a bit, because one thinks that they are going to die and that the world has ended and things like that, it cuts you.
How did you consider your state of health before being diagnosed with diabetes?
Normal.
What did you consider normal about your state of health?
Without a need to…for example, I didn’t need to think about whether a kind of food was going to make me sick, if sodas and snacks and all that were going to be harmful. No, no, no, I didn’t think about that.
(Male, 6 July 2017, Transcript)

Patients felt a sense of normalcy when they were not preoccupied with watching their diet.

Patients at the clubs are often reminded that they are no longer who they were because they are frequently given talks about diet changes, but they are also made aware of a community that is
also struggling with their diet for the same illness. However, diabetes clubs only meet once a month for a couple of hours, meaning that there needs to be a support group consistently available for people with type II diabetes in order to provide community support.

MIS embodies the biomedical view of health which does not support collectivism, a defining feature of indigenous Maya culture. Ethnomedical systems do not distinguish the body, mind, and self, and therefore illness is situated in both the body and self in a unitary form (Scheper-Hughes and Lock, 1990, 492). This is a major difference between biomedicine and non-Western ethnomedical systems. This is ethnomedical view is present in patients’ narratives they described both physical and mental health features when asked about their perception of their health. There were some people who were less affected than others, and it made me wonder as to why some people had a certain reaction and others did not. “Well, your self-esteem drops a bit because you think you are going to die and the world has ended… But then you relax and you talk to several people, and then the person has a personal dominion in which he can support himself” (Male, 6 July 2017, Transcript). This person was from a community that had one of the nicer Puestos de Salud from the ones I had visited that summer. It was situated along a large, main road, and it was easy to spot from a distance. A solid group of ten attended the diabetes club there. This person also had several family members who had been diagnosed with diabetes before him. Participants in Carolan’s study “highlighted the impact of diabetes on the family, and the importance of family members in providing support and encouragement to assist their self-management efforts” (Carolan et al., 2014, 1011). Bockwoldt’s study on medication experience among African Americans also found that family plays an important role in diabetes medication adherence. “Crucial to diabetes medication adherence are health beliefs and perceptions about the diabetes and its treatments (Harvey & Lawson, 2009), which are often formed by experiences
with family members who have diabetes” (Bockwoldt, et al., 2017, 363). A strong familial support system, such as in the case of the patient I interviewed, plays a crucial role in helping people diagnosed with type II diabetes transition into their new care routine.

While health centers are the places people are expected to turn to for self-care, a concern that surfaced in the narratives was the inconsistency of the health center personnel. One patient described the first time she was diagnosed with diabetes. She was satisfied with the care she received from a physician, but when she taken care of by the nurses, she demonstrated dissatisfaction.

How has your experience been here at the Puesto de Salud?

Good…but sometimes when I come with my daughter, the staff changes and there are some who don’t treat us well.

(Female, 6 July 2017, Transcript)

In a month, I went back and the doctor took good care of me. She was very kind. (Lowers her voice.) But she left, and now there are only nurses.

(Female, 6 July 2017, Transcript)

How long have you gone to the health center?

I don’t go there anymore. I don’t go there because they don’t take good care of my mom. Because when I took her, they hurt her, and she doesn’t like it when they’re rough with her because she bruises quickly. I’ve seen them pull her. So, I quickly learned how to inject my mom.

(Female, 26 July 2017, Transcript)

These experiences could have also added to the stress of diagnosis, because it would mean that these patients would have to go back to the places where they have had a terrible experience in order to continue their diabetes care routine.

Familial support is a crucial part of a person’s life, especially when managing a chronic illness. A patient from another town that had a nicer health center described the support he received from his sons. “I diet and exercise a bit. And I take the medication. I said that I was not going to die of this. Live my life, and that’s what my sons tell me. If you are going to live your
life complaining, that’s no way to live. And they said to take the medication and obey the doctor and that’s going to help you” (Male, 20 July 2017, Transcript). Schepers-Hughes and Lock define body image as “the collective and idiosyncratic representations an individual entertains about the body in its relationship to the environment, including internal and external perceptions, memories, affects, cognition, and actions” (1990, 489). In this case, the location of the health center in a convenient part of the neighborhood, familial support, interaction with others who have type II diabetes, and thinking positively have all contributed to a positive body image of power over the illness. However, if patients wish to seek assistance at the health center, they are then expected to “focus on the individualized goal of achieving good health and to focus on the body as a site of moral responsibility that requires routine intervention” (Langdridge, 2016, 1392).

