

DIABETES, GENDER, AND POVERTY IN GHANA

By

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## **ABSTRACT**

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This dissertation examines the lived experience of people with diabetes in Kumasi, Ghana, and places their stories and health outcomes within the greater structural and social climate, both within West Africa and globally. It utilizes chronicity theory, which considers structural forces such as poverty and gender inequality as chronic and comorbid conditions, in that they are unending and worsening and exacerbate the illness itself. The first chapter examines how diabetic patients grapple with the weight of expectations placed on them through the diabetes self-management model while living in a context of income insecurity and gender inequality, and how they utilize personal responsibility discourse to demand increased resources from the government. The second chapter investigates how diabetes impacts patients' ability to fulfill gendered expectations in the areas of sexuality and physical work, and the resulting distress and worsened economic states that arise. The third chapter analyzes diabetes management outcome biomarkers at the intersections of multiple disadvantaged identities in order to better understand how the economic and gendered realities of diabetes self-management evaluated in the previous chapters may be reflected in tendencies in measurable health outcomes at the group level. Findings from these studies have implications for policy and clinical practice and contribute to the anthropological literature on chronic illness, economic precarity, and gender.

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## **Chapter 1: Introduction**

This introduction provides background information about the study site, study methodology, and data collection methods, and outlines the three analytical chapters. Each analytical chapter functions as a standalone article with its own introduction, background, analysis, findings, discussion, and references.

The research presented in this dissertation seeks to understand the lived experience of Ghanaians with diabetes and examine how sociocultural systems of disadvantage impact diabetes management and health outcomes. Using the lens of chronicity theory, it views these systems of disadvantage, such as gender and income inequality, as chronic conditions that accompany diabetes in its life course and exacerbate negative health outcomes (Estroff 1993; Manderson and Smith-Morris 2010; Weaver and Mendenhall 2014). It seeks to prioritize stories and emotions and uplift people living with diabetes as having expertise on the condition and invaluable contributions to knowledge production. It also critically examines how the culture of biomedicine takes root uniquely in Ghana, adopting local and global values and reinforcing them in its subjects. It highlights how women exercise agency among the power structures that surround them and features women's lived worlds.

This dissertation interrogates how women and men with diabetes navigate the structures that contribute to illness and reclaim discourses of personal responsibility to garner more state responsibility. It aims to uncover hidden consequences of diabetes that interact with cultural and gendered expectations and may contribute to decreased success in diabetes management and quality of life. It also draws out the biological realities of belonging to one or more disadvantaged group and highlights the importance of integrating both quantitative and

qualitative data on lived experience in getting the full picture of diabetes, gender, poverty, and health outcomes. The results have implications for policy and clinical practice and contributes to the anthropological literature on chronic illness, economic precarity, and gender.

### Fieldwork and Research Sites

This research took place in Ghana over 11 months during 2016 and 2017. Ghana is a low-to-middle income country, and while conditions in health care, the economy, and education are greatly improving, it has also taken on some of the burdens of change, like more sedentary lifestyles and an imbalance of calorie intake and expenditure. The combination of decreased physical activity, increased incomes, urbanization, and higher access to more processed, calorie dense foods contributes to the escalation of diabetes in Ghana, which has afflicted as much as 9% of the population (Tagoe 2012). This section introduces the fieldwork and research sites, Kumasi, Ghana, and the diabetes clinic at Komfo Anokye Teaching Hospital (KATH), providing context in order to understand the findings. As a frequent target of international investment in various sectors, Ghana is an important site to study the influence of global and local influence on growing diabetes rates. Additionally, much of the social science research on chronic illness is conducted in Western countries, leaving a gap in understanding of how these trends are experienced in Sub-Saharan Africa.

### *Kumasi*

Kumasi is the second largest city in Ghana with a population of nearly 3 million and is the traditional cultural center of the Asante, the country's dominant ethnic group. Kumasi is the home of the typical Asante Twi dialect, the Asantehene (Asante King) palace, the largest open-air market in West Africa, and relics of colonial British-Asante struggle. One of the most notable

features of this cultural hub of Ghana is the prolific traditional funerals that occur every weekend on almost any street you look down: a sea of people wearing red and black and a traditional band of drums loudly amplified for the whole neighborhood to hear. While Kumasi is a major urban area, the capital of Accra is more cosmopolitan with high rise buildings and luxury apartments, whereas Kumasi opened its first shopping mall after this research took place in 2016 to 2017. Kumasi is referred to as the Garden City due to its many trees and green space, but is experiencing rapid sprawl and more forest is being cut down to build new houses and accommodate growing business opportunities. Kumasi boasts a dominant Asante culture whereas Accra is more diverse with people of all ethnic groups from around Ghana and neighboring countries.

From living in Kumasi and listening to Ghanaians, I learned about the unique brand of femininity and masculinity among Asantes. There is a distinct divide between men and women in perceived qualities, responsibilities, and abilities. Though Asantes have a matrilineal lineage, inheritance is given to the males in the mother's lineage. There is an impression in Ghana of Asante women as strong, bossy, and entrepreneurial, but women are largely expected to defer to men. Men are given assumed authority and expertise and take up most of the leadership roles in government and commerce. Less than 11% of seats in Parliament are occupied by women, compared to an average of 24% in Sub-Saharan Africa (World Bank 2016).

### *Komfo Anokye Teaching Hospital*

A major feature of Kumasi is KATH. The teaching hospital is the second largest in Ghana and is affiliated with the Kwame Nkrumah University of Science and Technology medical school. It was established in 1954, three years before Ghana declared independence from the British. It

is built on sacred land where Okomfo Anokye, a fetish priest who was integral in establishing the Asante kingdom, placed a sword in the ground that is said to have not been able to be removed by anyone since the 17<sup>th</sup> century, including Europeans with machines. The hospital property still boasts the sword in the ground in a small museum (McCaskie 1986). This monument alludes to the values of strength and masculinity that interact with diabetes management, as I will take up in this dissertation.

Walking around the KATH campus, crowds of people can be seen walking to various wards, several waiting areas with hundreds of people sitting on the chairs and concrete, groups of medical students in white coats following professors around as they lecture, patients being pushed on stretchers, wailing patients being consoled by family, construction being done on an elevator or a roof, and many people sleeping on cardboard sheets under the shade of the stairwell of the accident and emergency ward, perhaps waiting for a family member to be discharged.

People shared that Ghanaians deeply fear KATH. They view it as a place one goes to die. It is said that when a person receives a call that a family member is at KATH, they will burst into tears. This likely has two major reasons: first, that preventative care is seriously lacking in Ghana so that by the time a person encounters biomedicine it is at the late stages of disease. Second, that the lack of resources and efficiency in the health system often causes unnecessary deaths. For example, I was told that ambulances are simply private vehicles with sirens to carry people to the hospital and have no medical equipment inside nor paramedics to keep people alive in transit. Many people who arrive at the emergency room are already dead or die soon after. I often saw people brought to the hospital in a taxi that honks its horn repeatedly to

maneuver around traffic. People also had a generally negative view of nurses. I often heard that nurses were rude, slow, and generally unhelpful. That was not my experience in the diabetes clinic but tended to be the impression in the inpatient wards. The nurses I observed would spend their weekends and their own money trying to spread awareness of diabetes or help patients that could not afford care. Some hospital staff members acted very rudely to patients, even to their elders, which is frowned upon in every other sector of life in Ghana. For example, when speaking to an elder you must start every sentence with *mepa wo kyew*, or please/excuse me. I observed a staff member telling multiple elderly patients, “*Tena se*” (sit down) in a very stern and impolite voice, without saying the appropriate please first, when the patients were simply asking for direction or assistance. Working in the medical realm seemed to give some people a sense of superiority or self-importance, and patients also viewed medical workers as important, trends that I take up in Chapters 2 and 3.

Worker strikes are a common way of dealing with the government in public institutions in Ghana, and unfortunately for the patients, public hospitals are no exception. Because the health system in Ghana has its challenges, strikes happen frequently. Usually the group of workers in question will demand better pay or working conditions and be ignored by the government, and then as a last resort will coordinate amongst themselves to go on strike and refuse to work until their demands are heard. Going on strike appears to be an effective strategy when all other avenues are exhausted, but it comes at the cost of patient health. Patients cannot get care during those days, weeks, or even months of the strike. Earlier in the year of this research, the hospital pharmacists went on a three-month strike. This had a serious impact on the diabetic patients. The National Health Insurance Scheme (NHIS) only covers drugs

that are dispensed at the hospital pharmacy. The only way to get prescriptions filled at a private pharmacy is if a hospital pharmacist stamps a form saying the drug is out of stock and you are permitted to collect it elsewhere. Without the pharmacy and this form, patients were forced to pay out of pocket for their drugs, which led to many of the patients not taking their essential diabetes drugs for over 3 months. The doctors and patients note the high blood sugars that occurred during this time. Additionally, toward the end of fieldwork, there was a nurse strike throughout the whole hospital and the diabetes clinic was closed for three days, to demand better pay and working conditions. Many patients did not hear about the strike and made the journey to attend their appointment for review only to be met with a closed diabetes clinic. These strikes represent a social, political, and economic barrier to diabetes management.

#### *Diabetes Clinic at KATH*

KATH was selected as the research site because it hosts a dedicated specialist diabetes clinic, which would allow for convenience sampling of people with diabetes who are engaged in diabetes management. The diabetes clinic was founded about 20 years ago by a senior doctor who noticed that the number of diabetic patients and acute complications was rising and felt that the hospital needed a designated place to give them specialized care and attention. The clinic is a specialist referral center to which patients are sent by doctors in the hospital and in hospitals or clinics in the surrounding metropolitan area, if they feel the patient needs dedicated care that local medical clinics are not equipped to provide. There are an estimated 2,500 patients that are actively attending the clinic and around 10,000 patients who have open files. There are anywhere from 20 to 100 patients that come in a single day, ranging in age from 20 to over 100. Mirroring the population of Ghana, most of the patients are of low-income



status and a minority is of higher income status. The bulk of my time was spent in the patient waiting area, which I call the waiting “room” but was actually outdoors under a wooden awning, just opposite the clinic in the bottom floor of an uncompleted building. Between the clinic and the waiting room was a small path that was frequented by hospital patients and staff. There are rows of benches arranged closely to each other, enough to seat about 80 people. In the waiting room are also other stations to be visited before and after the doctor consultation, including retrieval of their patient folders, insurance verification, and photocopying of their prescriptions. There is also a food vendor with a table and cookware who sells porridge, egg sandwiches, tea and hot chocolate, bread, and other items. Many of the patients eat food from this vendor after being weighed by the nurses and while waiting for the doctor to arrive. They do not want to eat before being weighed as they feared this would raise their weight and indicate poor self-management.

Though the existence of this clinic was beneficial to diabetes patients, it was not without its challenges. The clinic itself was four small rooms and a hallway. One room was for the nurses to consult with patients, sell test strips and sucralose sweetener, and instruct them on taking insulin. Another room was the nurse’s break room with a refrigerator and piles of paperwork, which is also sometimes used by researchers for interviews. The other two rooms and the hallway were used as doctor consulting rooms and there were at times up to six doctors consulting patients at once, leaving no privacy for the patients. Throughout the hallways are benches and chairs filled with patients waiting in a queue to see their doctor, so the place was extremely crowded and hard to walk through.

Though the nurses and staff were assigned exclusively to the diabetes clinic, the physicians were not. They were often assigned to the inpatient wards or another department and would come to the clinic one day a week before going back to their post. Therefore, it was very common that the doctors would get held up elsewhere in the hospital and arrive very late to the diabetes clinic. I observed doctors arriving as early as 9:00 am and as late as 12:00 noon. Patients were seen on a first come first serve basis, which caused them to come very early; many would arrive before 5:00 am and wait many hours for clinic to begin once the doctor arrived. There were several instances when doctors did not show up at all. The excuses given were that he has travelled (gone out of town), he is stuck in another part of the hospital, or even that they had no idea where he is. So these patients have gotten up at dawn, traveled sometimes up to 50 miles, paid money for transport, had to purchase breakfast at the kiosk, and sat around waiting for hours, just to be eventually told that the doctor is not coming and they should come get a new appointment date to do this all over again. For some patients, making the trip to the hospital was cost prohibitive and they could only make it once or twice a year instead of every other month. If this happened on their appointment date, it would be very detrimental to their financial situation, not to mention their physical health and wellbeing, as their blood sugars and medications are not being monitored for a longer period of time than prescribed.

### Research Questions

This dissertation uses the theory of chronicity, which considers illness as an interaction between the body, subjectivity, social worlds, and poverty, to examine the “intensive identity

work” involved in overcoming the disruptions and responsibilities of self-management (Weaver and Mendenhall 2014). I set out to investigate the following research questions:

1. Do gender identities and diabetes self-management responsibilities influence each other? If so, what are the impacts on health? How does this occur in a context of poverty?
2. Are clinicians’ conceptions and explanations of personal responsibility ingrained with notions of gender? If so, how might these shape patient identities? How might these further or counter gender inequalities?
3. Do patients use these gendered diabetic identities to challenge or employ the patient responsibility model of disease management? How is responsibility understood in diverse ways by individual patients, among groups of patients, among clinicians, and at the level of state and public health institutions?

The research questions were refined or revised via an iterative process in the field. While conducting research, sexuality emerged as an important element of gender and identity as well as the opportunity to collect patient medical record data to triangulate qualitative impacts on health. These questions and tools used to answer them were informed by a feminist critique of science, which has historically obstructed equitable social relations (Harding and Norberg 2005) and excluded information about women’s bodies and experiences (Cook 1983). This study instead elicited women’s experiences and analyzed data in consideration of social inequality.

## Research Methods

This section provides an overview of the research methods utilized to answer the questions of this study: participant observation, semi-structured interviews, and retrieving patient medical record data. This research was approved by the diabetes clinic, Kwame Nkrumah University of Science and Technology School of Medical Science Committee for Human Research, Publishing and Ethics (CHRPE) and the Institutional Review Board at Michigan State University. All research participants were volunteers and were informed of all procedures,

benefits, and risks before giving a signature or fingerprint consent to participate. A summary of all data collected is presented in Table 1.

Francis Akutey-Baffoe was the research assistant on this study. Francis was the instructor when I studied Twi at University of Cape Coast during my first visit to Ghana. As a graduate student and lecturer in Ghanaian languages and culture, his expertise was invaluable to the development and completion of this research. His in-depth knowledge of the Twi language and Akan culture was an asset when building rapport and communicating with the elder patients in the diabetes clinic.

The research methods utilized mirror other studies that employed semi-structured interviews with patients and clinicians in clinical settings in order to understand the illness and illness management experience (Ferzacca 2000; Hunt et al. 1998; Martinez 2005) and to collect biological data to paint a picture of the biological trends related to this illness experience (Mendenhall et al. 2019).

#### *Participant Observation*

I spent many days sitting in the diabetes clinic waiting room observing the system put in place for patients to check-in, be triaged, wait together while receiving patient education, and see the doctor. I wrote quick notes during the day and completed them in more detail when I arrived home each afternoon. I asked questions of staff to better understand what was happening and built relationships with other researchers who were also working in the clinic.

Because of my appearance as a foreigner and the frequency of research projects at KATH, many of the patients approached me to ask me what research I was doing as well as

share information about their challenges in managing their disease. I was able to hear complaints and experiences that were shared of patients' own volition without directing the conversation. I learned a lot about the diabetes experience this way.

