Therapeutic Clientship Of Diabetes Clubs: Engagement In Chronic Disease Management Programs In Guatemala’s Western Highlands

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Abstract
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Keywords
diabetes, chronic disease, Guatemala, disease management, diabetes engagement, therapeutic clientship, Lake Atitlán

Disciplines
Anthropology | Community Health and Preventive Medicine | Endocrine System Diseases | International Public Health
THERAPEUTIC CLIENTSHIP OF DIABETES CLUBS: ENGAGEMENT IN CHRONIC DISEASE MANAGEMENT PROGRAMS IN GUATEMALA’S WESTERN HIGHLANDS

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In

Anthropology

Submitted to the
Department of Anthropology
University of Pennsylvania

Thesis Advisor: Fran Barg

2018
Abstract

The increasing global mortality and morbidity of chronic disease signals that a major epidemiological shift is underway in more-economically developed and less-economically developed countries. This epidemiological transition is especially salient in the Western Highlands of Guatemala as the prevalence of type 2 diabetes has risen steeply and poses great challenges for health practitioners and the public health system. This thesis is based from ten weeks of ethnographic fieldwork that I conducted in region surrounding Lake Atitlán. Collected through participant observation and semi-structured interviews, the data this thesis analyses attempts to examine the nature of and motivations for engagement in a diabetes management program that focuses on “self-care” as a form of therapy. I argue that engagement is socially mediated. A heuristic of therapeutic clientship offers analytical tools with which to understand the behaviors that express engagement. First, I unpack the diabetes management methodologies and philosophies behind one programmatic attempt to address the growing incidence of diabetes called diabetes clubs. Next, I demonstrate the centrality of relationships between club-goers and clinical staff that drive patterns of decentralized and centralized recruitment into clubs, sustained attendance, and active participation. Though the social theory of therapeutic clientship, I examine the exchange of “transactables” between clients and patrons, the existence of disparities of accessibility for diabetes treatments, and the discourse of compliance that “self-care” treatment modalities assert. I end with a discussion of how treatment-associated technologies, simple and complex, shape the way that people makes sense of their illness.
Introduction

A global epidemiological shift is underway as the burden of disease transitions from communicable diseases to noncommunicable diseases (NCDs). Across the world, chronic diseases have replaced acute and infectious diseases as the primary cause of mortality and morbidity (Rosenthal 2015; Bukhman et al. 2015; Ferzacca 2012). This epidemiological transition is especially pronounced in less economically developed countries (LEDCs). However, this is not to say that the increasing mortality and morbidity due to cardiovascular, metabolic, mental health conditions and cancer in less economically-resourced areas is supplementing a disappearing burden of infectious disease, rather, it increases the number of afflictions from which people suffer (Rosenthal 2015; Bukhman et al. 2015). The international community considers the growing burden of NCDs in LEDCs one of the most pressing global health challenges in the coming decades (World Health Organization 2016a). Causes of this phenomenon are diverse and can be unpacked through studying diabetes, a major contributor to the epidemiological shift. LEDCs in Asia and Latin America account for a large portion of the growing global diabetes burden. This analysis of diabetes management will focus on the Western Highlands of Guatemala, a region in Central America experiencing a great increase in diabetes prevalence.

This thesis aims to offer an anthropological analysis on chronic disease management methodologies based from ethnographic fieldwork studying diabetes clubs, diabetes management programs focused on “self-care” in rural Guatemala. I unpack the intricacies of local conceptualization of illness experience, biomedical modes disease management, and the availability and accessibility of therapies. This research build from three areas of focus: first, participant’s diagnosis narratives; second, details surrounding recruitment to diabetes clubs; and
third, the club-goers experience of attendance and attitudes towards diabetes management. Specifically, I explore how and why patients actively engage in diabetes clubs. Applying a heuristic of therapeutic clientship, I present a series of questions to evaluate the nature of and motivation for engagement. I argue that the social forces, both internal and external to clinical spaces, that mediate engagement of those afflicted with chronic disease in diabetes clubs.
Methods

This thesis is based from 10 weeks of fieldwork that I conducted in the Sololá Department located in the Western Highlands of Guatemala between early-June and mid-August of 2016. This fieldwork was performed as part of the Guatemala Health Initiative (GHI), a partnership between the University of Pennsylvania (Penn) and Hospitalito Atitlán (HA), a non-profit, non-governmental organization hospital located in Santiago Atitlán. The striking ancient volcanic crater lake called Lake Atitlán, that some refer to as the eighth Wonder of the World, defines the ethnic and physical geography of the Sololá Department. The linguistic and ethnic group of the Tz’utujil Maya inhabit the southern half of the region and Kaqchikel Maya live in the north. Communities of all sizes, ranging from lake shore urban municipalities to hill towns nestled in the rim of the caldera, dot the perimeter of the lake. HA serves the entire lake community with a fully functioning emergency department, outpatient primary care and dental clinic, and a robust women’s and children’s care program. In addition to clinical health services, HA also operates several community public health programs around the lake focusing on nutrition and anemia, sexual health, and diabetes (Hospitalito Atitlán 2017).