The increasing presence of biomedical health in the current health care system of Guatemala combines personal responsibility with access, and this continues to carry the processes from repeated cycles of conquest that keep marginalizing indigenous Maya. Although the previous patients had family near them, there were patients who did not have their families close them, in distance and in relationship. The indigenous Maya of the lake region have very close ties to their culture and traditions that pushing for a health care system that refuses to acknowledge this and incorporate it is only working to alienate this group. We have a group of oppressed people trying to manage type II diabetes within a health care system established by a government that has a legacy of responding to local and national politics and other issues in a way that has continued to propel the forces that continue to marginalize these communities, and, as a result, do not allow them to take proper care of themselves. Structural violence in this case encompasses the structures and factors that contribute to the difficulty in seeking treatment as an individual (Galtung, 1969). Biomedicine’s culture of no culture is “a
community defined by the shared cultural conviction that its shared convictions were not in the least cultural, but, rather, timeless truths” (Taylor, 2003, 556). In establishing this notion of no culture in a collective community, it only causing more harm than good.

The people of the lake region are struggling with an illness. “Illness refers to how the sick person and the members of the family or wider social network perceive, live with, and respond to symptoms and disability” (Kleinman, 1988, 3). There are many divides when it comes to health care because the government has not made the effort to integrate ethnomedicine in the health care system. Here we have the ethno clinical-citizen vowing to “treat all patients equally” with universal health care coverage, “an individualized subject (imagined to be) unencumbered by the systems that create both health disparities and broader inequalities based in race and citizenship” (Rivkin-Fish, 2011, 187). In a political context, the government’s failure to implement a universal health care program speaks of the kind of situation it has created. “It is true that biological citizenship speaks to health as a political project. But more centrally, it speaks to a failure of politics and science to account for human welfare, compounding vulnerability for citizens whose practices of survival have never fit neatly into our efforts to conceptualize them” (Petryna, 2013, 36).

On another point, many other patient narratives, however, expressed despair at the news of being diagnosed with type II diabetes. Some people were in denial of it, not wanting to believe they had something that they felt was out of their control. “The first time I didn’t know. I was sleeping and then all of sudden I was so thirsty… One of my sisters told me I was diabetic…I told her it can’t be possible. When they checked my blood, I was diabetic” (26 July 2017). When asked her why that could not be possible, she responded, “I told her it couldn’t be because I don’t want it. She said not to get scared because we all have that in our blood… but I began to cry
because I didn’t want it” (26 July 2017). Another person conveyed a sense of hopelessness when diagnosed. “I said I am going to die. There is no solution for this, I said. Your vision isn’t the same. It’s not the same as before… I had no control, nothing” (July 2017). The uncertainty of diagnosis is a theme that often comes out in narratives among minorities managing type II diabetes. Participants in a study in Chicago on type II diabetes expressed uncertainty about the accuracy of their diagnosis, especially when there was no known family history (Bockwoldt et al., 2017, 366). The silent nature of the illness brought concerns regarding their future. In another study, participants were troubled by the uncertainties of the illness, and they were concerned with the difficulty of not knowing what could happen to them, and they were concerned that the need to depend on others meant a loss of independence (Carolan et al., 2014, 1018).

Another narrative described how the mother’s diagnosis had impacted the family. “We went to the doctor, to see what was happening, to see what she had. And they told us, unfortunately, that she had diabetes… And since then it’s been a psychological blow to the family. Listening a bit to the experience of others who are affected by it… Loss of weight, the most terrible for a person are the amputations at the extremities. That’s what’s most painful for us” (12 July 2017). Here we see unitary body of a person whose illness has become an integrated aspect of self and social relations (Scheper-Hughes and Lock, 1990, 492). Illness here is a collective experience because the daughter described how the situation affected them as a family and not the grandmother as an individual, and this is important because it means that self-care is not a realistic goal in this situation. Research on this aspect expresses the burden people who have been diagnosed with type II diabetes feel. “A number of participants raised concerns about the impact of their diabetes on the wider family and were keen not to be a burden on family members. Some felt their relationship with family members was impacted by the additional
doctors’ and other appointments they must now attend and the extra work of managing their
disease” (Carolan et al., 2014, 1016). Another patient explained that her diagnosis affects her
role as the cook in the family. “I didn’t change my diet, and that’s the problem. I need money to
do that. I have a husband and three grandchildren. I don’t have enough money to make different
meals for everyone” (Female, 12 July 2017, Transcript). The patient described herself as a
burden to her family because her illness required her to make changes to her diet, which required
buying items different from those she would use to cook for the rest of the family. She decided
not to change her diet in order to avoid putting her family in financial distress. While she is in
charge of cooking for the family, what she makes depends on what her husband can provide and
what the rest of the family wants to eat.