Spending the time in the clinic almost daily was indispensable to answering my research questions. I was able to build rapport with staff, which was invaluable to my understanding of the context and situations that would arise. I would also help with small tasks when requested when the staff was overwhelmed with many patients at a time. This helped me to grasp the bureaucracy and hoops that the patients must jump through to get care. The Twi I had learned before coming and upon arrival helped me to converse with the patients. Some were amused that I was there while others seemed not to notice and treated me as just another employee. Some preferred to speak English to me and some demanded that I speak Twi.

Because the patients were usually only there once or twice during the field work, it was not easy to build long-term rapport with individual patients. I experienced intense and meaningful one-time encounters with some of the patients where they shared their financial and health struggles. I became close with the Chairman of the Diabetic Association who was himself a diabetic of over 40 years and comes to the waiting room daily to advertise the next meeting date and collect dues.

Though many days of observation were indistinguishable from the days before, an additional benefit of being present in the clinic was that I was able to witness different crises and upsets from the patients and use these events to better understand the intricacies of life with diabetes. There were several instances where the patients of the day got upset as a group

and made their opinions known. There were other times where a single patient would protest something that was happening to him. Once, a patient experienced a hypoglycemic episode while waiting for the doctor and a staff member saved his life by realizing he was acting strange and alerted the nurses to give him glucose. Some did not like the setup of the clinic and felt their time was being wasted. Others were confused about what to do and were being dismissed by certain staff. I was also able to observe the nature of the interactions between patients and clinicians with patients. I observed the power dynamics that were present, some of which reflected Kumasi life outside of the clinic, and others that were specific to the hospital setting. I also observed inside the clinic rooms the interactions between patients and doctors. I got a sense of the length of time a doctor would spend with a patient and how much listening versus talking they did. I observed the tone of voice used and body language.

An important aspect of observation in the clinic was to witness the health talks given to the patients by the assistant head nurse, while they waited. These talks would happen a few times a week and usually last about 20 minutes. She would cover a topic related to self-managing diabetes and troubleshooting issues, as well as have a question-and-answer segment. This was an invaluable way for me to learn the messages that patients receive from clinicians and the way ideas about responsibility and gender were framed.

Another significant event in the clinic was the Diabetic Association of Ghana meetings that would occur there every three months. These would have a specific topic to be covered with the appropriate experts from the hospital appearing to teach in detail about how to self-manage, for instance, dentists or nutritionists. Many more patients would come than in a typical day and they would receive a gift of some sort, such as a meal or dry porridge to take

home, paid for by the association dues. The next meeting would be advertised daily in the clinic by the Chairman of the association.

I also attended and observed other diabetes related events that occurred during my time in Kumasi, including a World Diabetes Day parade and a two-day Continuing Education Workshop for doctors.

### *Semi-Structured Interviews*

Semi-structured, open-ended, ethnographic interviews were employed with patients to understand the everyday experiences and nuances of managing diabetes. The interview questions were designed to situate diabetes as one thread in the weave of life's tasks and problems and to draw out how patients shift their lives to make room for diabetes. The questions also sought to elicit ideas about gender so that I could understand the ways that men and women "do gender" as they "do diabetes." The assistant head nurse would greet the patients respectfully as her elders and introduce me and the purpose of the project. She would then briefly describe the interview process and the voice recording and ask for a show of hands of who would like to volunteer to be interviewed while waiting for the doctor. I gave each patient a gift of 5 cedis for their participation but did not inform them of the gift until after they went through the consent process in private, as we did not want the money to coerce anyone into volunteering. We would say we needed six people: four women and two men. Usually the numbers did not work out perfectly in this way. Some days not enough people would volunteer and other days too many people would volunteer, leaving some disappointed to not participate due to a lack of time. Some days no men would volunteer. We would just go forward with the

volunteers we had. We would ask them to wait until one patient left the room and then whoever is next should enter.

Francis would conduct the interview, usually in Twi, while I listened and occasionally interjected for a follow-up question. I took notes about the patient's demeanor and body language. I would also take note at the instances where the patient cried or had an intense emotional response, and Francis or I would offer comfort or words of encouragement afterward. The interviews lasted between 15 minutes and an hour, depending on how much the patient would elaborate on their responses. We thanked them with the 5 cedis and a few packets of sugar-free sweetener. Most but not all patients knew what the sweetener was as it is sold in the clinic. Some patients tried to deny the money and a couple others tried to ask for more. Most appeared to be very touched by how attentive and understanding Francis was and for the chance to share their stories. Afterward, another Ghanaian research assistant, Kwame, as well as Francis, transcribed and translated the interviews.

Interviews were also conducted with doctors and the assistant head nurse about their perceptions and strategies of diabetes care. They were asked to participate in an interview after they saw all the patients and were offered lunch and a drink from a local restaurant as incentive. The interviews lasted about 15 to 20 minutes. Often the doctors would say they did not have much time and we needed to keep it short, but then once we got started they had a lot to say and elaborated on their answers. I conducted these interviews in English and recorded and later transcribed them. I learned a lot from them about what it is like to be a doctor in Ghana and to treat diabetic patients. I also tried to draw out gender dynamics present in their own interactions in the clinic. I ended with the general impression that these doctors



really cared about their patients and were doing the best they could with the given constraints to help their patients to be healthy and live long lives.

There were also many informal interviews with various staff members, who I spent most of my time conversing with on a daily basis. As the staff members were steeped in the routine of the clinic and had witnessed many of the complications and challenges, they were able to fill in the gaps for me in my observations and conversations with patients.

#### *Recording of Patient Medical Record Data*

After the interviews, I recorded health data from each participant's patient folder, which is their clinic-specific medical record. I collected height, weight, body mass index (BMI), blood pressure (BP), and fasting blood sugar (FBS) from the day of their interview, from two visits in each of the preceding three years, and from their initial visit at the clinic. This was recorded along with patient interview number in order to keep the interview and health data connected without maintaining identifiable information.

Table 1. Total Data Collected

Data Type	Number Collected
Participant Observation in Diabetes Clinic	
Waiting Room	50 days, 6 hours each
Consulting Rooms	10 days, 1 hour each
Health Talks	10 patient education presentations
Diabetic Association Meetings	4 meetings/patient education presentations
Diabetes Events	3 all day events, e.g. awareness and screening
Semi-Structured Interviews	
Diabetes Clinic Patients	40 women; 20 men
Diabetes Clinic Clinicians	6 doctors; 1 nurse; 3 staff
Data from Patient Medical Records	
Fasting Blood Sugar, etc.	40 women; 19 men

## Chapter Overview

Chapter Two, entitled, “Diabetes Self-Management and the State: Embracing Personal Responsibility Rhetoric to Demand Greater Government Responsibility,” explores the ways in which clinicians and patients understand responsibility for health and diabetes management in Ghana. It examines discourses used by clinicians and patients to determine types of rhetoric that shape patients as responsible for their own health. The mainstream personal responsibility for health model of diabetes care and education emphasizes individual accountability for self-management under the guise of empowerment; it also sustains the hierarchical knowledge structure that shapes clinician-provider relations. Previous research has argued that emphasis on personal responsibility places blame for illness solely on the individual, neglecting structural influences on illness and obscuring government responsibility for citizen health. Because some previous studies on chronic illness demonstrated that patients resist having their illness being defined as a biomedical problem and the multitude of structural and societal forces that contribute to lack of resources needed to self-manage diabetes, it is expected that these diabetes patients would reject direction based on the personal responsibility model. However, interviews with patients and clinicians alike showed that these institutional and social obstacles did not cause them to question or challenge the idea of personal responsibility, but rather they pointed to the importance of personal responsibility to justify their demands of increased attention and funding for diabetes from the government. Patients embraced and utilized personal responsibility rhetoric, not as passive subjects of neoliberal conditioning, but to position themselves as in need of government support for successful self-management and to explicitly call out state failures and poor global distribution of resources. This study shines light

on how knowledge and practice around responsibility and choice is co-constructed between those in power and everyday citizens.

Chapter Three, entitled, “Sex and Work: Diabetic Disruptions to Gender,” looks at how diabetes-related sexual dysfunction and inability to work impacted female and male patients. Existing research has demonstrated that gender impacts chronic illness management, but less is understood about how chronic illness affects gender. This study examines how chronic illness, particularly diabetes, disrupted gender performativity, impacting patients’ ability to fulfill important elements of being an ideal man or woman. These diabetic disruptions to sexuality and work were a source of distress, which often led to loss of income and relationships, exacerbated their economic precarity, and contributed to diminished diabetes self-management and poorer health outcomes. Furthermore, current approaches to diabetes management reify hegemonic notions of gender and neglect patients’ social and physical suffering, ignoring women’s experiences of sexual dysfunction, potentially contributing to further inequality between men and women in diabetes outcomes.

Lastly, Chapter Four, which is entitled, “Gender, Poverty, and Diabetes Health Outcomes,” leans on intersectionality theory to understand the layers of struggle that disadvantaged individuals experience, which are brought about by structural inequalities. Intersectionality theory contends that examining multiple disadvantaged statuses reveals hidden trends that are obscured when considering just one. Furthermore, it argues that when individuals belong to more than one disadvantaged group, the consequences of more than one disadvantage will have compounding effects. Multiple variables that are typically associated with disadvantages, including poverty, female sex, and older age, were analyzed for their effect

on fasting blood sugar (FBS) as an indicator of diabetes management success and health outcomes among individuals participating in diabetes management. The results show that poverty and male sex were associated with lower FBS values. These results only partially provided evidence for intersectionality; looking through multiple layers of disadvantage did reveal trends of worse FBS for women but did not provide statistical support that women in poverty would experience a *compounding* effect of worse FBS. Qualitative data from semi-structured interviews with diabetes patients and clinicians and participant observation at the clinic provide insights into the social meanings of these results, at times corroborating or complicating the findings.

The value of this research is to add quantitative data into the chronicity theory literature, contribute West African context to the diabetes and gender literature, and highlight women's experience with diabetes-related sexual dysfunction. The results have implications for public policy and health care practice.

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## **Chapter 2: Diabetes Self-Management and the State: Embracing Personal Responsibility Rhetoric to Demand Greater Government Responsibility**

### **Abstract**

This chapter examines how blame and responsibility are understood and distributed among diabetes patients and clinicians in the management of diabetes in a context of income insecurity. Using ethnographic research in a diabetes clinic in Kumasi, Ghana, I examine discourse used by clinicians and patients to determine types of rhetoric that shape patients as responsible for their own health. I then examine how patients and clinicians grapple with personal responsibility despite structural barriers to diabetes self-management. Previous research has argued that emphasis on personal responsibility places blame for illness solely on the individual, neglecting structural influences on illness and obscuring government responsibility for citizen health. However, this study shows that patients embraced and utilized personal responsibility rhetoric, not as passive subjects of neoliberal conditioning, but to position themselves as in need of government support for successful self-management and to explicitly call out state failures and poor global distribution of resources.

### **Introduction**

This chapter examines how blame and responsibility are understood and distributed among clinicians and patients in the management of diabetes in a context of income insecurity. It seeks to understand how in places like Kumasi, Ghana, patients and clinicians grapple with diabetes care models that place personal responsibility for health on the patient's shoulders, despite limited personal and health resources. Clinicians typically utilize protocols and rhetoric of personal responsibility for health by advancing the idea of controlling diabetes through self-management and prescribing patients with numerous tasks to control their own blood sugar, such as coordination of daily meals and drugs or insulin injections, watchful care and structuring of diet, and intentional incorporation of regular exercise (Nam et al. 2011). This contrasts with models used to treat acute illnesses where physicians take over and provide care, representing a significant shift in the way clinicians and patients have often understand



their roles in relation to each other. In the self-management system, clinicians generally serve as advisors, coaching diabetic patients around the idea that they are empowered with the personal responsibility to manage their disease. The personal responsibility for health model casts clinicians as consultants and patients as empowered self-managers. Previous scholarship argues that emphasis on personal responsibility places blame for illness solely on the individual, neglects structural influences on illness, and obscures government responsibility for citizen health (Brownell et al. 2010; Miewald 1997; Minkler 1999). This analysis sought to understand how these tensions play out in patients' and clinicians' talk: whether they embrace ideas of personal responsibility or resist them due to their contradictions. Through critical discourse analysis of semi-structured interviews, this study investigates how patients and clinicians in a diabetes clinic in Ghana utilize personal responsibility rhetoric and for what ends. It examines the role of discourse in reproducing and challenging power relations in and out of the clinic (Bélanger et al. 2016). It shows how patients grapple with the numerous, cost-intensive diabetes self-management tasks they are assigned, all while struggling to maintain their livelihoods. It also demonstrates how diabetic citizens view themselves in relation to the government, expectations they hold of themselves and the state, and the different targets of blame for diabetes diagnosis and failures to self-manage.

### *Diabetes in Ghana*

Diabetes rates are growing exponentially in low-to-middle income countries and faster in sub-Saharan Africa than any region in the world (Abegunde et al. 2007; IDF 2015). Changes such as increased consumption of calorie-dense, nutrient-poor foods, and decreased physical activity due to less physically demanding jobs are major contributors to the rise in metabolic

disorders such as diabetes (Ferzacca 2012; Little et al. 2017). Although rural populations are increasing in Sub-Saharan Africa, farm sizes are becoming smaller and many rural dwellers turn to off-farm work (Masters 2013; Muyanga and Jayne 2014), contributing to lower physical activity levels. Medical anthropologists have looked to the lasting impacts of colonialism and postcolonialism, such as high levels of psychosocial stress, limited food choices, volatile crop yields, and epigenetic changes in metabolism, to explain this shift in disease patterns (Ferzacca 2012; Landecker 2011). Many of these countries experience the double burden of infectious and chronic diseases, but communicable and infectious diseases such as HIV and malaria continue to garner the focus of national and international public health efforts, while far fewer resources are devoted to preventing and treating chronic illnesses (Agyei-Mensah and de-Graft Aikins 2010). These structural dynamics leave diabetes patients with little institutional and social support and those in poverty often have an even harder time securing access to the basic resources they need to manage diabetes (Kolling et al. 2010; Seligman et al 2010).

In Ghana, 5% of the population is estimated to have diabetes (World Bank 2017). This compares to 9.4% in the USA, which has the highest rate in the developed world (CDC 2017). In the literature examining diabetes in Ghana, researchers have found that low socioeconomic status is strongly associated with type 2 diabetes (Danquah et al. 2012). Some contributors to diabetes for people with low income include low uptake of prevention messages, low health care utilization, stressful living conditions, physical inactivity, and nutritional deficits (Danquah et al. 2012). Poverty is an important mediator of self-care practices, often leading to less adherence to diabetes management (de-Graft Aikins et al. 2014). Traditional diets such as plantains, green leafy vegetables, fish, fermented maize, and palm oil have been associated

with older, heavier, and poorer adults, and with increased odds for developing type 2 diabetes (Frank et al. 2014). For patients in urban Ghana, the economic burden of diabetes is high, resulting in over half of households experiencing what is called “catastrophic health expenditure” (Pei 2015), defined as out-of-pocket spending for health care that exceeds a certain proportion of a household's income (Ekman 2007).

The government of Ghana hosts a National Health Insurance Scheme (NHIS), which citizens pay into and receive free doctor visits and discounted procedures and drugs. But even with the provisions of this health insurance, diabetes related coverage is uneven and, in some areas, regressing. Facilities are lacking and long distances often must be travelled to access diabetes health services (Amoah et al. 2000). Patients’ failure to self-manage often reflects institutional factors such as drug cost and availability, health policy disparities, and culturally inappropriate lifestyle recommendations (Danquah et al. 2012). Patients primarily get money to manage diabetes from personal and family resources rather than public resources (Pei 2015). As a coping strategy for the ongoing financial burden, patients may abandon their biomedical treatment and turn to herbal medicine practitioners who assure patients they will lead them to be healed (de-Graft Aikins 2002).