Since 2005, Penn students, participating in GHI’s Medical Anthropology Field School, have traveled to Santiago Atitlán for 10 weeks of community-based participatory research exploring various aspects of health and wellbeing. This program aims to generate knowledge for the local community through a partnership model of global public health research. Projects and areas of need identified by local public health leaders and members of the community define GHI research inquiries. This form of global health engagement values shared-decision making and ownership by many stakeholders to generate knowledge and assist action.
Beyond treatment and clinical services, HA runs a series of community public health programs serving the entire Lake Atitlán and Sololá Department. My GHI experience centered around HA’s chronic disease diabetes programs. HA received a 3-year grant from the World Diabetes Foundation (WDF) to increase access to information about prevention, treatment, and management of diabetes (K’aslimaal and Hospitalito Atitlán 2014). The grant supported several individual initiatives to address the growing prevalence of type 2 diabetes in the region through: (1) charlas, didactic health talks about diabetes in primary and secondary schools, (2) capacitaciones, community health worker training sessions, (3) jornadas, diabetes public screening drives, and (4) clubes de diabetes, diabetes clubs. These four diabetes programs are organized by diabetes subcoordinators from HA with professional backgrounds as auxiliary public health nurses and licensed Rural Health Technicians. Due to the region being linguistically and ethnically divided between the Tz’utujil Maya and Kaqchikel Maya, the diabetes subcoordinator, fluent in Spanish and a Maya language, split their jurisdiction based on their own ethnic identity. My participation in GHI and the research for this thesis stemmed from a HA-identified project to evaluate the diabetes programs supported by the WDF grant. Along with my peer student-researchers from Penn, I worked closely with diabetes program subcoordinators at HA.

My fieldwork primarily focused on the diabetes clubs; however, I did engage in all four programs throughout my 10 weeks in the Lake Atitlán region. Diabetes clubs are monthly meetings of diabetics occurring in seven towns around Lake Atitlán, specifically Santiago Atitlán, San Lucas Tolíman, Godínez, Agua Escondida, San Andrés Semetabaj, and San Antonio Palopó, and Panajachel.
This thesis builds from fieldwork exploring diabetes club participation as I tried to understand the reach and efficacy of diabetes clubs in managing the participants’ diabetes. My primary fieldwork consisted of participant observation and semi-structured interviews. I employed ethnographic research methods because I sought to understand why actors in diabetes clubs pursued their life practices and routines. Foundational in these methods is the ability to highlight individual and community processes driving behavior in spaces steeped with power dynamics and limited choices.

As an Indian-American male and, from the perspective of my informants, a representative and extension of HA, I recognized that my positionality affected my observations, interactions with informants and interlocutors, and the responses to my interviews. Interestingly, my identity confused some of my informants and interlocutors. Because of the color of my skin, a feature of my Indian heritage, I did not look like the “typical” White American medical researcher. I received varied comments on whether I was indeed a gringo, a common term for a person from the United States. Foreign health and development volunteers are no strangers to the people of Lake Atitlán. There is a robust system of North American and European medical missions and volunteer service activity that pours thousands of dollars in cash, services, and products into this region’s health system and economy. Marginally existing in this globalized volunteer and tourism structure, I understand that it is quite likely that my informants may have altered their responses in my interviews to better appeal to me, make me feel comfortable, or perhaps to receive more attention or services at the clinics. With clearly being a outsider, especially one who turned out to be from gringolandia, I routinely confronted my privilege and examined my positionality in various research and non-research spaces.
My participant observation predominantly occurred at the diabetes clubs in the Ministry of Public Health and Social Assistance (MSPAS) clinical spaces of the Puestos de Salud and the Centros De Salud. Employing participant-as-observer, I took on the role of a health volunteer shadowing the Kaqchikel-speaking Diabetes Subcoordinator, named Bayro, and assisting with the activities that he normally performed alone. This materialized as me helping him run the diabetes clubs in each town for the course of my fieldwork. Bayro was the primary gatekeeper for my fieldwork and I built from his established social connection and professional relationship with individual staff members at each MSPAS health facility. My participation in each diabetes club began by obtaining permission to assist, observe, and speak to patients from the clinical staff at each Puesto and Centro I entered.

With prior clinical experience as a licensed Emergency Medical Technician in Pennsylvania, I participated in the clubs by assisting with all the technical components of the club including taking height, weight, blood pressure, blood glucose measurements, and transcribing this health data into HA and MSPAS records. I spoke with patients and MSPAS workers at the various health facilities where clubs were held in the waiting room, while setting up, and operating the clubs. I paid close attention to understanding the interpersonal dynamics between clinical and non-clinical agents at the clubs and regularly engaged in conversations before and after the clubs with the clinical and support staff. I kept field jotting at various points throughout the day noting prominent details about patient interactions and behaviors, patient characteristics, interactions among clinical and support staff at the health facilities, and sketches of clinical spaces. I complied these jottings into fieldnotes every evening.

I performed nineteen semi-structured interviews (16 female, 3 male) using an interview guide that sought to capture four broad categories of data from patient-participants: demographic
data, pattern of participation, experience with the clubs, and experience with diabetes. The semi-structured interviews originally aimed to understand the reach and efficacy of diabetes clubs in managing the chronic disease. This question emerged from collaborative research discussions with HA, which sought an evaluation of the clubs as my summer GHI project. I wanted the informants to drive the flow of the conversation as I attempted to employ the prepared questions as probes or fallbacks rather than as a strict protocol. However, I initially had difficulty in fostering an ethnographic environment in which my informants controlled the direction of the stories they shared. Throughout my fieldwork, my interview guide changed as I refined my specific aims and became more comfortable with open-ended questions that dove into the individual histories of diagnosis and club recruitment narratives. I framed my interviews as a way for informants to share their perceptions and concerns about diabetes clubs as feedback for improvement by HA and MSPAS. Informants understood that their information would be deidentified and shared as feedback for the club.

Informants in the research were collected using purposive convenience sampling. Inclusion criteria included individuals diagnosed with diabetes that attended a diabetes club in the towns of Santiago Atitlán, San Lucas Tolíman, Godínez, Agua Escondida, San Andres Semetebaj, and San Antonio Palopó, and Panajachel between June 2016 and August 2016. Informants all had had one blood glucose test that categorized them as diabetic: a fasting blood glucose measurement higher than 126 mg/dl and a non-fasting blood glucose measurement higher than 200 mg/dl. A plasma glucose measurement between 100-126 mg/dl classifies people as “pre-diabetic” and at risk of developing more serious metabolic conditions. HA’s diagnostic criteria coincides with the definitions established by the American Diabetes Association (American Diabetes Association 2011).
I obtained verbal consent for participation in the qualitative study before engaging with each patient. If consent was granted, I asked the participant where they felt comfortable to speak about their experience in the clubs and experience having diabetes. I prefaced the semi-structured interviews by informing the participant that they are not required to answer questions they did not want to and retained the right end the interview at any point without it affecting their participation in the club. Additionally, I gave participants the right to reject my use of an electronic tape recorder to record their responses.