When patients were asked to describe their current perceptions of their state of health
after diagnosis, they generally had an indifferent to slightly positive outlook for their future that
in some cases still expressed the sense of hopelessness others felt when first diagnosed. One
person described what he did in order to make himself feel better after having eaten something
he knew was not good for him. “Yes, I feel good. Calm. Well, when you eat too much fat you
feel down. Like the body is disconnected, without movement. For example, one time I was given
a sandwich. I ate it, and I drank a coke, and I felt my mood drop. I went to bed with only a glass
of water. That’s when I calmed down” (Male, 6 July 2017, Transcript). This is the same person I
mentioned before who has familial support and has managed to remain positive about his future.
However, he reverted to his old eating habits, which caused him to feel sick, and this was a
reminder to him that he cannot eat the same things that he used to. While he has been able to find
ways to manage his ups and downs with type II diabetes, these small events contribute to the
emotionally difficulty in managing a chronic illness.
There are others who have found reassurance with their decision to take the medicine and diet. “Right now, thanks to God, I take my pill, I feel good, I take the pill. Not a lot of sugar and less fat” (Male, 12 July 2017, Transcript). A closer tie with God also seems to have a connection with people’s ability to manage their diabetes and retain a positive outlook for the future. “I feel different because now I can’t eat things with a lot of sugar, I had to diet. But thank God it has not affected me too much” (Female, 6 July 2017, Transcript). Patients generally demonstrated recognition of changes of in their lives due to diabetes, but they have been able to cope with faith. Religion is also important to note because another patient had briefly mentioned that her priest had recommended she take herbal medicine instead of pills in order to manage her illness. Further research on the role of the church and religion in managing type II diabetes would be useful to further understanding the different factors that influence medication adherence.

Other people, however, expressed an indifference due to a loss of hope of being the person they were when they considered themselves healthy. “Well, I’m just going through it [life] because where else? Only taking medication. Making sure I don’t lack any and they tell you that it’s not like before” (Male, 6 July 2017, Transcript). We might consider the impact their transition from a healthy patient to a person with diabetes has had on their experience managing diabetes. There is one important aspect of biomedicalization to consider, and Langdridge defines it as “the transformation of the body from normalization to personalization” (Langdridge, 2016, 1392). I will instead refer to this transformation of the body as one from a healthy person to a person with diabetes. This is not to imply that one cannot feel the same as before after diagnosed with diabetes, but rather to convey the feeling expressed by patients when describing their transition. “[B]iomedicine has both extended its reach into and become entangled with other
spheres of society.” (Hallin, Brandt, & Briggs, 2013, 121). Patients experienced difficulty transitioning into a routine form of care.

Some patients were not reassured by the pill and often commented that the pills had caused them aches and pains. Some misconceptions of the pills arose in the narratives.

What could it be? When I take the pills, my feet hurt a lot. I took the pills, and I felt a burn. I stopped taking them for four days. It hurt.

(Female, 12 July 2017, Transcript)

Is there a reason you didn’t take pills before?
   I thought that taking them would harm me, taking too many pills. So, I discouraged myself from taking them.

What kind of harm did you believe they would do to you?
   Well, I thought that perhaps those pills would accumulate in my stomach, and that could harm my stomach.

(Female, 26 July 2017, Transcript)

I’ve always struggled with how to treat my diabetes, because there are so many classes of diabetic. There is a diabetic you can combat with pills or with natural medicine, but there is a diabetic that doesn’t respect natural medicine or pills, so you have to go to insulin, injections.