Additionally, outside of the health system, the globalization of food markets, industrialization, and urbanization produce structural and social barriers to self-management (de-Graft Aikins et al. 2010). Diabetic patients are directed to eat more fruits and vegetables and reduce intake of fats and simple carbohydrates such as starchy vegetables, corn, rice, and sugar, but due to the high price and limited seasonality of fresh foods, this is cost prohibitive. Many work long hours to make enough money to subsist, leaving little time and energy left

over for physical exercise. Increasingly, employment is highly sedentary and is accompanied by a long commute sitting in a bus. There is a lack of safe public places to do physical activity outdoors and roadways are dangerous for pedestrians. Furthermore, the social atmosphere encourages consumption of large portions of starches such as cassava, yam, and plantain-based foods. Integral cultural functions such as funerals and weddings usually include sugary beverages. Convenience foods that are widely available are usually fried in oils and have high amounts of sodium, contributing to poorer metabolic health and challenges in diabetes diet adherence.

Ghana provides an important case study to examine the complexities of how people with diabetes in low-to-middle income countries negotiate their daily subsistence with their diabetes self-management responsibilities. It also allows for examination of how citizens grappling with socioeconomic precarity view themselves in relation to the state and their perceptions and expectations of the government to contribute to their health and healing.

### *Personal Responsibility*

According to Anderson and colleagues (1991), two contrasting approaches dominate clinical diabetes care: the compliance model and the patient empowerment model. In the compliance approach, the clinician chooses the patient's path; in the empowerment approach, patients choose their own path under the guidance of clinicians. The compliance model's major aim is to increase patient adherence to clinicians' treatment plans and assumes that health care professionals are the experts in diabetes management (Anderson et al. 1991). In the view of the patient empowerment model, patients are experts in their own lives, are capable of educating themselves about treatment options, and should be the primary decision makers in their

treatment plans (Anderson et al. 1991). It aims to be personalized to individual patients and take into consideration their socioeconomic environments and how these might interfere with self-management (Wan et al. 2012). The patient empowerment model is presented as a more realistic, effective, and even revolutionary response to the traditional compliance model. However, the major aim of patient empowerment is not different from compliance; it still seeks to garner adherence to self-management behaviors. Wan et al. (2012) found that in a clinic modeled on patient empowerment, patients often were not consulted on their treatment goals and did not make meaningful decisions regarding their care. In fact, the patients understood patient empowerment to mean taking responsibility for self-care behaviors (Wan et al. 2012). In this sense, notions of personal responsibility for health underpin both the compliance and patient empowerment models.

Personal responsibility in health is the idea that individuals are responsible for their sickness and health through their own actions (Leichter 2003; Minkler 1999). This ideology is often given institutional and political primacy (Leichter 2003). The individual is the focus of intervention, which often consists of providing knowledge and skills for changing unhealthy behaviors and avoiding controllable risk factors (Minkler 1999). Some of the criticisms of the personal responsibility model are that it blames the victims, minimizes the social context and health environment, relieves governments of financial culpability for regulation and basic provision, and overestimates the ability of an individual to change habits or control her own health over the long term (Brownell et al. 2010; Miewald 1997; Minkler 1999).

In a health system overburdened with communicable diseases such as is the case in Ghana, it can be highly attractive to focus on patient responsibility for chronic disease

management in order to relieve the state of increasing financial burden (Brownell et al. 2010; Minkler 1999). Resources are spent on patient education under the assumption that if patients had more or improved education about their condition, their better understanding would empower them to make healthier choices (Brownell et al. 2010). When failure occurs, blame can be deflected to the patient for not fulfilling the self-management plan (Wan et al. 2012), rather than to the social obstacles to health (Miewald 1997). For example, when a diabetic patient appears at the clinic with high blood sugars, the assumption is that she chose not to be diligent in taking her medication or was flippant of dietary guidelines to limit carbohydrate intake, rather than pointing to an inefficient health delivery system.

As the number of people developing diabetes grows and with so many of them unable to access the resources needed to self-manage, the efficacy of this model has been called into question. This is supported in the general scholarly literature where some have shown patient empowerment methods and programs are coercive, counterproductive, and merely shift the cost from the state to the patient (Steinbrook 2006; Wan et al. 2012). Others maintain that there is a lack of evidence that more education leads to better self-management outcomes (Brownell et al. 2010; Salmon and Hall 2003). Therefore, clinicians and social scientists have shown the need to determine the ideal synergy between personal responsibility and social responsibility in addressing illness (Brownell et al. 2010; Minkler 1999; Weaver et al. 2014). They argue that governments have the authority and responsibility to create conditions that support personal responsibility by structural interventions that change the environment and foster healthy choices. In Ghana, current conditions encourage obesity and metabolic disease, a

force that no amount of education or imploring of individuals can reverse (Brownell et al. 2010).

Anthropologists have thoroughly critiqued the notions of compliance, patient empowerment, and personal responsibility in health. The early social critiques of compliance argued that it is a form of medical control over patients, ignores their experiences, and defines them by medical expectations (Mykhalovskiy et al. 2004; Rifkin 2006; Salmon and Hall 2003). These scholars took issue with how compliance rhetoric positioned patients as deviant and irrational and sought to decenter the medical perspective and instead focus on things outside of the clinic (Mykhalovskiy et al. 2004). Hunt and Arar (2001) argued that what appears as non-compliance from a clinician's perspective are actually reasonable actions when viewed from the context of patients' everyday lives, and that patients need strategies to control symptoms with treatments they can live with.

When biomedicine began shifting from compliance to patient empowerment strategies, some anthropologists felt that it was simply a rhetorical cloak over the original goal of patient compliance (Rifkin 2006). Empowered patients are still being forced to be in control of their illness management, when some may not want to be, or cannot be because the means of control are out of their hands (Bell 2017; Bishop and Brodkey 2006; Rifkin 2006; Salmon and Hall 2003). Discourse of self-control transforms the patient from a sufferer into manager of suffering, which is akin to giving the patient a moral responsibility to become well and placing blame when they cannot (Broom and Whittaker 2004; Leichter 2003; Salmon and Hall 2003; Wan et al. 2012).

Some scholars see personal responsibility in health as a symptom of neoliberal governance, in which “economic rationality and self-sufficiency [is] the personal responsibility of individuals and families, and poverty is understood to be rooted in individual deficiencies in motivation, discipline and human capital limitations” (Morgen and Gonzales 2008). They argue that compliance tasks patients with a responsibility and ethical obligation to discipline the self into a biomedical subject and to know and care for the self through biomedical logics (Whitmarsh 2013). Some argue that personal responsibility obscures the structural obstacles to self-managing illness, letting governments off the hook for the defaults in their countries that are fueling increasing chronic illness rates (Brownell et al. 2010; Marsland and Prince 2012). Others argue that although they are powerful and deep-seated, discourses and practices of neoliberalism do not control all of an individual’s thoughts and behaviors (Kingfisher and Maskovsky 2008), and are applied unevenly to global practices; therefore, research and analysis should pay special attention to refusal, resistance, and alternatives that arise in different contexts (Morgen and Gonzales 2008). Scholars purport that patients are not passive victims of these structures and ideas (Bell 2017; Heitmeyer 2017; Mykhalovskiy et al. 2004; Morgen and Gonzales 2008); rather, these gaps in neoliberal hegemony create space for patients and clinicians alike to accept, reject, or amend personal responsibility rhetoric and practices for their own benefit. This study seeks to understand how these actors in a diabetes clinic in Ghana utilize personal responsibility rhetoric and to what results.

Previous studies have examined specifically how clinicians and patients take up compliance and personal responsibility rhetoric in chronic illness care, particularly in low-income settings. Turkish migrants in Germany assumed the role of “expert patients” and



deliberately used self-care to make their chronic illness experience manageable to make up for the lack of formal support by the German healthcare system (Guell 2012). Ferzacca (2000) found that male veterans with diabetes in the southwest United States embraced self-management but executed the tasks in ways that clinicians categorized as non-compliant. Borovoy and Hine (2008) found that Russian migrants in the US with diabetes were considered noncompliant for the fact that they were used to a medical system in which they were trained to trust and defer to physicians and to depend on the state for health care, rather than to prioritize managing one's self. Mykhalovskiy and colleagues (2004) showed that people living with HIV in Toronto drew upon compliance perspectives as tools when thinking about themselves in relation to diabetes and were not simply being dominated by biomedical colonization (Mykhalovskiy et al. 2004). In this case, "being 'adherent' was not a matter of yielding to medical authority, but of overcoming emotional and physical resistance to a difficult regimen by expanding self-knowledge and developing forms of self-management" (Mykhalovskiy et al. 2004: 326). Thus, personal responsibility was not simply oppressive but used as a mode of self-empowerment. In South Africa, men with HIV embraced personal responsibility rhetoric in order to refashion their identities as men, where masculinity was intertwined with their responsibility as breadwinners for their family, sparking motivation to adhere to medication regimes (Colvin and Robins 2009). This study examines how patients with diabetes in Ghana grapple with expectations of compliance as a result of personal responsibility logics.

This chapter turns now to how patients in a diabetes clinic in Ghana take up personal responsibility for health rhetoric to illustrate that it can be simultaneously embraced, rejected,

and modified for a range of reasons. The chapter emphasizes the importance of understanding the nuances of how patients grapple with clinic-imposed diabetes self-management while experiencing resource scarcity. It draws together the ways in which diabetic citizens and clinicians view themselves in relation to the government and the different targets of blame for diabetes diagnosis and failures in self-management.

## Findings

### *Context*

Over the last 20 years, the two major teaching hospitals in the country as well as regional hospitals have established diabetes clinics to give specialized care and attention to the increasing number of diabetic patients. One of these diabetes clinics, at Komfo Anokye Teaching Hospital (KATH), an urban public hospital in Kumasi, is the site of this study. At this specialist referral diabetes clinic, up to one hundred patients per day come on a first-come-first-served basis to see their doctor for their bimonthly appointments. They arrive as early as five o'clock in the morning and wait several hours for the handful of doctors to arrive from other wards in the hospital and slowly make their way through all the patients needing to be seen. While waiting, the nurses often deliver a lecture on a topic relating to diabetes self-management, such as troubleshooting drug timing or the appropriate spacing between meals. The patients have a short consultation with their doctor, receive their prescription for the next 3 months, then go on to the hospital or outside pharmacy to collect their drugs. The head nurse manages donations for very poor patients and sometimes doctors even pay for the medications of patients who could not afford them. Of course, they cannot provide for every patient. Due to the long waiting periods and short physician consultation times, the nurses have the most

contact with patients and are therefore the primary source of the disease management education provided to patients. Nurses teach new patients how to use insulin and take time out of their own weekends to conduct outreach screening events in highly trafficked public areas.

Patients, clinicians, and citizens in general view the medical system and hospital as inefficient and under resourced. Current issues that are widely discussed in news and social media are the low ratio of hospital beds and ambulances to people, debate about the delayed opening of a new hospital in Accra, and the financial problems of the NHIS. The major obstacles for diabetes care at the research site are the small size of the clinic, the lack of doctors dedicated solely to the diabetes clinic, the small number of doctors relative to the large number of patients, the hospital pharmacy not having enough stock of necessary drugs, and the number of stops a patient must make for their testing, consultation, and drugs. Widespread corruption by private pharmacies means that patients could be forced to pay out-of-pocket for drugs that should be covered by NHIS or be provided with less than their doctor prescribed, while the pharmacy bills the NHIS for the full amount. There are also periodic strikes in the hospital. Strikes are commonly used by clinicians such as nurses and pharmacists as a last resort measure to get the attention of the government to give higher wages, time off work, and other demands. Disrupting the function of the hospital is viewed as the only way to get the government to take their concerns seriously. Unfortunately, the patients suffer as collateral as they are not able to be treated or renew their prescriptions, which can have dire consequences for diabetic patients. It can also contribute to catastrophic healthcare expenditure for households as they must pay for return transportation again at a later date.

## Methods

The research reported here was carried out with men and women in the Ashanti Region over a period of ten months during two trips in 2016 and 2017, which was preceded by a pilot study in the Central Region for two months in 2014 during which preliminary data on context and themes was collected. Research in the Ashanti Region included a cross section of diabetic patients and diabetes clinicians in the KATH Diabetic Centre. Data were collected using semi-structured interviews, participant observation, and biomarker and medical record information. All study participants gave signed or fingerprinted informed consent prior to participation. For incentive, patients were given 5 Ghana Cedis (equivalent to \$1.25) and clinicians were given a meal. All study procedures were approved by the Committee for Human Research, Publication and Ethics, jointly run by KATH and Kwame Nkrumah University of Science and Technology, as well as by the Institutional Review Board of Michigan State University.

A purposive sample of 60 patients was recruited according to the proportion of men and women who attend the clinic, equaling 40 women and 20 men. For patient recruitment, the assistant head nurse, research assistant, and the author stood in front of the diabetic clinic waiting area and asked all patients present if any would like to participate in an interview while they waited to see their doctor. They were informed that it was completely voluntary and that there would be no consequence or benefit for participation. There were days when only a few patients volunteered and other days where many volunteered and, in this case, due to time constraints, we took only the first ten volunteers. We repeated this process daily until we reached 60 patients.

For patient participants, the semi-structured interviews lasted from twenty minutes to one hour and covered questions about perceptions of what caused their illness, roles and responsibilities in diabetes care, gender roles and relations, self-management challenges and strategies, and demographic and socioeconomic status information. Patient interviews were conducted by the research assistant while the author was present, recorded, and later transcribed and translated. All patient interviews were conducted in Twi except for three in English. Medical record data collected consisted of fasting blood sugar (FBS), blood pressure, weight, and body mass index (BMI) values. These were recorded after the interview and matched with deidentified participant interviews. This chapter mainly utilizes the interview data for analysis.

For clinician data, a convenience sample of six clinicians was recruited by a research coordinator of another ongoing study in the clinic inquiring with clinicians if they would be willing to stay after their shift and participate in a twenty-minute interview if a meal was provided. The author conducted the interviews in English. Four interviews were recorded and transcribed, while two clinicians declined to be recorded and therefore only handwritten notes were taken. The semi-structured interview consisted of questions about the unique opportunities and challenges in the Diabetic Centre, patient and clinician roles in managing diabetes, gender dynamics in treating patients of the same and opposite sex, and structural and cultural dimensions of treating diabetes in Ghana.

Additionally, 50 days of participant observation were conducted in the waiting room where the investigator observed patient and clinician interactions and self-management lectures called “health talks” given by a nurse and assisted in clerical duties for the clinic or the

Diabetes Association of Ghana. Participant observation was also conducted during 3 Diabetes Association of Ghana (DAG) trimonthly meetings. Field notes were recorded each day in the clinic and 2 of the 4 DAG meetings were audio recorded, translated, and transcribed.

Transcribed interview data and field notes were coded in an iterative manner for any emergent themes. After the theme of *responsibility for health* emerged as a common thread among the interviews, presentations, and lectures, the relevant data were analyzed utilizing a Critical Discourse Analysis (CDA) approach. CDA is a way of examining speech acts in cultural context, such as lectures, announcements, consultations, and conversations, to investigate the ways in which power is inscribed in language (Bélanger et al. 2016; Rogers 2002; Poole 1990). CDA looks at patterns in vocabulary and modality, including word choice, positioning, importance, and meaning, to elucidate structural relationships of dominance, discrimination, and control, as they manifest in and are constituted by language (Fairclough 2013; Poole 1990; Wodack 2006).