I conducted my study in Spanish, which is for many Maya people is their second language. Although the most common language spoken nationally and the sole official language of Guatemala, Spanish fluency is not a guarantee in the Western Highlands because of the large population of Maya people. The clubs serve a population that primarily speaks two indigenous Maya languages—Tz’utujil and Kaqchikel. Many older Maya people do not speak Spanish fluently or feel completely comfortable conversing in Spanish. In addition to the presence of two primary Maya ethnic groups around Lake Atitlán, there exist many pockets of Ladino people who identify with the Mestizo or mixed European-Indigenous descent and speak Spanish as the native-tongue. One of the distinguishing factors is their clothing; they do not wear traditional Maya clothing. Almost all of my interviews were conducted in Spanish (15 out of 19). At times, language did limit data collection and present as an obstacle for me. When writing down field jottings, I often could not understand some conversations that people were having around me. When possible, I asked my research gatekeeper, Bayro, or the clinical staff to translate. Some patients I approached to interview declined to participate because they could not communicate effectively in Spanish. When appropriate, I asked Bayro, to translated for me. This occurred in
the town of San Antonio Palopó where Bayro translated between Spanish and Kaqchikel for four interviews at the Centro de Salud club in San Antionio Palopó.

The interviews were recorded on an electronic hand-held recorder and directly transcribed onto a computer word processor. Field jotting were compiled into typed fieldnotes. I coded the interviews and fieldnotes using electronic software into coding buckets thematically defined by the interview guide. These coding buckets were analyzed using a combination of deductive and inductive reasoning through which an I constructed assertions.
Background on Chronic Disease and Diabetes in Guatemala

Diabetes mellitus (diabetes) is a chronic metabolic syndrome characterized by an abnormal level of glucose in the blood and the inability of the body to properly process serum glucose. There are three types of diabetes—gestational diabetes, type 1, and type 2. Gestational diabetes affects pregnant women and indicates a greater risk of developing diabetes later in life. Type 1 diabetes, formerly known as insulin-dependent or juvenile diabetes, is the inability of the body to produce insulin, a hormone necessary for the intake of glucose into cells and subsequent metabolism. Those with type 1 diabetes require daily doses of insulin to manage the condition the cause of which is unknown. Type 2 diabetes is the most common type of diabetes in Guatemala and the rest of the world. It is formerly known as non-insulin dependent or adult-onset diabetes, and results from improperly functioning insulin that leads to harmfully elevated or reduced blood glucose levels (World Health Organization 2016a).

In 2010, the editorial board of The Lancet published a special edition on diabetes and described the considerable global risk presented by the growing prevalence of diabetes in the United States and globally. They detail how in the last ten years, the number of people with diabetes has more than doubled to 285 million with the majority, over 200 million people, residing in LEDCs (The Lancet 2010). The increasing prevalence of diabetes will reach 592 million people by 2035, which by many definitions constitutes an “epidemic” (Bukhman et al. 2015). The cause of diabetes is largely understood as combination of diverse risk factors including age, obesity, genetic predisposition denoted by family history, and lifestyle characteristics and risky behavior like unhealthy diet and low physical activity (World Health Organization 2016a). Though some of the rise in prevalence may be due to better detection rates,
the authors believe that there is an underlying increase in overall incidence driving the epidemic, and call on practitioners, researchers, and policy makers to prioritize this public health issue.

In Guatemala, a country with total population of roughly 16 million. The official prevalence of diabetes according to the World Health Organization is 7.5%. This is not especially large as prevalence in the United States is 9.4% (Centers for Disease Control and Prevention 2017). However, the actual incidence in Guatemala is most definitely much higher than its official rate (Hospitalito Atitlán 2017; World Health Organization 2016b; Chen et al. 2017). The Health Information Management System (SIGSA), part of (MSPAS) reports that that diabetes has the second highest morbidity and accounts for the third highest cause of mortality among chronic diseases (Sistema de Información Gerencial de Salud 2017). According to a recent study, it is believed that 36.0% of the population meet the criteria for metabolic syndrome based on the incidence of risk factors and that most diabetics are undiagnosed and unaware of their condition (Hospitalito Atitlán 2017; Chen et al. 2017).

In discussing the causes of the epidemiological shift towards NCDs and the etiology of diabetes epidemics across LEDCs, researchers have categorized diabetes as a ‘disease of modernization.’ A disease formerly thought to only be expressed in more economically-developed countries (MEDCs), diabetes is becoming global. The distribution and prevalence of diabetes correlate with patterns of economic development, urbanization, and globalization (Mendenhall et al. 2010; Lieberman 2003; Ferzacca 2012; Bukhman et al. 2015; Chen et al. 2017). Increasingly urban, Western, and modern lifestyles and structural inequalities promote risk factors that change the quantity and quality of energy consumption (unhealthy diets), energy expenditure (physical activity), obesity, and stress (Ferzacca 2012; Mendenhall et al. 2010) Globalization drives the availability of high calorie, lower fiber, and high glycemic index food
and the adoption of sedentary forms of movement and activity (Lieberman 2003). For example, Nataga et al. (2011) explore the process of “Coca-Colonization” in the Western Highlands of Guatemala. Economic forces drive the large-scale consumption of sugary beverages and cultural hybridization of soft drinks into quotidian food culture. The high consumption of sugar through beverages alarms biomedical health providers.