(Male, 20 July 2017, Transcript)

Patients mentioned that they would stop taking the medication when they felt sick. Others would take the medication sometimes, and other times they would take natural remedies. Some people would take the medicine only when they felt symptoms. There was uncertainty and inconsistency when it came to taking diabetes medication. I asked people about alternative treatments they sought to treat diabetes, and many were able to name specific plants and even describe recipes in order to make the herbal remedies. The patients named several plants and fruits that they have heard of or that they have found useful, such as mispero, punta de guayaba, zacate, ajenjo, anona, yerba mora, and gongora. One person mentioned that ajenjo had effective for her brother. She explained that accessing this grass was not difficult, and it did not cost anything.
The patient herself would take herbal remedies as supplements while continuing with her prescription medication.

Where did you get the grass?
In the mountains. Mispero and anona are known, and guava is known. And that’s what my brother-in-law said...he is strong, and when he got his blood checked, normal.

(Female, 12 July 2017, Transcript)

These herbal remedies involve boiling different plants and herbs in water and drinking the water when cooled. These remedies were like teas. There was no mention of difficulty in accessing these herbs. One patient explained that she had not taken prescription medication for the last six years. Instead, she had been boiling yerbamora. However, yerbamora alone was not enough. She was at the diabetes club when I interviewed her because her symptoms had come back, and her glucose levels were extremely high. She had to come to receive diabetes medication.

Many of the patients’ comments regarding herbal remedies were reminiscent of a study conducted on herbal self-care remedies by Latinos/Hispanics for type II diabetes. “The perceived effectiveness of the products varied; some said they helped “a lot” while others note the development of side effects… some participants reported skipping or altering the dose of diabetes medications when using herbal remedies” (Amirehsani and Wallace, 2013, 828). Additional research comparing indigenous health to non-indigenous health states that “indigenous people define wellbeing far more broadly than merely physical health or the absence of disease…connections, relations, and family are among the many essential components of wellbeing” (King, Smith, and Gracey, 2009, 76). Therefore, it makes sense that the pills (metformin/glyburide) alone are not seen as something that can fully heal, and there is a desire to fulfill the sense of being fully healed with the addition of another component: herbal remedies.
One patient in particular gave indication of the roots of capitalism and their influence on the community. The patient was explaining that he had proposed an idea to the community, that someone should set up a smoothie stand in order to create drinks for people with diabetes. His idea was not supported by the community, and he explained why he thought they weren’t supportive.

Our people don’t like anything good. Because at home you can’t make smoothies, they can’t do it, they won’t do it, but there’s an option. I gave them those options, but they don’t like it because they think you’re going to make money off of it. That’s the kind of mentality that doesn’t help us overcome this illness, that doesn’t help us succeed. ‘If someone wants to put up a business, don’t help him so he’s not exceeding us. Ah, this guy is just looking to make money. I shouldn’t help them, right?’ And then not even that person succeeds.

(Male, 6 July 2017, Transcript)

The patient’s option refers to the idea of having someone in town make smoothies. He says people often do not have time to make smoothies themselves or they put off making them because they don’t feel like making them at the moment. He thought that having one person do it would make it easier for everyone, but everyone’s minds went immediately to the money-making prospect of it.

Referring back to the mind-body dichotomy of the biomedical model, I cite a quote here from Scheper-Hughes and Lock to highlight the relationship between this view and the capitalist mode of production: “The mind-body dichotomy and body alienation characteristic of contemporary society may be linked not simply to reductionist post-Cartesian thinking but also to capitalist modes of production in which manual and mental labors are divided and ordered into a hierarchy” (Scheper-Hughes and Lock, 1990, 492). At the individual level, people are supposed to go to health centers to receive treatment and medication. At the community level, health centers are supposed to provide medicine and treatment free of charge. However, since there is a lack of funds, they often charge ‘donations’, fees a patient must pay if they want to
receive medicine that should be available free of charge. At the institutional level, the Ministry of Public Health is in charge of providing and distributing the funds to the health centers. Due to the neglect from the ministry, health centers have been pushed to collect funds in the only way they could: “donations.” However, the people they are collecting these funds from are already at an economic disadvantage, and so this may present itself to the people as a money-making venture of the health care system. “The biological traits of a population become relevant factors for economic management, and it becomes necessary to organize around them an apparatus which will ensure not only their subjection but the constant increase of their utility” (Foucault, 1980, 172). In a way, the government’s lack of work in providing more funds for health centers has created a capitalist mode of production among health centers, and this has affected the way the community sees health care and any movement associated with health and money. I would argue that this situation is an example of structural vulnerability because vulnerable populations are being excluded at the economic, political and sociocultural level by larger powers.