Using CDA, special attention was paid to the ways that men and women were instructed to manage their diabetes and the rhetoric that was used by both clinicians and patients to talk about responsibility for diabetes care. Data that utilized personal responsibility rhetoric were coded as either compliance or empowerment. Table 2 outlines examples of speech acts and how they were coded under this scheme. This analysis elucidates how personal responsibility for health discourse is utilized in the clinic by both clinicians and patients and for what purposes it is used, including to garner patient compliance or to demand greater public assistance.

Table 2. Examples of Personal Responsibility Rhetoric Used by Clinicians and Patients

Type of Rhetoric	Example Statements (Vocabulary or modality bolded)	
	Clinician	Patient
Personal Responsibility: Empowerment Rhetoric		
	Patients <b>should</b> be <b>serious</b> about their disease, better educate themselves	<b>Morally</b> , we <b>need</b> to educate ourselves
	Patients should do it based on their <b>free will</b>	<b>Self-control</b> ; I take my prescriptions <b>seriously</b>
Personal Responsibility: Compliance Rhetoric		
	Patient's responsibility is to be <b>compliant</b>	I choose life so whatever I am <b>told to do</b> , I do
	Do what you are <b>supposed</b> to do	We <b>should</b> try as much as possible to <b>follow</b> the directives
	We will <b>manage</b> you; It is difficult to <b>manage</b> them	<b>Confess</b> to taking herbal medicines; <b>Listen</b> to our doctors for they are our healers
Government Support Rhetoric		
	Government <b>should</b> educate people about risks, enforce regulations	Doctors <b>should</b> not keep us waiting long as it delays our self-care; Government <b>should</b> regulate use of chemicals on crops that cause diabetes; Government <b>should</b> educate public on prevention
	<b>Hands are tied</b> in care if public insurance does not cover drugs	If insurance does not cover my medication, I <b>cannot follow</b> the directives

### *Participant Characteristics*

Tables 3 through 5 below present information obtained from patient medical records reviewed in conjunction with the semi-structured interview. In this sample of 60 patients, 33 were currently taking metformin, a commonly prescribed oral pharmaceutical for the treatment of diabetes, 25 were taking metformin along with insulin injections, and 2 patients were taking insulin injections only (see Table 3). Almost half of the participants were on insulin injections. A type 2 diabetes patient having to take insulin injections often indicates a further progression of their disease or lack of ability to create sufficient insulin (Davies 2004).

The average patient FBS value on the day of the interview was 10.3 mmol/L, well over the ADA target range of 4.4-7.2 mmol/L (ADA 2017), indicating poor blood glucose control for the group on average. On the day of their interview, only 16 patients had a FBS value in the target range, while 44 were over that range and none were below. Of those 44 who were over the target range, 11 were over 13.3 mmol/L, which is a critically high FBS level indicating uncontrolled hyperglycemia (Haring et al. 2013) (see Table 4). Additionally, income, age, and gender information were gathered from the semi-structured interview. Patients' estimates of their income were assigned to categories determined by 2016 poverty line levels (Cooke et al. 2016) (see Table 5).



Table 3. Participant Current Medication Treatment (n=60)

Type of medication	Metformin	Metformin and Insulin	Insulin
No. of patients (% of total)	33 (55%)	25 (42%)	2 (3%)

Table 4. Participant FBS Level on Day of Interview (n=60)

FBS range	Low <4.4 mmol/L	Target Range 4.4 – 7.2 mmol/L	High 7.3 – 13.2 mmol/L	Critically High >13.2 mmol/L
No. of patients (% of total)	0	16 (27%)	33 (55%)	11 (18%)

Table 5. Participant Socioeconomic Demographic Information

Variable	No. of Patients	
	N	%
Age (n=60)		
30-39	2	3%
40-49	14	23%
50-59	18	30%
60-69	19	32%
70-79	7	12%
Gender (n=60)		
Female	40	67%
Male	20	33%
Years Since Diagnosis (n=60)		
0-5	8	13%
6-15	36	60%
16-25	9	15%
26+	7	12%
Estimated Income (n=57) (Ghana Cedis/adult/year)		
Lower poverty line (<792)	23	40%
Upper poverty line (<1,314)	13	23%
Lower class (<3000)	15	26%
Lower middle class (<10,000)	6	11%

### *Perceptions of Responsibility*

Patient and clinician participants in this study did not reject the notion of personal responsibility, but instead garnered personal responsibility as reason itself for further social support in diabetes care and prevention. All 60 patients and 6 clinicians interviewed used descriptions that indicated patients are responsible for their diabetes care. Additionally, 48 patients and 5 clinicians indicated that the state has some responsibility in preventing and treating diabetes. Many patients described their experiences with self-management and personal responsibility by emphasizing the importance of being responsible for their own diabetes management, their views of doctors as experts, encouragers, and partners in their care, and the recognition of the government as insufficiently responsible for their health. Their calls to the government and clinicians for improvement were predicated upon the fact that they needed certain resources to be able to self-manage.

Among the clinicians, common themes included shifting between use of compliance and empowerment rhetoric to encourage patient self-management adherence, the lack of resources that present major obstacles to this very self-management, and how the government should improve. Although some clinicians emphasized the need for patients to be self-motivated and in charge of their care, this did not deter them from using compliance language when talking to and about patients.

### ***Clinicians' Notions of Responsibility for Health***

Clinicians held fast to the personal responsibility for health model. Clinicians tended to represent themselves as experts that patients should consult frequently in order to fulfill their self-management responsibilities and be the “bosses” (Nurse 1) of their own health. They were

adamant that patients needed to be better educated on their disease and to be “serious” (Doctor 1) about self-management.

They used both empowerment and compliance rhetoric to describe how they reach the core goal of treatment adherence. One doctor explained, clinicians’ responsibility is to educate and patients’ responsibility is “to be compliant” (Doctor 4). They did not fully embrace the patient empowerment model as patients were not free to choose their own treatment plan and goals and prohibited some health seeking behaviors such as going to herbal healers. Yet, empowerment and compliance terms could be used in the same thought as the words of the one nurse indicate:

Our role is to educate them [patients] on their condition and the management, and theirs is to comply to whatever that we say. In taking care of diabetes patients, they are the chiefs, they are the bosses. We talk to them and they will be doing everything so we shouldn’t impose. We have to let them understand whatever that they are doing. So if they get to know that it will help them, they will do it on their free will. So our responsibility is to let them know what they are supposed to do. [Nurse 1]

Clinicians appeared to define empowerment as patients being motivated to choose to follow the doctors’ self-management directives on their own free will. Clinicians recognized that not all patients behaved this way and therefore had strategies to coax the patient to feel empowered so that they would comply. They sometimes used horror stories of past diabetic patients in order to provide a fear-based motivation for keeping up with self-management. One doctor explained, “We inform them of consequences, management, and make it clear that this is for a lifetime and we are going to manage you until you die” (Doctor 1). Although they wanted patients to be accountable for their self-management, they still sometimes portrayed their relationship with patients as having to manage them and their inconsistencies.

Others wanted to build rapport with patients and change the traditional authoritative relationship of doctors to patients in order to get them to trust and divulge the right information needed to help manage their disease. They were aware of the general respect for doctors that patients had, largely due to class hierarchy. Again, the goal was to promote compliance and to make it easier to “manage” patients by maintaining relationships:

Once you are able to listen to them [patients] then it makes it easier for them to listen to you. [Doctor 2]

But the older people really have issues already, arthritis, so they really want to listen to everything you have to say and obey because they want relief from their problems. But the younger people are physically fit and feel fine, so yeah, sometimes it's difficult to manage them. [Doctor 2]

Additionally, though clinicians were aware of the significant economic and structural barriers to patient self-management, they still focused on improving patient adherence and education, although most connected this with government responsibility, for example as the following physician noted:

They [the government] should educate people about the risk of diabetes, diet, exercise, as far as the government is concerned, our dietary requirements, I think the government should come in to regulate in terms of these beverages. They should be more stringent like they are for smoking... in primary [school], JHS [junior high school], while they're still developing. That's where I think we should focus our attention: regulate the environment, regulate fast foods, and educate risk factors on TV, mass media. [Doctor 3]

Clinicians pointed to the government in a number of areas for improvement noting that there were basic provisions needed in order for them to do their jobs well and for the patients to succeed in self-management. Namely, they wanted the government to expand NHIS drug coverage, improve facilities, increase screenings, spread awareness and education, and regulate foods, advertising, and environments. For example, as one physician put it:

Money is a significant barrier. Most of them are on insurance, and insurance doesn't provide. They're not extensive in its coverage. For example, if you're prescribing diabetes

drugs you get no more than 2 - 3 classes of drugs available. So it's quite limited and makes it quite difficult. [Doctor 3]

And as a nurse described, the number of stops diabetic patients must make for their checkups was prohibitive:

The changes I would like to see starts with... for the patients to get their medications for free, to get free glucometers, and to have a center of our own that the patient enters [where] there's a place for exercise, there's a place for ECG. Even though we have them, they are scattered. They have to come together so that the patients may not be suffering because that alone can put the patients off from coming to the clinic. You have to go at a distance to check the lab, to check this, to go for medication, and then come and see the doctor. So if they're all gathered at a place, it's convenient and they will be willing to come so that's what I'm expecting. [Nurse 1]

Lastly, the clinicians recognized how government shortcomings could lead to strikes and thus negative impacts on patients. One doctor explained that during the pharmacist strike, patients had noticeably higher blood sugars due to the difficulty of obtaining drugs without the hospital pharmacy's stamp of approval to get their drugs covered at a private pharmacy. This perspective was not supported by the health record data collected from those who participated in this study, however. Here a functioning health system is recognized as essential to patient self-management, in this case so that patients can responsibly take their drugs. Clinicians recognized the need for government support and health system improvements in order to sustain patients' personal responsibility in health.

Physicians did not appear to be involved in petitioning the government for such improvements. Only the head nurse and assistant head nurse were explicitly involved in government activism for diabetes care, perhaps because they were dedicated to the diabetes clinic full time while the physicians rotated between other units. Some physicians donated their

own money at times and tried to prescribe drugs that were covered under NHIS, but beyond that explained, “There’s really little we can do when there is no money” (Doctor 4).

The clinicians made clear that the responsibility for diabetes care work lies largely with the patient. Nonetheless, they acknowledged that patients’ efforts needed to be supplemented by the government, who has the responsibility to enable patients to self-manage by providing at least the bare minimum in resources and education.

### ***Patients’ Notions of Responsibility for Health***

Diabetic patients also saw themselves as responsible for managing their illness according to the directives of their doctors and the clinic nurses. They looked to clinicians as experts and the authority in treatment of diabetes and as important allies in their self-management responsibilities. Straying from the authorized recommendations was frowned upon. They viewed themselves and fellow patients as morally obligated to their diabetes care and often expressed a life-or-death seriousness of self-management responsibilities. As one woman patient said, “My life is precious to me so I take the prescriptions seriously” (Patient 35, female age 53). Other patients described it similarly:

If you know that what you are doing is not going to be of help to you and you don’t follow the directives given you, then you are definitely going to die. Am I right? So, you should try as much as possible to follow the directives. [Patient 10, male age 69]

At this stage if you fail to manage your diet you will kill yourself. [Patient 3, male age 56]

I therefore decided that whether life or death, I was going to see this doctor to get my drugs. Whatever it takes, I will come for my drugs. [Patient 27, female age 43]

I choose life so whatever I’m told to do, I do. I don’t want to die and leave behind the kids... they [patients] must be encouraged to take very good care of themselves. [Patient 31, female age 74]

I see it as something I live with and it's not going anywhere. As a result, I have to take care of it, or should I say, myself. If someone wants to help you and you don't take the advice, then it's like planning your own death. [Patient 58, female age 74]

Some patients chastised those who were irresponsible with their diabetes care and behaved flippantly, using moral terms to describe their responsibility to have self-control:

We need to continue to educate ourselves and morally we need to... the moral side if you say no, it means no... and yes, yes. Some of these things, I see it to be that morally we need to be sound and see that if the thing is not good, we should stop. By that way, we can control a lot of things. [Patient 36, male age 55]

Diabetes comes with self-control... Some of us have that problem because we like tasty foods therefore we cannot stop eating certain foods. Especially the women, when I listen to their conversation I realize they cannot stop eating certain foods. But if you are able to avoid certain foods you will not encounter any problem. [Patient 18, male age 68]

Patient culpability reached to their ideas about the cause of their diabetes; often the perceived cause was something wrong they had done earlier in life. For example, one male patient said:

So, when I was told that I did not pay attention to my diet and that has caused this sickness, I humbly accepted it because I took tea [sugary beverages] every morning. [Patient 4, male age 56]

Personal responsibility ideology spilled over to their faith in God; God would help them cover their mistakes when they failed to perfectly comply. One man shared, "Prayer has helped me in not getting into trouble whenever I did not heed to advice" (Patient 2, male age 62). Some viewed God as a solution to lack of resources and gaps in coverage and access to the necessities for self-management.

The diabetes clinic, including the doctors and nurses, were considered a function of the government, as they knew it was a state funded enterprise. Further, the patients viewed doctors and nurses as experts, allies, and potential impediments to their self-management work. The patients seemed to highly admire the clinicians, especially the senior doctors in the

clinic, seeing them as authorities to be respected. Many of them felt their doctors were instrumental in adjusting their outlook about their disease and motivating them to self-manage and stay alive. One woman shared how she began crying upon her diabetes diagnosis, but that the doctor “consoled” her and reassured her that if she followed the directives, she would be alright (Patient 22; female age 60). Another woman had a similar experience:

After hearing that news, I was so saddened that I shed tears but the doctor said, “Mother don’t cry, if you abide by our directives you will be fine. If you continue taking the drugs and you don’t quit...then I assure you that you will be fine.” [Patient 15; female age 78]

As a means of asserting the authoritative knowledge of the clinic doctors, patients and clinicians would contrast herbal remedies with biomedicine. Patients aligned themselves with biomedicine and against herbal or religious healers and against patients that utilized them. For example, one man urged to his fellow patients:

When we got here the doctor asked her to confess to taking herbal medicines, which she denied. The doctor had her take a scan and she finally confessed because both her kidneys were damage. So to my fellow family here, let’s not give in to people who claim they have herbal cures for diabetes. Let’s listen to our doctors, for they are our healers, amen. [Male patient at Diabetes Association of Ghana meeting 2]

Patients also had expectations of the clinicians to show up, be good consultants, and give them the foundation on which to base their self-management (Stimson 1974). Seeing the doctor was the only way to get their prescriptions renewed for 2 more months and if the doctors did not come to the clinic that day, their self-management would be impossible. One patient elaborated on the issue:

The doctors must make us aware of the time they come to the hospital or if they are working elsewhere, they should make us aware because the time we are given does not help us at all. Diabetes as a sickness is not something we should be kept waiting here for several hours before we are treated. When you are done, you have to struggle before you get your drugs. When it happens that way, it becomes a worry especially for those who



take the injection as well as the aged among us. This worsens their situation. It is something that does not help. [Patient 4, male age 56]

There were also complaints about how patients were delayed and treated by the hospital pharmacists as well as tricked at outside pharmacies, emphasizing how important clinicians' behaviors were in the outcome of patient self-management.