There are three factors in Guatemalan food culture that lead to diabetogenic consumption. In terms of knowledge, there exist misconceptions in what constitutes healthy diets. The Guatemalan, and especially the Maya, diet features corn as a prominent component (re)appearing in multiple forms including in a sweet breakfast beverage called *atol* and corn tortillas, a nearly ubiquitous meal accompaniment. While corn is a traditional food indigenous to this region and a staple in Maya food culture for centuries, neoliberal trade and agriculture policies of the late 20th century reduced the price of corn locally. These policies expanded accessibility to cheaper corn for people with constrain economic resources; people in poverty could supplement smaller meals with more corn (Cabrera-Schneider 2010). Furthermore, major structural and economic features of the food industry in Guatemala constrain accessibility of healthier food options. *Tiendas*, or small convenience stores or stands featuring soft drinks, Tortrix, a corn-based chip product, and other snack foods, are highly accessible geographically and economically in almost all population centers (Lim 2016).

To understand why rates of diabetes differ between populations, scholars examine the interaction between genetics and behavior (biocultural analysis). Initially, genetic anthropologist, James Neel, posited that indigenous peoples of the Americas face a particularly high genetic predisposition to developing diabetes due to the “thriftiness genotype” (Ferzacca 2012). The resulting phenotype supposedly was a prehistoric asset for populations without steady food
supply. Neel’s research served as a catalyst inciting many others to explore the biocultural interface between disease and genetics. Modern theories rely on epigenetic change where environmental variables, described by lifestyle factors’ as products of cultural change, interact with a genetic variant of biochemical processes to give rise to “diabetes without borders” (Ferzacca 2012). Given these genetic and environmental factors, the Maya communities of the Western Highlands experience staggeringly high disease causation.
Diabetes Clubs as Chronic Disease Management Programs

Hospitalito Atitlán (HA), an NGO hospital located in Santiago Atitlán, emerged as a main player in health in the Sololá Department (population of 505,500) offering crucial primary and emergency care to neighboring municipalities (Sistema de Información Gerencial de Salud 2016). In addition to serving as a regional hub for high-quality private care, they organize and operate a number of public health initiatives, of which diabetes care in the Sololá Department is one. The Guatemalan central healthcare system is governed by MSPAS. In principle, MSPAS realizes a constitutionally mandated right to health and operates differing degrees of medical services to all citizens. In smaller towns, MSPAS operates a health post called *Puesto de Salud* staffed by a few auxiliary nurse. In larger towns, MSPAS operates a health center called *Centro de Salud* staffed by a physician, professional and auxiliary nurses, and rural health technicians.

On paper, MSPAS provides access to health care for the people of the Western Highlands. This “access,” achieved by the presence of *Puestos* and *Centros* in rural areas, often fails to adequately address the health needs of all individuals, especially those of vulnerable and historically marginalized indigenous community (Lawton 2015).

In the void of adequate chronic disease care in the region, Hospitalito Atitlán applied for a grant from the World Diabetes Foundation (WDF) to increase diabetes education efforts. Their programming can be understood through the three types of prevention. One, primary prevention that aims to promote behaviors that prevent the development of a disease. HA promotes higher diabetes health literacy in the lay population through *charlas* in primary and secondary schools. Literally translating to “chats,” *charlas* are didactic health talks where diabetes subcoordinators share information on diabetes’ causes, risk factors, symptoms, and preventative strategies including healthy diets and physical activity. Two, the grant promotes earlier diagnosis so that
treatment of the disease can be initiated. HA runs jornadas, public detection drives, in towns all over the lake. Setting up tables and often partnering with a MSPAS health facilities, HA invites any member of the public to receive a free finger-prick blood glucose exam along with a measurement of vitals. In this resource-limited setting, blood glucose levels serve as the only basis of diagnosis that is economically feasible at this time. If a patient is deemed pre-diabetic or diabetic, the subcoordinator operating the jornada explains the disease and treatment options available. Frequently, the subcoordinator recommends to the person to visit the local MSPAS facility, a Puesto or a Centro, within a few days to repeat the test and get connected with treatment resources. Third, the program aims to prevent diabetes-related complications among which diabetic neuropathy, diabetic retinopathy, ad chronic kidney disease significant. This tertiary prevention often focuses on a combination of pharmacological therapy with lifestyle interventions aimed at promoting ‘healthful’ behaviors. Diabetes clubs, which this thesis will explore focuses on, are monthly gathering of diabetics to promote disease management through a focus on the prevention of diabetes-related complications.

The theoretical agenda of a club begins with an introduction by Hospitalito’s subcoordinator of the diabetes program or by a MSPAS nurse stationed at that center. The introduction explains what will occur in the club and when the next one will happen. Next, each attendee receives a blood glucose finger prick test. Attendees are encouraged to arrive without having eaten breakfast the blood glucose levels measured can be compared fasting standards. After all patients receive their checks, often a snack is provided to the attendees as they listen to a charla, a didactic chat, presented by either the subcoordinator of the diabetes program or a MSPAS nurse. In addition to explaining the causes, symptoms, and complication of diabetes, the charlas detail foot and wound care practices, components of healthy diets, advocate for daily
physical activities, and stress the importance of frequent blood glucose checks to monitor the progression of the disease. Finally, the club ends with announcements of the date for the next club and promotions for upcoming HA or MSPAS events. However, I learned that the format and schedule differ greatly based on the medical capacity of the staffers and the resources available.

HA and MSPAS co-sponsor the clubs as they take place in a town’s MSPAS health facility—*Puesto de Salud* or *Centro de Salud*—with HA-provided the materials for the blood glucose testing. The clubs vary between locations in their actual operation ranging from a solo visiting diabetes subcoordinators from HA running the club, to joint operation with local MSPAS health workers, or fully independent functioning of the clubs by local MSPAS workers with check-ins by diabetes subcoordinators. Each town and health facility where the clubs occurred vary in the number of health persons participating in contributing and the resources available.