Patients’ feelings regarding taking medication to treat diabetes were ambivalent. Patients often referred to their prescribed medication as simply pills. It was an ambiguous mix of positive and negative feelings. There were three categories of treatments patients followed: those who only took pills (metformin/glyburide), those who only took natural medicine, and those who took both. A new person is created with the integration of they were and who they are now, a person with diabetes, mediated with biomedicine, a concept known as illness identity. This is good for government objectives of the medical profession which requires that the individual body take their pills in order to represent an active biological citizenship, taking personal responsibility of their health and taking the medication necessary. This produces the body politic because the government now regulates the person’s health through their sickness, and perhaps natural
medicine is a way of taking back your body from the government which seeks to regulate and discipline individual bodies (Scheper-Hughes, 1990, 483).

Other patients did not receive any consolation from the medicine. Some patients commented that they were always in pain. Whether the patient’s experiences were positive or negative, there was a general consensus that one was not the same after being diagnosed with diabetes, though some people did comment that they almost felt close to normal with the treatment they were receiving. “We were now different people, changed by our experience of a heart attack, always at risk whilst now apparently well once again” (Langdridge, 2017, 1391). Langdridge explains how the experience of always being at risk of having another heart attack has changed his life because his life has to revolved around taking care of himself to prevent another heart attack. In a similar way, people with type II diabetes are different now, changed by the experience of routine glucose checks and other precautions, always in risk of high glucose levels, even if their levels normalize after diagnosis. Some of the main indicators of risk of type II diabetes are genetics, if a member of the family has diabetes, and diet. The diabetes clubs of Hospitalito Atitlan have focused on the second indicator of risk in the times that I have attended the clubs. There were talks on the diet of a diabetic, and it is crucial to continue the efforts in obtaining a better comprehension of the everyday experience of managing diabetes in order to maximize the effectiveness of preventative strategies.
Conclusion:

Based on my analysis, I present some suggestions that will hopefully lead further research to find real-world outcomes in improving the lives of indigenous Maya who have been diagnosed with type II diabetes. While my suggestions may only assist at the micro level, I hope these small changes assist in creating a bigger change. Overall, the experience of managing type II diabetes among indigenous Maya in rural Guatemala is one filled with hardship and oppression. Patients are different in the sense that they are expected to enact an active biological citizenship because of their chronic illness, but also because they stated that they are also changed by their diagnosis experience.

One concern I mentioned was the government’s failure to effectively integrate ethnomedicine in the healthcare system. I mentioned Taylor’s culture of no culture, and in her conclusion, she states that “medical knowledge is no less cultural for being real, just as patients’ experiences and perspectives are no less real for being cultural” (Taylor, 2003, 559). In the future, if the health care system hopes to integrate community perspectives in order to improve doctor-patient relationships, it needs to start by acknowledging biomedicine as a culture, too. In my analysis, I also referred to the political and economic forces at play in creating the setting where people are struggling to manage their illness. I briefly mentioned how that situation reflects structural violence, and in order to address this risk factor in the context of treating a chronic illness, inequalities at the group level need to be addressed. This means addressing 500 years of violence and discrimination against an indigenous community.

Some patients demonstrated a sense of empowerment and others a sense of despair at the idea of taking pills. Perhaps one way to improve adherence without eliminating natural remedies could be to explain to the patient that they can take both, especially if they feel no adverse effects
from doing so. Of course, this could possibly only work, at the moment, with people who are attending diabetes clubs because they get free medication there. For those who are unable to reach the diabetes clubs and do not have the means to purchase medicine, their situation requires a larger change at the institutional level.

Diabetes is a chronic illness that has been detrimental to the population of the lake region in Guatemala, and I expect that my suggestions, based off patient narratives, may be of assistance in addressing some of the issues that patients pointed out about their transition to a diabetic and access to medication in order to improve the overall indigenous Maya experience with type II diabetes.
References Cited

http://www.diabetes.org/diabetes-basics/type-2/?loc=db-slabnav