Patients also expected the doctors to be on top of the latest research on drugs and the best treatment for the patients. They did not see themselves as qualified to make treatment plans or goals, but rather deferred to the clinicians:

I think you the doctors would be able to help us reduce diabetes... Excuse me to say, I am not a literate and I will not be able to say this or that. It is only you the doctors that could teach us what to do so the disease could be stopped. [Patient 15, female age 78]

Patients viewed clinicians as powerful actors that had the ability to make or break their diabetes self-management efforts.

Lastly, patients viewed the government as responsible for diabetics' health. They wanted the government to take responsibility for the health care of people with diabetes, particularly by doing more to enable them to achieve diabetes self-management adherence. First and foremost, they expected increased NHIS coverage of essential diabetes drugs.

It [NHIS] covers some; it covers some but not all. I feel that the insurance was previously helpful but for now it doesn't cover a lot of medications. Meaning, some prescribed medications which are now very expensive are not covered by the insurance. If you have no money to buy, then you won't be able to take that medication. About eight months ago, a medicine called Amaryl was prescribed for me to buy and I was told it cost 375 Ghana Cedis. I have no job, no child, no husband, and how will I be able to buy this medicine? Definitely I will not be able to. Therefore, even if the sickness subsidies, you will still need the medications to stay strong so your inability to buy the medicine could worsen the sickness. [Patient 20, female age 65]

Our medications are important to us. Insurance doesn't cover the ones given me. When you don't have the money to buy, it becomes stress on your head and can knock you

down to the point of death. No money for food either so you can't buy what is required like the plantains or some good soup and end up settling for anything. It's hard to live with this illness. The insurance scheme has collapsed. Back in the day, we got a lot of free medicines but it's not the same today. [Patient 25, female age 59]

Hmm, that depends on our leaders to create the awareness and to make our drugs always available so that when we come the doctors will get some for us. That can help us. We cannot buy the drugs. [Patient 3, male age 56]

Patients also insisted that the government should have a role in preventing new cases of diabetes by regulation of chemical usage on food crops, the amount of sugar in the food system, and the advertising claims of herbalists.

What I can say is that there should be a reduction or a halt in the use of chemicals in our crop cultivation. The government should also ensure that the right chemicals are used to treat our pipe borne waters. [Patient 11, male age 50]

What I think is that, if we can get advice like this one it will be of help because if the government realizes what I have seen. I think the government can make plans of reducing the sugary foods because there is too much sugar in the system, however, everything has to do with sugar, sugar, sugar. So, the advice I can give to the public is that they should put a stop to eating sugar. [Patient 2, male age 62]

Why don't they tell the herbalists what they are doing is not good? Because people go to them, take the herbal drugs, and end their lives. So, my problem is, why can't the doctors and the health sector condemn them? [Patient 47, male age 62]

Finally, patients asserted that the government should take up the responsibility to spread knowledge about the risks and symptoms of diabetes as well as the healthy way all Ghanaians should eat through public health initiatives.

So it is time the government or health sector organize weekly counsel or advice for Ghanaians so that people getting diabetes will reduce. They have to get a counselling unit all over. It is very important because diabetes or hypertension is a very serious illness that people die of so the government should come out and establish counselling centers so that people will know how to eat. The foods that we eat bring us diabetes and all these other illnesses. [Patient 47, male age 62]

The only thing we can do is to educate; whether one has it or not, the doctors or the National Commisison for Civic Education (NCCE) which represents the government should not keep mute. The education should be done either in the various regions or resort to the radio to keep telling the people about diabetes and I think that will go a long way to

help the people avoid it. The reason being that when more people get it, everything in the country goes wrong; it affects the economy, our development and our future and this will not help us. [Patient 4, Male age 56]

Patients in this study did not contest their status as responsible for their health through self-management. Patients accepted themselves and their disease in biomedical logics (Whitmarsh 2013) and expected to be a biomedical subject and expected the government to ensure the basic necessities were accessible so they could do so. They used personal responsibility rhetoric even while demanding more support from the government.

## Discussion

The structure and perceptions of diabetes care in the clinic largely follows the personal responsibility for health ideology. Clinicians are responsible for their own domain: to have knowledge, to expertly consult patients, and to prescribe medications. Patients are responsibilized to do the daily work of controlling their disease through biomedical technologies and strategies. This setup leaves both clinicians and patients at the mercy of the prevailing political-economic arrangement and forces them to make do with what those in power have made available to them. However, patients as the illness sufferers are not simply passive victims. They do not contest the idea of their personal responsibility for diabetes care but use it to bolster demands that the government step up its responsibility as a significant player in their disease causation and management.

Clinicians called upon personal responsibility rhetoric when encouraging their patients to comply with the diabetes regimen. The clinicians in this study felt their primary responsibilities for diabetes care was to educate and better connect with patients in order to

improve patient adherence. They emphasized that the patients were largely in charge of their own diabetes care. Physicians relied on the team of nurses, dieticians, and staff to educate and train the patients in their care work and used affective strategies to encourage the patients to engage with self-management (Howard et al. 2016). They used the language of patient empowerment, but still used words like comply and obey (Stimson 1974), and ultimately, their expertise would trump patients' desires. For example, they wanted patients to be proactive in learning about their disease but did not approve of them turning to herbal medicine due to the risk of acute complications or even death, despite the fact that herbal medicine is part of Ghanaians' healing traditions and practices. They consoled patients who were upset that their disease had progressed to require insulin injections, reassuring them that insulin is necessary and a natural component of the human body made by God, calling upon religious devotion to encourage compliance. There were also currents of blaming patients for their illness states, where clinicians envisioned patients either as careless, disobedient, forgetful, or lying about their noncompliance. However, what clinicians view as deviance or noncompliance often makes perfect sense in the context of patients' lives (Mykhalovskiy et al. 2004; Hunt and Arar 2001). In this study, patients could not comply for various reasons such as lack of finances and hid it from their doctors out of shame.

Clinicians' rhetoric about empowered patients who are informed and in charge of their diabetes care still has the goal of patient compliance in mind. Lip service is paid to the empowerment of patients, but in reality, patients are not in the position of power. They are still at the mercy of whether or not their doctor shows up to the clinic that day, to the chance that the pharmacy might try to charge them for their covered drugs, and the likelihood that there

will be no extra money to spend on vegetables and fruits that the diabetic diet demands. They emphasize the need for more education, but increased education cannot bring essential resources to patients. Discussion about how the patient needed to be empowered may serve to relieve clinicians of guilt and pain for the fact that they could not help so many of the diabetic patients (Salmon and Hall 2003). This is partially a result of lack of primary care in Ghana and overwhelming lack of resources and public health awareness of chronic diseases.

Clinicians maintained the personal responsibility perspective despite their recognition that patients without sufficient financial resources are not able to succeed in adhering to self-management recommendations. They frequently looked to the government's shortcomings as a major contributor to patients' noncompliance, but they were not able to offer many solutions to the dilemma of the profound financial struggles that prevent patients from even attempting to adhere to their recommendations. When asked what patients can do if they cannot afford insurance or to buy their drugs, the assistant head nurse answered, "There's nothing they can do." The overall sense was that the government should help so that these people can manage themselves.

This research shows that clinicians are not seeking to increase their power nor to portray noncompliance as irrationality, but rather recognize that past power relations between clinicians and patients have not served to make patients internalize their personal responsibility and thus have sought to make the accordant changes to promote patient self-management. They want to maintain control only over their jurisdiction of consultation and want patients to be responsible for theirs. In this context, clinicians are safest in a position of expert but not

boss, as the resources are not available to expect perfect compliance or to take the blame for unhealthy patients.

Clinicians' use of compliance rhetoric and authoritative stance over patients was not necessarily patronizing. The hierarchical relationship between clinicians and patients fit with normal social relations of respect and deference in this cultural context, especially between men and women and rich and poor. Clinicians used this stance mostly in positive ways, but due to the perception that clinicians are higher in status than them, patients would not feel very free to advocate for themselves or to divulge their true struggles in self-management. Some clinicians sought to improve the relationship between patient and doctor and make it more welcoming, but that too was a function of generating increased patient compliance.

As the main source of diabetes information for patients, clinicians shape how people with diabetes come to view themselves as biomedical subjects- as diabetic patients. In biomedicine and in society, clinicians hold authority over defining and treating diabetes, thus when they use personal responsibility rhetoric, they are able to impact patients' views of themselves and their role in their health. Responsibilization, a process that renders subjects individually responsible for a task that previously would have been the duty of a state agency (Wakefield and Fleming 2009), is a key element in shaping personal responsibility. This study views clinicians as the "effective sovereign" (Weber 1995), actors who implement the will of the state in daily life, namely, neoliberal logics of self-surveilling citizens. The state benefits from cultivating self-managing citizens who reduce public costs; therefore, the state generates patients' responsabilization in preventing and managing diabetes vis-à-vis clinicians at public hospitals. The patients in this study appeared to internalize neoliberal logics and have

rationalized their responsabilization (Beckmann 2013; Whitmarsh 2013) as a result of careful training by clinicians as well as the more widespread Western influence over the treatment pathways for chronic illness. Most of the patient interviewees take their self-management responsibilities very seriously and made it clear that they see themselves as primarily in charge of their health. Their expectations and demands of the government, including of pharmacists and clinicians, are aimed at support to their own self-management needs. For instance, they wish they would have known years ago through government-led education the risky behaviors they were engaging in so they could have acted preventatively. They fashion their identity as diabetics and as Ghanaians to embrace biomedical treatments and chastise the use of herbal medicines or spiritual healers for diabetes. This is evidence of very explicit shaping of health subjectivities in the form of health identities, as allegiance to one medicinal-cultural system by default places a person in opposition to another system (Whyte 2009). This internalized responsabilization reaches to their ideas about the cause of their diabetes where many of the patients believe it was self-caused or hereditary, and not because of the social conditions in which many Ghanaians live, including food-insecurity and economic precarity and stress.

Though neoliberalism shapes individuals understandings of themselves in relation to power, it is not a uniform, all-powerful force in society, but rather an “incomplete social project” that unevenly influences citizens’ thoughts and behaviors (Kingfisher and Maskovsky 2008). Neoliberalism demands self-governing individuals, but in many local contexts has not generated the structures necessary for individuals to embody this fully. Therefore, those with more resources are better able to shape themselves according to neoliberal logics, and others are excluded from this expectation of self-surveillance and are essentially left to die without

medical intervention or basic human rights (Fassin 2009; Marsland and Prince 2012). These patients are not passive actors; they neither accept their exclusion from biomedicine nor blindly accept clinicians' instructions. They pointed out this scarcity and demanded more support from the state in order that they may be personally responsible for their own diabetes. In this context, personal responsibility does not obscure the government's responsibility but rather draws attention to it.

The idea that personal responsibility for health in biomedicine is oppressive to patients leaves out experiences of those who are marginalized (Fassin 2009; Sparke 2017; Whyte 2012; Marsland and Prince 2012). Studies that make this argument are often basing this on the experiences of white and Western individuals whose lives and bodies have come to be defined and understood in biomedical logics and are seeking ways to escape this narrow view of health and illness (Brubaker 2007). However, for many in other parts of the world, biomedicine is out of reach and excludes those on the margins (Bell 2017). Thus, patients often demand a stake in biomedicine as a right to which they do not have access (Brubaker 2007). The patients in this study at times felt desperate to be able to access biomedical care for diabetes, especially when faced with insurmountable barriers such as lack of money for transportation, food, medicines, and insurance. They demanded government intervention, particularly in the area of insurance and medications, calling upon the state to provide coverage for essential drugs and insulin. Again, these demands are in light of personal responsibility and in support of patients to be able to self-manage, not for the state to take over their care. Likewise, personal responsibility in this case is not simply giving the state a pass; patients have found a way to utilize personal responsibility rhetoric to ensure that the state is not excused from caring for its citizens.



Perhaps embracing personal responsibility gave patients a sense of control in a very precarious social and political environment in which they have little control over their health.

This study brings attention to the contradictions of the personal responsibility model in a context of resource scarcity. This includes the notion that all choices are in the control of individual patients. Perhaps the general consensus of personal responsibility especially for chronic illness is partly what allows the state to neglect this portion of the population. On the contrary, perhaps activism utilizing personal responsibility rhetoric is precisely what is compatible with broader neoliberal ideology and will be what is needed to get the government's attention and resources.

While patients and clinicians seek enhanced state support of diabetes management activities, it is important to consider how the government should take up this call. For instance, if the solution is to provide more education and training of patients, the evidence does not support that this will improve health outcomes and it also neglects a huge sector of this society without literacy or access to primary care (Brownell et al. 2010). Without increasing access to essential diabetes medications and insulin, patients would be well educated but still unable to control their blood sugar. Further, providing free access to medications, which was the main call of many of the patients and clinicians in this study, would not solve all their self-management challenges (Wang et al. 2015; Smith-Spangler et al. 2012; Hsu et al. 2012). Similar research on free HIV antiretroviral medication access has shown that free drugs are not enough to solve self-management challenges that arise from poverty and structural barriers. For example, just like diabetes drugs, antiretrovirals must be taken with food, so for households grappling with food insecurity, free drugs would not be the full solution (Weiser et al. 2010;

Seligman et al. 2010). Additionally, transport is often a major personal healthcare expenditure that outright prevents many patients from even seeing a doctor and getting their tests and drugs (Etiaba et al. 2016). Increased awareness, education, and free access to essential drugs are important first steps, but changes cannot stop there. Governments should also look to evidence-based changes in their societies that can make lasting impacts on the number of new diabetes cases, the ability to self-manage well, and to enhance clinician care of diabetes (Nam 2011).

Future reforms in support of diabetic patients and other chronic illness sufferers should seek to target the structures and defaults in Ghana that promote obesity and metabolic illness. This means addressing the structural and societal influences on health that are beyond individuals' control. Policymakers and activists can examine the utility of the patient responsibility ideology alongside promoting policy changes that would enable a healthier population for nondiabetics and diabetics alike. Governments and other power brokers such as pharmaceutical corporations and large donor groups must target elements within their domains such as access to drugs, health care, transportation, changing culture around diet and activity, incentivizing agriculture of more nutritious foods, regulation of pesticide use (Sylvie et al. 2013), and safe places to exercise, in order to enhance the things patients can control and can reasonably be considered part of one's personal responsibility: taking medications, attending the clinic, eating nutritiously, and exercising.

## Conclusions

This chapter has explored the ways in which clinicians and patients understand responsibility for health and health care with regards to diabetes management in Ghana. The

personal responsibility for health model serves to emphasize individual accountability for self-management under the guise of empowerment while sustaining the hierarchical knowledge structure that shapes clinician-provider relations. In the context of income insecurity and an inefficient and underfunded medical system, the model also highlights how these relations are strained generating paradoxical perspectives shared by both clinicians and patients that the government has the ultimate responsibility for diabetes management. Because some previous studies on chronic illness demonstrated that patients resist having their illness being defined as a biomedical problem (Smith-Morris 2015; Wentzell 2013) and the multitude of structural and societal forces that contribute to lack of resources needed to self-manage diabetes (Marsland and Prince 2012; Brownell et al. 2010), one might assume that these diabetes patients would reject direction based on the personal responsibility model. However, interviews with patients and clinicians alike showed that these institutional and social obstacles did not cause them to question or challenge the idea of personal responsibility, but rather they pointed to the importance of personal responsibility as reason for their demands of increased attention and funding from the government. This local anthropological case study shines light on how knowledge and practice around responsibility and choice is co-constructed between those in power and everyday citizens.