To provide context on how diabetes clubs fit into a larger political economy of health, I present a multilayered schema of health care provision transferring between NGOs and the state. I start with a discussion of the problematic execution neoliberal reforms that sought to absolve the government from the burden of rural health provision. In the last twenty years, the Guatemalan healthcare system has increasingly become decentralized and democratized by public-private partnerships (PPPs). These neoliberal efforts to reform healthcare in Guatemala drive the government to contract with non-governmental organizations (NGOs) for “a basic package of services.” To improve “the equity, efficiency, and quality of health service,” the civil and private collaborations redefine antagonistic relationships between the citizen population and the state (Maupin 2009, 1459). This is especially significant in the context of the Western Highlands where indigenous communities at least partly blame the government for inciting
violence during the horrific Guatemalan Civil War throughout much of the late 20th century. Thus, Government-NGO collaborations theoretically allow for greater transparency, reflective, and community-based care, which “derives from their flexibility in adapting to local contexts and addressing diverse and interrelated needs” (Maupin 2009, 1456). NGO’s providing primary health services communities can complement an existing poorly-resourced structure or fill MSPAS’ absence all together.

However, in practice, this model typically relegates contracted NGOs “to serve as administrators, removed from the delivery of services [making them] highly dependent upon the traditional” government structure (Maupin 2009, 1458). Thus, the limited nature of the NGO’s involvement thwarts the larger effort increase the availability and accessibility of health. Maupin identifies a “mixed-contract model” where health service administration is delegated to the NGO and care provision to a team of NGO and MSPAS personnel. The schema he describes is of a centrally-positioned and stationary government health service incorporating several field-based NGOs into their system. The contracting of private services works towards the promoting greater access to health services, especially in remote and rural areas.

Based on this analysis of the broad structural reforms of Guatemalan care democratization, I show how HA flips government-NGO contracts to promote chronic disease management for diabetes clubs. For the purposes of understanding the nature of civil and private collaboration between HA and MSPAS, I propose an adapted schema of NGO governance over MSPAS health resources. The NGO, still working towards the realization of a larger—be it internationally, nationally, and institutionally defined—goal of chronic disease management, becomes the fixed health hub arranging partnerships with individual MSPAS facilities in nearby municipalities. Here the NGO, Hospitalito Atitlán, sends out representatives to incorporate local,
field-based partners into its mandate of diabetes care established by a grant from a larger international organization, World Diabetes Foundation. The contracts that HA secure with individual MSPAS units across Lake Atitlán allow both parties to work towards a priority, that is the provision of diabetes care in a region with great risk and skyrocketing incidence.

In accordance to principles of effective NGO-government collaboration that Maupin highlights, diabetes clubs could come short of offering quality care if the contracted local party, MSPAS facility, is relegated to an administrational role. The diabetes club contract takes into account this principle by allowing flexibility when determining the operational and clinical roles of the two health players, HA and MSPAS. HA’s basic role is to provide resources, specifically costly glucometers and diabetes test strips and diabetes management training for health workers, and the MSPAS units’ basic role is to offer their clinical spaces for the clubs. The division of the rest of the responsibilities in running the club varies across municipalities depending on local need and is jointly determined by representatives of HA and MSPAS. With the understanding that ultimately the focus of any public health program is the target community, the MSPAS staff’s involvement in decision-making reflects progress in the provision of community-based dynamic care. Their involvement varies from informing their communities of an upcoming club, assisting HA diabetes subcoordinators, to running the entire monthly service without help. MSPAS units maintains their prominent role as the local agent that engage with their constituent community most directly. Engagement in such programs emerges to constitute a form of treatment itself. The patterns of engagement in these programs that I identify through therapeutic citizenship reflect Maupin’s values of community-driven care.
Therapeutic Clientship

Susan Reynolds Whyte, Michael Whyte, Lotte Mienert, and Jenipher Twebaze (2013) outline the concept of therapeutic clientship in the projectified landscape of AIDS therapy programs in Uganda. In the context of AIDS as a widespread priority, Whyte et al. (2013) describe the sentiment of “belonging” to a particular antiretroviral (ARV) distribution program. Given the nature of ARV therapy, these programs assert the overwhelming importance of adherence to a lifelong regimen of pharmaceutical therapy and regular examination. I expand and adapt the model that they highlight of AIDS disease management to diabetes management. The behaviors of diabetes club-goers and their interactions with clinical staff suggest that therapeutic clientship serves as a useful paradigm for understanding the integral role relationships in engagement into diabetes management. Therapeutic clientship offers a series of questions with which I understand the link between sociality and health agency: through what channels do people access diabetes care, to which expectations are club-goers and clinical staff members held, and how does exchange and transaction bring people with diabetes into biomedicine. This thesis argues for the centrality of connection as the mechanism of engaging people in diabetes chronic disease management programs.

A diagnosis of diabetes is an alienating and frightening experience. It omens a life-long struggle without management through behavioral regulation, treatment of diabetes-related symptoms, and perhaps intervention in the underlying physiological dysfunction. In the Western Highlands, people with diagnosed diabetes have few resources with which to manage their symptoms and the progression of the disease. Diabetes clubs, focusing on the prevention of diabetes-related complication through “self-care,” offer counseling, blood glucose testing, and
information. Conceptually, I consider the motivations for and nature of engagement in diabetes clubs as a composite of recruitment, attendance, and participation.

Informants describe two main pathways through which they connected to diabetes clubs. The first way I call the ‘centralized’ or ‘official diagnosis pathway.’ People feel ill and seek medical care from professionals, be they private providers at an NGO or clinic or public practitioners at a MSPAS facility. They receive a blood glucose examination that reveals that they have high blood glucose levels diagnosing them with disease. Their diagnosing provider refers them to seek follow up care at their local MSPAS facility in the form of attending diabetes clubs. This official channel exists, but more often recruitment narratives demonstrate the exercise of personal and ‘decentralized diagnosis pathways.’