The findings in this study are not necessarily generalizable to all diabetics in Ghana, but rather those who attend the diabetes clinic appointments and meetings as part of their health work. Future research might explore if diabetics who have remained largely outside of biomedical contact have similar perspectives and experiences. Additionally, because this is a specialist referral clinic, the patients who attend are in need of focused care of their illness. This

could perhaps mean that these patients have a dire prognosis and could explain their desperation to attain their drugs. Further study could reveal whether diabetics whose blood sugar levels are well managed feel similarly. Another limitation to the research is that some of the patients may have assumed because the investigator was a white foreigner that she was a doctor, which may have encouraged them to shift their responses to be acceptable to a physician. However, some of the experiences conveyed by patients were surprising to the clinicians, and there were other instances of criticizing the doctors, indicating that some of the patients did feel a degree of freedom in expressing themselves. Lastly, future research could examine if and how clinicians' perceptions of personal responsibility can be adjusted and whether other models of diabetes care exist in Ghana.

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### Chapter 3: Sex and Work: Diabetic Disruptions to Gender

#### Abstract

Research has demonstrated that gender impacts chronic illness management, but less is understood about how chronic illness affects gender. This chapter examines how chronic illness, particularly diabetes, disrupts gender performativity. In semi-structured interviews with women and men with diabetes in Kumasi, Ghana, patients shared that diabetes “destroys women” and makes men “no longer a man” due to disruptions in sexual function and the ability to work. Current approaches to diabetes management reify hegemonic notions of gender and neglect patients’ social and physical suffering, particularly ignoring women’s experiences of sexual dysfunction. The stories of participants in the study reported here reveal that diabetes challenges the expectations of the “ideal” woman or man, which often leads to loss of income and relationships and exacerbates their state of precarity. These diabetic disruptions to sexuality and work are a source of distress, leading to poorer diabetes self-management and health outcomes.

#### Introduction

*“I think there should be a public awareness campaign about how bad diabetes is. When you get it, you lose your strength and makes you unable to have sex with your husband. It makes you lose a lot of things.” -Female Diabetes Patient*

In this chapter, I consider the implications of diabetes on the everyday performance of gender in Ghana. Gender, as a socially and culturally constructed, idealized performance of masculinity or femininity (Butler 1999), is a powerful influencer of behaviors that has health impacts (Courtenay 2000). Gender is one of what Ferzacca calls “fields of power from within which diabetes is produced and sustained” (Ferzacca 2012:419), making it an important vantage point to examine the experience of diabetes. Although it is clear that gender impacts disease and healing, the exact effects on men and women vary depending on context; therefore this study investigates the experience of illness through a gendered lens (Manderson and Smith-Morris 2010) in the specific context of Kumasi, a large city where Asantes are the majority. Understanding the experience of living with diabetes reveals much about expected

and actual gendered lives, and how people react when their ability to “do gender” (West and Zimmerman 1987) is disrupted.

The idea of “doing gender” was first coined in the 1980s (West and Zimmerman 1987) and described the processes through which people engage in a range of gendered practices as strongly influenced by cultural notions of masculinity and femininity. People do gender in a variety of contexts, meaning that when one is speaking, walking, or just sitting, they do so in ways that demonstrate their gender, usually without being conscious of it. This study utilizes the gender binary of male and female; the rationale behind this is explained in the discussion. Drawing on Butler's (1999) attention to the hierarchical and performative dimensions of gender, I consider the relationships between Ghanaian concepts and practices of masculinity and femininity and health (Courtenay 2000; Charmaz 1994) and how these interact with the diabetes experience.

Because doing gender happens throughout the variety of everyday activities and thoughts, health beliefs and behaviors exhibit masculinities and femininities (Courtenay 2000), particularly as these pertain to chronic illness management. The ways in which people grapple with their disease is done in gendered ways and is shaped by cultural and societal notions and expectations of feminine and masculine behaviors (Manderson and Warren 2016). Doing health in gendered ways has positive and negative ramifications for men and women. For example, attendance at a diabetes clinic and self-management in general is compatible with accepted modes of femininity. Scholars have suggested that chronic illness support groups offer women an avenue to participate in public and political discourse to which they may otherwise have less access (Kolling 2012), which would motivate women to attend and expose them to more

resources and information. Women are socialized as non-experts and thus may be more comfortable seeking help from a designated expert than are men, and therefore may be able to prevent or diagnose diseases earlier and be more diligent about following a physician's orders, resulting in better outcomes (Charmaz 1994). Consistent with these ideas, in this study site, women greatly outnumbered men at the diabetes clinic, despite evidence that men and women have similar rates of diabetes in Ghana (Asamoah-Boaheng et al. 2019; Gatimu et al. 2016).

Conversely, doing health as a woman may lead to worse outcomes. Women are not seen as experts over their own bodies and often have challenges getting doctors to believe their symptoms or take their concerns seriously (Charmaz 1994). Additionally, being submissive as a socialized feminine attribute can contribute to women not readily speaking up or demanding the best care, especially if the physician is male (Charmaz 1994). Intersectionality theory explains that the compounding effects of being lower on the hierarchy of gender, race, and class leads to greater social consequences including violence and exclusion (Crenshaw 1991). Women patients in this context are lower in the social hierarchy of gender and class in their interactions with clinicians. The class difference between physicians and patients, particularly women, contributes to challenges in mutual understanding and respect and can compromise medical care by precluding honest communication and partnership in diabetes management. Intersectionality theory applies also to contexts outside the clinic; Ghanaian women are expected to care for others, including children, husband, extended family, and in-laws. The high burden of care for others leaves little time for and acceptance of self-care and might lead to poorer health outcomes for women (Weaver 2016). Women also generally have less access to cash than men, often having to rely on husbands for a small daily allowance of

cash that is meant for household expenses, which may not be sufficient or permissible for their medical expenses. This arrangement can impede their ability to seek health care.

Men's health behaviors also demonstrate masculinities. Performing hegemonic masculinity encourages men to embrace risk and self-sufficiency; being careful, weak, or needy would be considered un-masculine (Courtenay 2000; Charmaz 1994). Self-care, vulnerability, and physical failings challenge notions of what it means to be a man, which influences the ways men care (or do not care) for their illness (Colvin and Robins 2009; Stansbury et al. 2003). Hegemonic masculinity also enforces a hierarchy of masculinities, which can generate resistance to submitting to the authority of a male physician or undermine the perception of a female physician's authority. Alternatively, men are socialized to have a "problem-focused coping and active behavioral style" (Stansbury et al. 2003:181), which could encourage devotion of their energy to self-management and prevention, particularly with incorporating regular exercise. These influences may explain why at this study site, men attended the diabetes clinic at lower rates than women but were more adherent in exercise, according to clinic physicians.

Not only can gender influence health outcomes, but disease can impact one's ability to do gender (Inhorn and Wentzell 2011; Shuttleworth 2000; Wentzell 2013; O'Brien et al. 2007; Kolling 2012). This chapter focuses on the ways diabetes impacts gender performance among Ghanaian men and women. A small body of ethnographic research on chronic illness impacting gender has largely focused on masculinities. The inability to work due to weakness from diabetes has been shown to have a profound effect on men's sense of self and their perceived ability to be a man. For example, Kolling's (2012) study of men with diabetes in Brazil described



how they felt emasculated by being confined to the home, which they considered a feminine space. This presented challenges for diabetes self-management, due to the reluctance to reduce work and stress to prioritize self-care. Colvin and Robins (2009) also describe how illness disrupted male responsibility as family income earners for men with HIV in South Africa, leading them to diligently take up their treatment regimen to ensure they fulfilled this responsibility and maintained masculinity. Challenges to one's ability to perform ideal gender expression can be a source of distress, which can negatively impact self-care, diabetes self-management, and diabetes outcomes (Mendenhall 2012; Rock 2003; Thapa 2012). These disruptions to gender expression can also be a source of empowerment, as Hunt showed with Mexican women with cancer, who strategically reconstructed gender roles to benefit them in their relationships and in society (Hunt 2000).

People grapple in different ways with challenges to being an ideal man or woman. When a chronic illness interferes with one's gender expression, individuals are often confronted with two competing priorities: to maintain expected gender expression at the expense of their chronic illness management, or to "renegotiate social roles and responsibilities" (de-Graft Aikins 2006:428) and change modes of gender expression in order to prioritize self-management. In order to keep a sense of normalcy, individuals might select certain aspects of masculinity or femininity to emphasize over others in order to highlight those they can maintain (Stansbury et al. 2003). Others choose to do away with diabetes care all together in favor of maintaining the full spectrum of expected gender expression (Kolling 2012), for instance, refusing to take insulin injections so as to not look weak.

Sexual dysfunction is another major way that chronic illness impacts gender. Scholars have shown that sexual dysfunction is a central concern of diabetes for men, leading to complex physical, psychological, and relational consequences such as a loss of a sense of masculinity and reduced ability to cope with diabetes, due to decrease in self-worth, high levels of stress, and loss of invaluable support from partners (Cooper et al. 2018; Kolling 2012). In resource poor contexts, the experience of poverty, diabetes, and sexual dysfunction can trigger a “recursive cascade” of increasing ill health and economic struggle (Manderson and Warren 2016). Men rely on partners when their ability to work diminishes, both for economic and diabetes management support; diabetes often leads to sexual dysfunction, distress, severed relationships, poorer self-management, and economic hardship. A recent preliminary study found that 38% of men in Ghana with diabetes had erectile dysfunction (Ekoru et al. 2019), but the study did not measure sexual dysfunction in women. Kolling found that Brazilian men with diabetes felt that lack of sexual potency meant one is not a man any longer (Kolling 2012). Cooper et al. (2018) found that in South Africa and Malawi, diabetic men felt that they were no longer a real man and had become more of a child or their wife’s friend, which impacted their self-image and caused feelings of powerlessness in performing their masculine role.

Little to no ethnographic research has been done to understand how femininities are impacted by chronic illness, inability to work, and sexual dysfunction. One study in Sweden found that women who experienced sexual dysfunction experienced guilt, shame, and embarrassment, which are potentially oppressive features of diabetes (Sarkadi and Rosenqvist 2003). Social norms that discourage women from discussing sex publicly may obscure the issue, resulting in a gap in the literature. A plethora of clinical research and systematic reviews have

verified that diabetic women experience sexual dysfunction caused by their illness, though the exact mechanisms are not yet well understood (Bhasin et al. 2007; Erol et al. 2002; Lemone 1996; Pontiroli et al. 2013; Yacan and Erol 2018). This chapter examines both men's and women's experiences of diabetes impacting their gender performance. It elucidates not just men's but also women's experiences with diabetes related sexual dysfunction, and the implications for improving the current modes for illness management that are often based on assumptions about gender roles, expectations, and experiences.

## Methods

This research study was conducted in the Ashanti Region of Ghana over the course of ten months in 2016 and 2017. Participants were recruited through purposive sampling from the Diabetic Centre at the Komfo Anokye Teaching Hospital (KATH) in Kumasi. Data presented here were collected through semi-structured interviews and participant observation. A stratified purposive sample of 40 women and 20 men were recruited as volunteer participants from the patient waiting area adjacent to the diabetes clinic and were interviewed in a nearby room while they waited for their physician consultation. In addition, 5 doctors and 1 nurse were interviewed, and several other nurses and staff were observed in their daily work routines in the clinic, including patient education lectures given in the waiting room and bimonthly diabetes management workshops.

Asking people to talk explicitly about gender is difficult. Because gender categories are constructed as natural, they often go unquestioned, and therefore a respondent may not have thought about gender in relation to their disease. In order to learn from patients how gender works in Ghanaian culture and how these views of gender apply to themselves, I employed a

strategy of asking directly about gender as well as asking non-gender related questions; gender themed responses emerged in both types of questions. I also observed the ways people spoke freely about men and women in the clinic; often ideas came out about the “nature” of men and women.

For the explicit questions about gender, the goal was to get patients brainstorming about gender norms and expectations in general and then ask them how these may or may not apply to their lives and their diabetes self-management. The three gender questions in the patient one-on-one interview guide were adapted from two separate interview instruments used for understanding how gender impacts everyday life for men and women: one instrument from Institute for Reproductive Health (IRP 2012), and the other from International Fund for Agricultural Development (IFAD 2002). Cultural and linguistic considerations shaped how the questions were posed in this study context, as explained below.

From IRP 2012, two questions were adapted, asking participants to describe the ideal man or woman in their society. Although the phrase ideal woman (*obaa sima*) is a common one in Ghana, there is not an equivalent phrase for ideal man. Therefore, participants were first asked how they would describe an ideal woman, then were asked, “And what about a man?” or “What would likewise qualify a man to be called a perfect/real man?” They were prompted to elaborate on behaviors and roles of the ideal man and woman. They were then asked if diabetes prevented them from being this ideal man or woman that they have described, and if so, how.

The third question was adapted from the IFAD instrument, which asks women what they like and dislike about being a woman and asks men what they like and dislike about being a man (2002). To ask a patient what they like about being a man or woman does not translate clearly to Twi, therefore we relied on a common phrase in Ghana in both English and Twi: To be a man is not easy (*Enye easy; yewo wo jbarima a due*). Thus, our question stated, “Have you ever felt it is not easy to be a man/woman? Why or why not?” This question was intended to generate responses from patients with specific reasons why they may agree or disagree in order to give the interviewer a lens into realities about gender that may go beyond stereotypes and idealizations.

Clinicians were asked if they have observed any differences between men and women in terms of diabetes self-management and disease course. They were also asked if patients bring up sexual dysfunction. Clinician interviews started after patient interviews were well underway and due to the iterative nature of the research, the frequent mention of sexual dysfunction by patients caused this question to be incorporated into the clinician one-on-one interview guide. Clinicians were also observed in their interactions with and rhetoric about men and women.

Data were themed and analyzed using Nvivo qualitative analysis software. The responses to all questions were coded for themes including sexuality, gender, gender roles, and relationships. Coding queries were run to see the relationships between themes, such as sexuality and gender roles. In addition, all responses to questions about the ideal man and woman, challenges to being ideal, and whether or not it is hard to be a man or woman, were analyzed and themed. Responses were also analyzed by the gender of the respondent. This

analysis probed how gender ideologies and practices might interfere or interact with diabetes self-management and vice versa.

## Findings

### *Hardworking Loyalty: Performing Gender Ideals*

The ideal woman was commonly described by both women and men as one who loves to keep a nice and clean house, takes care of her husband and kids (through services such as cooking meals and fetching water), is hardworking and industrious, pure and modest, attractive, loyal, and speaks respectfully to others. For instance, one woman used herself to illustrate:

In using my life as an example, everyone knows that I am very hardworking. Yesterday for instance, after the long hours of sitting and all that we did during the [bimonthly Diabetes Association] meeting, I went hawking when I got home so that I could get some money for my upkeep today at the hospital. So, I believe that these are the things that make us say a woman is ideal. Thus, a hardworking woman who when called upon is always available, a woman who is always ready to help anywhere. These are the things I see to be qualities of an ideal woman, or in summary, a hardworking and industrious woman. [Patient 5; woman, age 45]

One woman elaborated on expectations of women when asked whether or not it is hard to be a woman:

Being a woman is something difficult. As a woman you need to make your husband feel happy at home or else he will go out to take another woman, so you don't have to deny your husband access to your body. [Patient 6; woman, age 43]

Men also frequently emphasized these characteristics in the ideal woman:

An ideal woman is a woman who is matured and maybe married and can do something to help the husband and the family or her children, and nothing can convince her to live an infidel life. Such a woman is an ideal woman. Everything about her is in order and is faithful. She wakes up early before the husband. My mother used to say that, "It is only the lazy woman who feels cold because it is a man who has to feel cold rather." In Africa, the woman wakes up before the man. [Patient 4; man, age 56]

According to the study participants, an ideal woman is defined by her actions and character, with special emphasis on hard work in domestic duties and earning cash, being a wife and mother, and being modest and respectful. Strength and energy are needed to upkeep the home and care for children, bring in income, and enhance her husband's life (Van der Geest 2001).

The ideal man was described by both men and women as one who takes good care of his family financially, is hardworking and industrious, avoids bad habits such as drinking, teaches morality to children, speaks kindly to others, and can perform well in sexual relations with his wife. One man explained:

Sometimes when it is said that he is sexually weak; for instance, if before he had the sickness he could perform well in bed and after being diagnosed with it he is unable to perform, then we can say that he is no more a man...My main worry is that my energy and strength is not as it used to be and that affects me sometimes when I have to work and cannot work...A real man is the one who is able to work for hours. A real man is not the one who puts his hands in his pocket unconcerned and is always idle. That is also part of it. It is even the most important thing. If you are a man and you cannot work, then you cannot marry. [Patient 4; man, age 56]

Women often shared this view of the ideal man:

...A strong man. When he can do a lot of things, he is considered a real man. He can be judged by how his performance in bed. His strength also counts: his ability to carry heavy loads and to do hard work are key. [Patient 22; woman, age 60]

Strength was a key feature in the patients' descriptions of the ideal man; this includes strength of body, character, and sexual performance. In the view of many patients, a real man is strong in all areas. He is able to work long hours, stand up to his peers, and demonstrate sexual strength.

Although the particulars varied, the descriptions of ideal men and women at the core were not vastly different. The four central themes of being ideal were work, child rearing,

sexuality, and character. Ideal men and ideal women both are to be hardworking and take care of their children. They both must live up to sexual expectations. They both are also recognized by their morality and strength of character. Although cultural norms place an unequal burden of responsibility on women, patients' explanations of the core expectations of both genders were similar.

### *Diabetic Disruptions: Loss of Strength in Work and the Bedroom*

Patients who described diabetes as a disruption of their ability to perform ideal masculinities and femininities most often identified two of the four central themes of being ideal: work and sexuality. They pointed to changes in strength brought about by diabetes or its drugs that impacted their sexual ability and work ability, challenging their capability to behave in gender-expected ways. Male patients described why being a man is not easy, highlighting the pressure of demands in work and sexual ability:

Oh yes. If you are unable to perform your manhood actions [sexual performance], it also counts. I think you can understand what I mean. That reduces the respect your wife has for you. In addition, if you are unable to provide for your household, that also diminishes the respect given to you. That's why being a man is not easy. [Patient 33; man, age 79]

The disease has disturbed me. For instance, in my work. I'm a cobbler and a part-time farmer. I used to be able to walk for up to 8 miles. These days, I get exhausted from walking a mile. I can't do the work I used to do, and it has reduced my productivity. Buying the drugs has become an issue as a result. The disease has changed a lot of things because it reduces your strength and health. It causes erectile dysfunction at some point. So, as I stand here, I am no more a man. [Patient 11; man, age 50]

A conversation with another patient illustrated how diabetes can impact gendered expectations for sexual relationships:

Patient: A man's duty is to also work and when you live with a woman, you must be able to satisfy her in bed at night.

Interviewer: Does diabetes prevent you from any of these things?

Patient: I am now impotent. [Patient 26; man, age 61]



Other men described how their impotence caused them to divorce from their wives who were the ones who would cook for them and therefore lost their support in adhering to the diabetic diet. Some shifted to rely on extended female family members to help them with their dietary needs while others were left to purchase street food, which is often not adherent, causing them to have worse numbers in diabetes management indicators, including fasting blood sugar, weight, and blood pressure.

Women patients described similar diabetic disruptions in gendered work and sexual relationships:

Yes it [diabetes] prevents me, in the sense that as an ideal woman I can be active and cook for the children, but because I can't do it, I am hindered. I can't even wash my clothes with my hand. Someone has to cook for me. This hinders me. [Patient 17, woman, age 69]

When you get the disease, you don't get turned on before and during sex. When we come here, through conversation everyone says the same thing, both men and women. You can tell the difference from when you didn't have the disease. So it's like when you have a husband and he comes close to you, you feel nothing. [Patient 21; woman, age 46]

For women who divorced, the loss of a husband equated a loss of access to cash. One clinician lamented the state of women being reliant on men for access to money, as it is a powerful influence on their ability to care for their diabetes. Others felt so weak that they could not continue with their work and thus lost their source of income. Without cash, several women struggled to buy healthful foods to prepare, pay for transportation to the clinic, and afford desperately needed drugs. Normal gender relations often left women vulnerable both economically and in their ability to care for their health.

Sexual dysfunction as a result of diabetes was disturbing to many of the patients. Men appeared to experience profound emotional suffering from their new physical reality:

You realized that when you take in the [diabetes] drugs it makes you impotent. When diabetes gets a man, it can affect your sexual performance. If you are impotent you cannot sleep with your wife and [other] people will sleep with her. You are not a man... If I cannot sleep with my wife then why did I marry her? Someone will sleep with her and so you are not a man. If you are not able to do these things then you are useless. [Patient 3; man, age 56]

This kind of sickness brings about so many problems in the body...Diabetes is such that it makes men weak; when you have it as a man, you don't get back to your old self as a man again. [Patient 10; man, age 69]

Women also expressed strong feelings about the changes diabetes brings to their relationships and their sense of being a real woman:

I think there should be a public awareness campaign about how bad diabetes is. When you get it, you lose your strength and makes you unable to have sex with your husband. It makes you lose a lot of things. [Patient 35; woman, age 53]

Diabetes destroys women. It doesn't make your womanhood any good. It destroys women. With the women who have husbands, the husbands know how they used to be before the disease and how they are now. [Patient 38; woman, age 56]

Marriage was seen an important avenue for fulfilling ideal masculine and feminine expectations. Diabetes and sexual dysfunction at times caused ruptured marriages and prevented patients from entering new marriages.

Sexual dysfunction was commonly related to diabetes in this group of patients. Out of 60 participants, 35 brought up this subject during their interview. Among men, an overwhelming majority, 17 of 20 participants, mentioned sexual dysfunction. The proportion was much lower among women; still, almost every other woman, 18 of 40 participants, brought up sexual dysfunction. Notably, patients were not explicitly asked about sexual dysfunction in the interviews, yet many of the men and a moderate number of women felt comfortable in the interview space to bring up sexual dysfunction on their own.

In contrast, the doctors who were interviewed emphasized that men found it difficult to bring up the topic of sexual dysfunction to them and that women *never* brought it up to them. One doctor responded, “Actually, only men! I don’t think...no I definitely have not had a woman come to me about sexual...no its always the men. Always the men” (Doctor 2; woman).

Clinicians appeared to understand how serious the issue was, at least for men. One nurse explained, “...It is very important. Sexual life, you don’t joke with it. It can even lead to divorce and others [consequences] (Nurse 1; woman).” Some clinicians described working closely with male patients to improve their outcomes in the area of sexual dysfunction. They also pointed to the lack of privacy in the consulting rooms and cultural norms around not discussing sex that deter men from asking for help from their doctors. Additionally, social rules about proper gender relations impact patients’ ability to get care for sexual dysfunction as a symptom of diabetes. For instance, a female physician relayed instances of male patients assuming she was a nurse just because she was a woman, and some even refused to be treated by her because of their perception of her as less competent than a male physician. This gender hierarchy could deter some men from sharing their struggles and getting care if they were assigned to a woman physician. Conversely, women would likely feel that discussing their sexual needs with a male physician is inappropriate, especially in front of other patients when sharing a consulting room as was typically the case in this clinic.

Some clinicians suggested that advancing age likely contributed to sexual dysfunction in these patients, rather than being a direct cause of diabetes. The patients usually perceived that their problems were brought about by diabetes itself or prescribed diabetes drugs and had noticed a sudden onset that coincided with their disease, rather than more gradual transition

expected with general effect of aging. The broad age range of patients who brought up the problem of sexual dysfunction, spanning from as young as 37 years up to 78 years, likewise suggests that age is unlikely to be the major cause. If aging was the predominant cause, we would expect to observe an advanced age range in this group with sexual dysfunction than the rest of the patient interviewees, but this was not the case.

Some patients shared that they were not too disturbed by their sexual problems, framing their struggles as a part of sickness or old age in order to reconcile their perceived shortcomings in this area:

The only problem I have of late is that, it is as if my sexual life has dwindled but considering my age, I don't have problem with that. This is because in my current state, I don't need to worry about such things. [Patient 18; man, age 68]

I'm already an old lady so if it prevents me from acting in any of these ways I don't really care. Or don't you understand? I'm already old. I don't want to put my body through any kind of stress, so I don't even like to lay on the same bed with someone. [Patient 29; woman age 56]

Other examples of men reframing non-masculine behaviors as appropriate due to illness included when a male patient learned how to cook for himself in order to ensure adherence to the diabetic diet, or when another patient's wife paid for his trip to the clinic and his drugs while he was unemployed. These instances are examples of patients choosing diabetes self-management over maintaining gendered expectations.

Both men and women have gendered expectations in society for strength and energy to work long hours and be a satisfactory sexual partner in their marriages. Many patients of both genders described that diabetes or its drugs have caused loss of strength and energy needed to

fulfill these expectations. The diabetic disruptions that men and women experienced led to challenges in both self-management ability and performing gender.

## Discussion

This study set out to investigate how Ghanaian men and women with diabetes conceptualize gender in their society and how diabetes impacts the ability to “do gender.” According to the patients involved in this study, ideal masculinity and femininity in Ghana consists of four central aspects: hard work, sexuality, child rearing, and good character. Patients emphasized that diabetes took away the strength needed to fulfill two of these elements: work and sexuality. Patients explained that women in Ghana are expected to be hardworking, both in the home and in a cash earning enterprise, and to satisfy their husband in the bedroom. Men are expected to financially support the household and to be physically strong, both in work and in sexual performance. Diabetes drained them of strength, causing them to struggle to perform gender in ideal ways, including in hard work and sexual ability.

This diabetes-related decline in sexual and work abilities was distressing for most patients, at times impacting their perceptions of themselves as a real man or woman. These challenges often led to damaged relationships, decreased incomes, and impaired health-seeking, all of which contributed to their feelings of distress. For instance, weakness prevented some participants from working and earning the cash needed to buy their drugs, attend their appointments at the clinic, or change their diet. Others lost their spouse due to the stress of impaired intimacy, which impacted finances and the ability to eat a diabetic diet at home, either because of reliance on a wife to prepare meals or reliance on a husband to provide cash for buying meal ingredients. Having to purchase ready-made food, join extended family

members' meals, or buy the least expensive food lessened their ability to make the tweaks necessary to maintain a healthy blood sugar level as prescribed by their doctors and nurses.

### *Work and Gender*

Hard work was portrayed as an important part of doing gender. Men felt that if they could not work due to diabetes, that would cause them to lose the respect of those around them. Male patients who came to rely on their wives or extended family for cash and meals to care for their diabetes struggled with shame around not being able to provide for themselves and their families. Women would experience extreme financial precarity if they were unable to work, especially those who had no husband. Gender norms and relations in this context often corner women to be reliant on men for cash, leaving them vulnerable when husbands do not provide or marriages end. While many women can circumvent this by creating their own cash-earning enterprise, those who struggle with diabetes-related weakness are often not able to find the strength or energy to work as they once had. Those who did work long hours to support themselves often had little time left over to care for themselves through exercise or cooking balanced meals. For some patients, hard work and securing resources to sustain their families, essential parts of being a good man or woman, took precedence over looking after their health. Similarly, men in Brazil would prioritize traditional modes of masculinity and continued with long days at work, rather than resting and self-managing diabetes at home, which was associated with femininity (Kolling 2012). This demonstrates the influence that chronic illness can have on doing gender and the powerful incentives patients experience to maintain ideal gender expression.

### *Gender, Sexual Dysfunction, and Shame*

A surprising number of patients disclosed to the research team that they were experiencing sexual dysfunction, particularly in comparison to how seldom they disclose it to doctors during their consultations. More than half of patients initiated a discussion of their struggles with sexuality, including 17 of 20 men and 18 of 40 women. Conversely, the clinicians who were interviewed indicated that men rarely bring up sexual dysfunction to them and that women never do. Through the patient interviews, though, it became clear that it does affect many women and that it is an important concern for them. It is unclear why so many male and female patients disclosed their sexual struggles to the research team, which consisted of both a man and a woman, much more frequently than they did with clinicians. One clinician explained that it is critically important that patients feel safe to share any bodily changes they notice, as some symptoms may indicate serious diabetes complications. For instance, sexual dysfunction may signal poor blood glucose control.

There are some possible explanations for the difference in patterns of disclosure between interviews and doctor appointments. Lack of privacy in the doctor consultation rooms may have been a strong deterrent to speaking about one's sexual dysfunction, as patients are often being consulted right next to other doctors and patients who would hear their comments. Van der Geest found that for Ghanaian men, if their impotence was revealed, they would be subject to mockery and may be so ashamed as to lead to suicide (van der Geest 2001). There was more privacy in the room where the interviews took place than in the consultation rooms, and because patients see their doctor frequently but knew they would not see us again, it may have encouraged disclosure of an uncomfortable subject. Additionally, some patients expressed

that doctors did not listen to them or were short with them, which could discourage sharing of intimate problems and physical symptoms. On the contrary, during interviews patients were explicitly given space to talk about their personal struggles with diabetes and promised confidentiality, which may have allowed patients to see it as an opportunity to be heard and share their sexual challenges. Lastly, because the interviews were largely conducted in the Twi language, this could have contributed to the higher rate of disclosure compared to with doctors who do not always speak Twi with patients. It is preferred for most patients in the Ashanti Region to talk about sexuality in Twi using euphemisms. For instance, Ghanaian women use the word weakness as a euphemism for loss of sexual desire (van der Geest 2001). Speaking in the language one is most comfortable in allows for use of a wider range of euphemisms and idioms in order to avoid being crass and discussing sexual issues explicitly, which is socially discouraged.

Seeking help for sexual dysfunction in many cases would require breaking implicit and explicit rules about expected gender performance. Expectations for gender relations apply to patient-clinician interactions (Sandhu et al. 2009), preventing most women and many men from disclosing their sexual challenges to their doctor, resulting in many patients living with untreated sexual dysfunction. For instance, women may feel too embarrassed to discuss sexuality with a male doctor. The socialized feminine attribute of being submissive to authority may have contributed to women not readily speaking up or demanding the best care, especially if the physician is male. Moreover, women are less likely to have their physical concerns taken seriously by physicians (Charmaz 1994), which may lead to their sexual function being ignored as an important part of diabetes care. Likewise, internalized gender hierarchies can cause both



women and men to view women physicians as less credible (West 1984); therefore, if a patient is assigned to a woman physician, they may feel less inclined to believe she could help with such an issue. Gender hierarchies may also discourage men from disclosing to male doctors, for fear of appearing less masculine in front of another man.

Experiencing diabetes-related sexual dysfunction was sometimes the cause of marital strife and divorce. The inability to perform gender impacted diabetes self-management. Those who were married often described the support their spouse gave to them in managing their diabetes, through efforts such as providing cash, cooking diabetic diet meals, and reminding them to take their drugs and exercise. These supports would be lost for those who were unable to remain in their marriages or to find another partner, leading to lower capacity to self-manage and potentially worse health outcomes.