The second channel flows through ‘decentralized’ recruitment and horizontal extension of social networks. Sitting in the Centro in the large town of Panajachel, a 67-year-old woman shares with me how she first heard about the clubs. She tells me that her sister, a nurse with diabetes who worked at the National Hospital in Sololá, suspecting that my informant’s health issues stemmed from undiagnosed diabetes connected her with a doctor who ultimately diagnosed her. She continues describing how a few weeks later, her sister came to see her to inform her about the diabetes club in Panajachel where one received blood glucose tests and medication, all for “just 5 GTQ ($0.70)” (Interview on July 27th). Every month, she and her sister take the bus down to the Centro together. This engagement narrative demonstrates a key concept in predicting treatment seeking behavior in Guatemala that symptom recognition is the first step (Weller et al. 1997). The first step to join a program involves the primary diagnosis test; getting access to the diagnostic blood glucose test was mediated through strong, familial social connections.
Furthermore, a widely held common recruitment narrative focuses on the local health worker, acting as a community health worker, going door-by-door informing people of the upcoming diabetes club. One morning, Bayro and I arrived at a club in Godinez, a town up in the hills of the caldera. We arrived to find the club empty, so the local health worker in the Puesto traveled around town and personally inviting diabetics she knew to attend the club. Similarly, many participants described how local nurses and health workers showed up at their homes the day before to remind them of the diabetes clubs: “the nurses came yesterday to my home to inform me of the club” (Interview on July 7th). Both of these examples describe how health workers occupy important position in a community’s health advisory networks. Personally, recruited to attend diabetes, many participants are socially-embedded and positive seekers of healing.

Intrinsic to the nature of social networks that mediate health access are inequalities of social capital in kinship networks. Whyte et al. (2013) describe how these narratives of recruitment reflect inequities in clientship models. Attendance, the first step of engagement, is driven by “technical know-who” where relationships form the basis of accessing the bureaucratic health system. If one lives near the MSPAS clinic, often located in the center of town, or have social connections that place the local health worker in one’s kinship network, one can practice engagement without great difficulty. Club-goers are not “simply caught up as individuals in a net thrown out by providers,” but “achieve” services by exercising established networks of help of important others (Whyte et al. 2013, 114). This decentralized pathway based on horizontal extension of the biomedical system into the community reflect the grassroots nature of recruitment that characterizes entry into diabetes clubs.
Biomedical discourses represent diabetes, like many chronically diseases, as a lifestyle condition resulting from years of unhealthy, irresponsible, and risky behavior (Broom and Whittaker 2004; Whitmarsh 2013; Mendenhall et al. 2010). However, in Guatemala, lay explanatory narratives offer a broader illness causality narrative based on emotional and psychological stressors. This explanatory model, a narrative framework employed by people to make sense of illness, is called susto (Poss and Jezewski 2002; Mendenhall et al. 2010; Moreira et al. 2018). Arthur Kleinman (1988, 3-4) writes that “role of the health professional is not so much to ferret out the innermost secrets … as it is to assist the chronically ill and those around them come to terms with—that is, accept, master, or change—those personal significances that can be shown to be operating in their lives and in their case.” The local health care worker, who understands both the biomedical and lay narratives surrounding sickness, occupies a unique role as the Kleinman suggest in that they act as cultural brokers mediate care delivery. This idea can explain the broader role of community health workers shepherding people into disease management programs. Once club-goers enter diabetes clubs, engagement can be understood through participation.

The social milieu of diabetes clubs promotes an informal arena of social interaction between club-goers. One morning, while waiting for a club to begin, I noticed a group of female club participants chatting in the waiting room. The first woman reported the aching pain in her foot. The second women exclaimed how the pain in her knee disrupted her night of sleep. She finished her thought and promptly she and the first woman turned to the third sitting between them, as if they signaled an open floor upon which the third could air the woes associated her health issues. The woman hesitated for a moment and exclaimed “oh, how my back burns!” All three women broke into chuckling (Fieldnotes July 6\textsuperscript{th}).
This interaction was one of my favorites throughout the entire 10 weeks. The entire scene transpired quickly, but it dramatically lightened the three women’s disposition for the rest of the club. I propose that a significant feature of being a member of diabetes clubs is the unstructured social interaction between participants. The light-hearted practice of ‘communal complaining’ is a feature that forces relationships between club-goers and provides an opportunity to shed emotional distress. In interviews with participants, when asked about how diabetes affects their lives, many participants proceeded into a descriptive and performative narrative that detailing every ache and issue they are feeling. One informant responded to that question starting with:

“well, it’s okay. Look here, I woke up with head pain, with heel pain. Ah, how it hurts! I woke up with no appetite. Sometimes, I am very hungry. And we [referring to people with diabetes] cannot eat a great deal because they say no. They have told me yes to greens, vegetables, fruits. But sometimes, we cannot have them because of economic constrains…” (Interview on July 7th)

She continued describing how she slept poorly, ran out of medications, visited the doctor for cream to treat a rash on her leg, and how one at a time parts of her body fail (Interview on July 7th). It is not my place nor is it appropriate to evaluate the validity or weight of grievances. But rather, I recognize the dimension of self-making and the economic and social stressors in her life.

One interpretation for both ‘communal complaining’ and the performative nature of describing diabetes is that diabetes is an “idiom of distress” through which people construct and voice self-narratives. Informants articulate self-narratives as a sense-making practice to process emotion distress and stress of the past and present (Mendenhall et al. 2010). Engagement allowed the voicing of self-narratives and unloading of emotional grievances. The social milieu in diabetes clubs presents the gathering as monthly opportunities to release mental and emotional stress. Furthermore, clubs allow people to describe diabetes as a product and representation of social suffering, and for other to acknowledge it (Mendenhall et al. 2010). Sharing personal
stories and burdens constitute a form of opening up of embodied diabetes narratives. I demonstrated how at certain moments, the social milieu expected this behavior. I seek to further explore the nature of transactions and expectation in therapeutic clientship.

The client-patron relationship exercised by engaging in a diabetes club caries a set of obligations and expectations for each agent. Clientship in a diabetes management program requires the patron, a member of the clinical staff, to deliver a therapy (Whyte et al. 2013). The client must reciprocate to complete the transaction. Club-goers described in great detail how receiving glucose tests, knowledge about “self-care,” and pharmaceuticals motivated their presence in that club. I will unpack these ‘transactable therapies.’ I note that the extent of therapies that club-goers receive through their membership is contingent on the economic resources of each club. That is to say, all club-goers receive biomedical information about diabetes management from a charla and blood glucose checks, but only well-resourced clubs present club-goers the opportunity to receive pharmaceutical therapy.

All the clubs are posited as a way increase access to biomedical knowledge about diabetes, diabetes management, and diabetes-related complication. During an interview on July 6th in the town of San Andres Semetebaj, I tried to understand what drove one informant to attend her first club, why she continues to engage, and what she gets from it:

(Spanish)

E: ¿Por qué vino Usted esa vez?
P: Porque para ver es una obligación.
E: ¿Qué le motivó a continuar asistiendo a los clubes después de la primera vez?
P: Pues sí, Para saber, verdad. Como está.
E: ¿Pensando en su vida y sus hábitos antes de venir por la primera vez y ahora, hay diferencias? ¿Cuáles son?
P: Sí, que se siente uno mejor.

(English)

I: Why did you come that time?
P: Because seeing is an obligation.
I: What motivated you to continue attending clubs after the first time?
P: Well, yes. Knowing, right? How it is.
I: Thinking about your life and habits before coming for the first and of now, are there differences? What are they?
P: Yes, that one feels better.
My informant shared how she believed to that she benefited from receiving information and this motivated her to re-attend the clubs. This reflects how centrally the club attempts to address gaps in knowledge through the routine of a *charla*. The emphasis on health illiteracy as the root of chronic disease crises becomes problematic as it strives to promote ‘compliant’ behavior change (Chary et al. 2012; Shaw et al. 2008). The narrative of ‘if they only knew, their diabetes would be under control’ proports that proper acceptance of biomedical information and the rejection of disease-causing familial practices, cultural mannerisms, and desires emancipates suffers from their “non-compliant subjectivities” (Whitmarsh 2013). The notion that availability of information transforms a diabetic into an “ascetic subject of compliance” forms a moralizing discourse. However, after five months of attending, this club-goer could articulate how *charla*-based recommendations of “self-care” promoted positive changes in her symptoms. This reflects the way in which information-as-therapy for diabetes management fails due to possible the cultural incongruencies between lay and biomedical narratives of sickness and deep structural ravines make biomedical perspectives inaccessible.

All clubs provide free finger-prick blood glucose tests to check a club-goer’s “sugars.” I wish to highlight how the same informant from San Andres Semetabaj understood the results of her blood glucose test:

(Spanish)  
E: Ok, entonces, por qué Usted esta aquí hoy? I: So, why are you here today?  
P: Para saber de mi salud. (señalando a los números)  

(English)  
P: To know about my health. (pointing at the glucose numbers)
E: ¿Y que piensa sobre los números, de que quiere saber de la glucosa?
P: Como está mi azúcar, está alto o bajo.
E: ¿Cómo le ayuda esta información?
P: Está uno pues satisfecho de que el azúcar está bien. Se siente bien, ¿Verdad? Y así está pasando uno.

I: And, what do you think of the numbers, that you want to know of the sugar?
P: How my sugar is, is it high or low.
I: How does this information help you?
P: One is, well, satisfied that the sugar is good. One feels good. Right? This is how it goes.

Modern logic of public health sometimes diminishes the significant role that glucose testing plays because it seen by biomedical providers as a “decades-old standard of basic care” (Moran-Thomas 2016). The glucometer is a highly specialized life-saving piece of technology to which access is appallingly weak. For many participants, having ‘good’ glucose numbers, semantically suggesting adequate control of diabetes, is conflated with good health. In a resource-scare medical environment, the general population has little access to these devices that seem to impart more insight about wellbeing than one’s own individual subjectivity (Biehl and Moran-Thomas 2009). Engagement at clubs presents an opportunity to gain access to this powerful technology that reshapes the experience of symptoms.

As is the nature of therapeutic clientship, inequalities exist between different programs that allow privileged access to certain treatments. The WDF grant does not provide funding for pharmaceutical therapy for diabetes management. It proposes that information access constitutes a form of treatment because it promotes management vis-à-vis “self-care” behaviors. The larger diabetes clubs taking place in the Centros in Panajachel, San Lucas Tolíman, and San Antonio Palopó independently secured funding through small grants and private donors to provide discounted pharmaceutical therapy. What costs normally 85 GTQ ($11.58) at a private pharmacy for a month-long pack of metformin or glibenclamide, costs a “small collaboration fee” of 15 GTQ ($2.40) in San Lucas, 5 GTQ ($0.70) in San Antonio, and 5 GTQ ($0.70) in Panajachel. The other diabetes clubs do not provide discounted medications.
Informants and interlocuters at diabetes clubs expressed the desire for widespread pharmaceutical therapy for diabetes. MSPAS workers held metformin and glibenclamide, the two main available oral medicine for type 2 diabetes sugar control, in high regard. They attribute low attendance at clubs to the widespread conception that non-pharmaceutical ‘transactable therapies’ are not valuable. People did not show up to clubs that did not provide medications. In theory, the MSPAS should carry metformin and provide it all primary care facilities in the public system. However, this is rarely the case. At the club in San Andres Semetebaj on July 6th, the MSPAS nurse repeatedly informed Bayro and I that that day he had medications to distribute to club-goers. I write in my fieldnotes that “his repeated insistence on distributing meds suggests that having meds on stock in the Puesto is a new and special” (Fieldnotes Wednesday, July 6th). I continue, “there were 5 employees, but Bayro, Lynn, and I did all the tests … Bayro said that people do not come because they used to not have medications to give out (Fieldnotes Wednesday, July 6th). Why do pharmaceuticals drive engagement in some places?

The next day on Thursday, July 7th at a club in Agua Escondida, an informant shared with me her suggestions on how HA and MSPAS can improve the clubs. She told me that she thinks the club functions well, but gingerly mentioned that the club could be improved if we provided medications or even just vitamins. (Interview July 7th). My informant and the MSPAS nurse from the previous day support that idea that pharmaceuticals as a ‘transactable therapy’ carry symbolic and cultural gravitas. Western pharmaceuticals, pills, tablets, capsules, and even vitamins, have a “concreteness” to them. Some suggest a theory that pharmaceuticals, as commodified material objects, make the disease being treated more physical and therefore, vulnerable to therapies. As a form of Western material culture, pharmaceuticals carry social and symbolic weight because of the power and biomedical authority of Western cultures. (van de
Geest and Whyte 1989). Regardless of why exactly people hold pharmaceutical therapies in high regard, each ‘transactable’ carries semantic meaning of value and efficacy.

In exchange for this transactable, clients barter for the ‘treatment transactables.’ For example, clients must attend and be present, requiring the investment of time and energy. Diabetes clubs are public meetings, and participants must relinquish the right for medical privacy. Club-goers subject their bodies to examination and their donations, as droplets of blood, represent embodied contributions of engagement.

The final aspect of therapeutic clientship that I seek to understand for diabetes club engagement is the idea of “belonging,” which describes the sentiments of obligation and reciprocity arising from the transaction between clients and patrons. Belonging makes concrete a system of membership that records people over time through the keeping of paperwork. In certain towns, club goers receive a carnets, a four-by-six-inch ticket made from thick stock paper on which health workers note glucose measurements, vitals, and height and weight. I argue here that carnets mediate the belonging of patrons to clients. Every month, the club-goer carries with them this piece of paper imbued with the symbolic weight of engagement in diabetes management. The act of keeping records and tracking the changes in blood glucose represent the crux of what “self-care” for lifestyle diseases management programs aim to promote, that is individual club-goer ownership of biomedical conditions and empowerment for long-term management through various ‘transactables.’

However, not all clubs keep track of the carnets and not all club-goers bring them each month and frequently lose them. Larger clubs, those that regularly offer discounted medications and take place in Centros, promote the use of carnets. HA and other MSPAS units say that it is not worth the money to print and distribute them because people lose them. This suggests a
disappointment and distain for the supposed carelessness of the club-goer when they misplace carnets. This symbolizes the potential failure of the type of engagement that diabetes clubs attempt to engender for successful “self-care.” When engagement in diabetes management program is posited as a form a treatment itself, the moralized language of compliance and responsibility becomes attached to all aspects of membership. The carnet represents the first step in transforming oneself into a client ready to (re)engage in lifestyle management programs.
Conclusions

Through this thesis, I have aimed to demonstrate how social forces mediate engagement in diabetes management programs in the Western Highlands of Guatemala called diabetes club. These diabetes clubs present as opportunities to promote a biomedical treatment discourse centered around “self-care.” I argue that a heuristic of therapeutic clientship highlights a series of questions to examine the motivations for and processes by which participants in diabetes clubs make use of their access to health resources. Some of the key principles include the centralized and decentralized recruitment networks, the relationship between clients and patrons of disease management programs, the sentiment of belonging. The ideas that build therapeutic clientship function as analytical tools with which I unpack the social, symbolic, and cultural forces of that impact perceptions of pharmaceutical therapy, biomedical compliance, subjectivity, and illness causality and self-narratives. I also offer a structural analysis that explores the ways that NGOs and the Ministry of Public Health and Social Assistance collaborate to realize provision of health care services to the Guatemalan people.

The purpose of this thesis is to understand features of chronic disease management programs and how those components impact patient and provider behavior. Given the context of rapidly growing prevalence of chronic diseases in more-economically developed and less-economically developed countries, this research aims to add an anthropological analysis on diabetes treatment seeking.

One aspect that I did not develop in great detail in my analysis is the implication of reduced barriers. What happens the barriers impeding rollout and accessibility of diabetes technological and pharmaceutical resources cease to exist? Even as an idealistic thinker, I am not convinced that this will be achievable in my lifetime. One idea is that the social, economic, and
political factors of a society that formerly posed a barrier will transform into new challenging
hampering the realization of health equity globally. As the technological solutions to once
significant health emerge, I wonder how the forces of human sociality surrounding disease will
transform. Lessons can be learned from studying the transformations that other disease processes
experience when efficacious therapies become widely accessible. What is clear is that the global
health researchers and practitioners will face greater epidemics chronic diseases. As disease of
lifestyle, diseases of culture, anthropologists will play a significant role in unpacking the socio-
cultural norms that influence how illness is experienced and political economic barriers that
thwart successful intervention.
I could not have successfully completed this thesis without the support of many individuals and institutions with whom I worked. I would like to thank my thesis advisor, Dr. Fran Barg, for her academic and personal encouragement throughout the fieldwork, analysis, and composition process. I would also like to thank the Department of Anthropology, the Penn Museum, and Penn Global’s International Internship Program. Without their educational and financial contributions, I would not have had the opportunity to conduct the research from which this thesis builds. I thank to Dr. Kent Bream. I am grateful for the incredible amount of personal and professional investment he pours into GHI. I thank to Lyn Dickey, Bayro Bocel, the rest of the Development Office, and the entire Hospitalito Atitlán family for granting me access and allowing me to contribute to the wonderful services they provide to their community. I could not have done the fieldwork without daily conceptual feedback, technical help, and social support from my GHI 2016 peers, Lynn Hur, Christina Roldan, and Natalie Koch. I thank to all the informants and interlocutors that allowed me to engage them in conversations. I appreciate the time, effort, and trust they invested in me through sharing their experiences, feelings, assessments, and stories.
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