### *Women and Sexual Dysfunction*

An important finding of this study was that women with diabetes experience sexual dysfunction more than was expected given the current literature and clinicians' experiences. Nearly half of the women brought up their experiences with sexual dysfunction as a challenge of diabetes. Many grappled with negative emotions surrounding these bodily changes. Diabetes disrupted women's gender performativity by reducing the strength needed to engage in behaviors that are highly expected of them, including household and cash-earning work and sexual relations with their partners. Women shared the importance of making the home comfortable and being available to their partners sexually in order to maintain the relationship. The inability to do these can diminish their perceived value as a woman and a wife. In this study, women, not just men, often felt disturbed by sexual dysfunction and held sexuality as an

important part of femininity that is interrupted by diabetes. In fact, women often described their feelings about and experiences with sexual challenges similarly to men, for instance that sexual dysfunction takes away one's manhood/womanhood. Yet, these struggles were rendered invisible by assumptions about gender that are embedded in local and global discourses.

Sexuality and gender are framed and reified through fields of power (Ferzacca 2012) such as society, science (including anthropology), and medicine. Society considers sexual function and pleasure to be in the realm of masculinity; consequently, biomedicine approaches sexual dysfunction as primarily a man's problem. This framing is further reinforced by scientific and social research, where the focus is on men's experience of sexual dysfunction, and women are not even asked if they experience it (Kolling 2012; Cooper et al. 2018; Ekoru et al. 2019), leaving a gap in the literature that might reinforce beliefs that it is not a women's issue. The systematic neglect to attend to female sexuality and experience, particularly how it relates to chronic illness and doing gender, serves to maintain its invisibility and reify gender as a "natural" division between men and women. Due to a host of social norms surrounding gender and sexuality that are shaped both by local and foreign forces, including religion, tradition, and postcolonialism (Oyěwùmí 1997; Van Allen 1972), women continue to suffer physically and relationally as their experiences and needs are ignored.

### *Money, Sex, and Distress*

Many patients felt that diabetes robbed them of strength and energy, leading to challenges in performing important elements of ideal men and women, including sexual relations and work. Those who must spend a large proportion of their income on diabetes-

related expenses, particularly those with little ability to work, experienced worry and desperation. These challenges then led to increased obstacles in diabetes self-management, including lack of resources and motivation and profound distress from the perceived inability to be a real man or woman. The distress stemming from these social, economic, and self-management struggles often snowballed, potentially compounding poor diabetes outcomes and poor economic status, in what might be considered a “recursive cascade” (Manderson and Warren 2016) of increasing ill health and financial struggle. Depression, distress, and diabetes are interrelated, leading to worse self-management than those who have diabetes without depression or distress (Fisher et al. 2007; Gonzalez et al. 2007). Distress can negatively impact blood glucose levels and depression can impede individuals from proactively caring for their disease (Cooper et al. 2018; Mendenhall 2012; Rock 2003; Thapa 2012; Sarkadi and Rosenqvist 2003).

### *Gender Flexibility*

A nuance of these findings was that not all those who experienced sexual dysfunction and loss of ability to work felt distressed by these physical changes. For example, one patient shared that her desire to conserve energy and protect her health was more important than doing the work and sexual behaviors that would qualify her as an ideal woman. Others explained that in their old age, they have no interest in sexuality. Van der Geest (2001) found that older Ghanaian women were not perturbed by loss of sexual desire and saw it as a natural part of aging and being modest, and that women were not taunted if exposed as unable to sleep with a man in the same way that men were ridiculed for impotence. Likewise, a few male patients shared that they were not disturbed by their sexual dysfunction and that due to their

advanced age, they did not need to worry about the concerns of younger men. Van der Geest learned that important male elders gained respect through having three virtues: wisdom, self-restraint, and dedication to his family (van der Geest 2001). Going against these values to pursue romantic relationships with women was considered foolish in older age, and therefore older men found it easier to accept impotence (Van der Geest 2001). For diabetic patients, accepting sexual dysfunction as part of old age may help to alleviate the distress of such a change, an important protection that may enhance diabetes health outcomes through reduction in depression and social stress.

Being flexible in what it means to be a man or woman may enhance diabetes self-management by reducing the distress that contributes to poor motivation for self-care. This finding mirrored other studies where people suffering with chronic illness embraced changes to expected gender expression and used it to empower themselves (De-Graft Aikins 2006; Stansbury et al. 2003; Hunt 2000; Wentzell 2013). In this current study, some patients embraced their physical changes, which empowered them to prioritize their health. Behaviors that would normally be seen as un-feminine or un-masculine became part of a new feminine or new masculine, where due to age and illness, typical gender expectations no longer apply. For instance, when a male patient learned how to cook for himself in order to ensure adherence to the diabetic diet, or when another allowed his wife to pay for his trip to the clinic and his drugs when he was unemployed, these men found a way to reframe these behaviors as masculine. Both behaviors would normally be considered un-masculine (Courtenay 2000; Charmaz 1994; Colvin and Robins 2009; Stansbury et al. 2003), but in the context of diabetes are reframed as taking initiative to self-manage one's health; taking initiative is seen as a masculine trait.

Likewise, a good wife and mother is expected to care for all others before herself (Weaver 2016), but women with diabetes can envision diabetes self-management as a way to ensure she will be alive to care for her children. Gender flexibility may serve as an asset to those who decide to prioritize diabetes self-management when diabetes prevents them from achieving all the ideals of masculine or feminine.

## Conclusions

The results of this study have implications for clinical practice. Diabetes self-management education should take into consideration that men and women both experience a loss of strength and energy to work and earn cash, exacerbating financial situations that are already precarious due to economic realities in Ghana, as described in Chapter Two. The self-management model must be augmented to address this physical and financial dilemma of diabetes patients who are expected to spend a large amount of their household income on diabetes care. Although systems are in place in the diabetes clinic to support a small number of the poorest of the patients when possible, diabetes self-management supports that alleviate the financial burden of exercise, food, transportation, and medicine requirements will be invaluable to maintaining the health status of diabetic patients. This is especially true for households where there is only one income-earner, such as single women or men who were formerly working and had to stop due to diabetes, and those with no income source.

Additionally, highlighting the profound impact that sexual dysfunction has on patients grappling with financial and social challenges to manage diabetes, these results point to the need to understand gendered barriers to disclosing sexual dysfunction, especially for women, and to implement clinic systems that ensure both men and women are screened for sexual

dysfunction by default and allow for patients to discreetly elect for counseling and treatment (Sarkadi and Rosenqvist 2003). Many patients in this study embraced the medicalization of sexual dysfunction, or the consideration of sexual challenges as a medical issue, and in fact wished their physicians would take their concerns seriously and find a way to help them address it, whether through introducing a new medication or changing current medications to reduce side effects. Patients described going to herbal healers to try and fix their sexual dysfunction when they could not access biomedical interventions. Studies have shown that the relationship between diabetes and sexual dysfunction is multifactorial, through neurologic, vascular, endocrine, and psychosocial mechanisms related to both the disease and treatment (Cooper et al. 2018), and thus can be addressed through blood sugar management and adjustment of drugs. In Ghana, women do not broach the subject with clinicians despite sexual challenges they experience and believe are caused by diabetes; therefore, diabetes clinics can bridge this gender gap by implementing systems and structures in intake and consultation to detect sexual dysfunction and support women. Acknowledging how common these challenges are and helping patients navigate changes to their sexuality and gender expression can decrease stress, increase motivation for self-management, and improve health outcomes. Patients trust and look to nurses for guidance, so nurses will have an essential role in education, screening, and discreetly communicating individual patients' concerns to physicians, especially for women patients. Acknowledging women's sexual needs and experiences will address gender inequalities that exist in diabetes care and society as a whole and make a way for more equitable health outcomes.

A limitation of this study is that it is difficult to decipher whether participants' statements arose from the stereotypes or idealizations about gender they held or from their lived experiences with diabetes. Asking patients to describe the ideal man and woman might have elicited stereotypes rather than what they actually expect of themselves or others. Alternatively, some of the older patients may have at one time experienced the gendered pressures they described but not be currently under distress for inability to meet these expectations, as they are beyond their childbearing and courting years. Therefore, the findings may not reflect present struggles of these patients and may not be a component of any distress they may currently experience.

This study utilizes the gender binary of man and woman. As in much of the world, there is currently little acceptance for non-binary individuals in mainstream Ghana, and thus speaking about gender is still closely aligned with speaking about men and women. This may not have always been the case, though, as research has shown that European colonization in Africa distorted the preexisting ideas about gender. For instance, in precolonial Igbo society, biological sex did not always correspond with gender; women in positions of power were called men (Amadiume 1987; Korieh 2001). Colonialism sought to change these perceptions and practices in order to align them more with Christianity, introducing the idea of the superiority of men over women (Oyěwùmí 1997; Van Allen 1972). Somewhat to the contrary, Miescher argues preexisting gender practices were not simply erased by colonialism and missionary activities, but they were rather contested and reformulated (Miescher 2005), and now are a unique reformulation of Christian and precolonial African ideas. Those following conservative Christianity currently hold most social and political power in southern Ghana. Women are seen

as subordinate to men and non-binary expressions of gender and sexual orientation are considered deviant and sinful. Some Ghanaians debate whether these views are truly “African” or are “foreign,” with some of the view that non-binary individuals were accepted before Christianity, while others view the growing acceptance of non-binary individuals as an evil, Western imposition (Baisley 2015). In Ghana, as in much of the world including the Western world, non-binary individuals are not safe to express their identities in public, making it difficult to capture the health-seeking experiences of these individuals. The use of the gender binary in this chapter is not meant to erase legitimate identities beside man and woman, but rather reflects how gender is framed in the existing literature and how the majority of people express or discuss gender in Ghana, particularly the middle-aged to older population. Future studies can and should consider all genders, especially as understanding and acceptance of non-binary individuals continues to expand.

By combining the perspectives of gender performativity and chronic illness experience, this study adds to current understandings of social relations of gender, gender and chronic illness, chronicity and economic and social precarity, and the impact of sexual dysfunction on gender expression, particularly for women. The common diabetes illness management model that places much of the burden of care on the individual amidst the multitude of their daily activities, with the external care given to them limited to consult by a physician, a prescription for medications, and education, is strongly interrelated with doing gender. It is well understood in the literature that gender impacts the way illness and related symptoms are experienced, understood, treated, and self-managed. Gender inequality contributes to differential experiences, with women facing additional socioeconomic pressures. Cultural and social norms



about gender and the “right way” of doing things, such as the enforcement of suitable topics of conversation, appropriate interactions between men and women, unequal burdens on women, hegemonic masculinity, proper behavior of older people, and the hierarchy of patient and clinician, can all lead to enhanced or diminished care and impact health outcomes. This study shows that the opposite is also true: health, illness, and care systems impact doing gender. Gender impacts the ways in which men and women develop diabetes and confront its intrusion in their lives, but this study showed that diabetes likewise impacts patients’ ability to fulfill important elements of being an ideal man or woman. Diabetes causes a loss of strength and energy, which prevents men and women from the hard work and sexual relationships that are expected of them, leading to distress and lessened self-management. These findings of the realities of living with diabetes should help improve design and delivery of education, support, and treatment.

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## Chapter 4: Gender, Poverty, and Diabetes Health Outcomes

### Abstract

When individuals belong to a disadvantaged group, there are often health consequences. Intersectionality theory contends that belonging to more than one disadvantaged group results in further and unique health consequences and inequalities, and that this is obscured when considering just one disadvantage. This study used qualitative and quantitative methods to understand the impact of multiple disadvantages, including poverty, female sex, and older age, on diabetes management success and health outcomes among individuals participating in diabetes management. The research was conducted with 60 men and women with diabetes at a diabetes clinic in Kumasi, Ghana. Fasting blood sugar (FBS) test values were utilized in this study as a health outcome indicator, and were evaluated for association with poverty, sex, age, and their interactions using box plots and multiple regression models. Results show that patients in poverty had better FBS than those not in poverty, but women had worse FBS than men regardless of income group. This finding did not support intersectionality theory as poverty was associated with better outcomes. However, the results support an important element of intersectionality, which is that examining just one disadvantage obscures the unique and worse impacts of experiencing more than one disadvantage, as the possible protective factor of poverty was lesser for women than for men. Qualitative data, including semi-structured interviews and participant observation, show that women had additional and distinctive challenges to diabetes management and subsisting economically compared to men, and that impoverished patients had additional burdens compared to nonpoor, which did support intersectionality theory. Further research can interrogate what about being a woman and being nonpoor contribute to worse diabetes outcomes in this context.

### Introduction

Previous research on diabetes outcomes for different groups has primarily focused on singular identities, such as sex or race, rather than the unique outcomes for different intersections of identities, such as for women of color in racialized societies. This study considers the intersection of gender, class, and age, and how it impacts diabetes outcomes.

When examining just one identity and its impact on diabetes outcomes, other nuances may be obscured. For example, low income has been demonstrated to be associated with higher rates of diabetes as well as increased complications, comorbidities, and worse outcomes

(Chaufan et al. 2011; Connolly et al. 2000; Gaskin et al. 2013; Saydah and Lochner 2010).

However, when looking at more than one variable, such as poverty and gender, the impact of poverty on women's health outcomes appear worse (Amin et al. 2014; Crenshaw 1991; Kavanagh et al. 2010; Robbins et al. 2005). In some studies, black women had the worst outcomes among all combinations of identities, and independent factors that contribute to poorer diabetes outcomes appear to impact black women the worst (Brown et al. 2016; Naqvi et al. 2019). This study examines the factors that influence diabetes outcomes by investigating the effects of multiple identity variables and their intersections using data collected from 60 diabetic patients who attend a diabetes clinic in an urban public hospital in Kumasi, Ghana. Based on the overall trends in the literature that examine diabetes with an intersectional lens, it is expected that in this study, older women in poverty would have the worst diabetes outcomes compared to other subgroups, and that the best outcomes would appear in younger men with higher income.

Fasting blood sugar (FBS) values from participants' medical charts were analyzed to evaluate the relationships with gender, age and poverty, and to elucidate how these categories and intersections may impact self-management health outcomes. Results were interpreted in light of ethnographic data pertaining to the patients' lived experience of being diabetic along with the multiple identities people inhabit.

### *Literature Background*

The majority of previous research on diabetes and group status have examined singular disadvantages, such as those based on income, gender, or race. Many of these studies look at income and diabetes risk, prevalence, outcomes, and complications. Studies on poverty and



diabetes outcomes in the United States and the United Kingdom show that low-income groups experience health disparities in higher rates of diabetes, outcomes, and mortality (Chaufan et al. 2011; Connolly et al. 2000; Gaskin et al. 2013; Saydah and Lochner 2010). In Ghana, researchers have found that low socioeconomic status is strongly associated with type 2 diabetes (Danquah et al. 2012). In Ethiopia, diabetes incidence was strongly associated with subsistence farming, illiteracy and low education levels, history of childhood malnutrition, and other markers of poverty (Fekadu et al. 2010). In India, people with diabetes who had low income had higher prevalence of heart disease, diabetes complications, and risk factors than those with high income (Ramachandran et al. 2002). Additionally, low-income, marginalized populations experience risk factors for increased diabetes comorbidities, such as depression (Mendenhall et al. 2017). Exposure to food insecurity predisposes individuals to chronic illness, including diabetes (Carruth and Mendenhall 2019). Low socioeconomic status also led to higher diabetes incidence for Mexican-born individuals in the United States compared with their white counterparts, a disparity that increased with age (Villa et al. 2012). Many maintain that as people age, disparities stemming from low socioeconomic status can accumulate over time (Everson et al. 2002; Dannefer 2003). In contrast, the age as leveler hypothesis argue that socioeconomic disparities in health tend to even out as people enter older age (House 1994). In terms of diabetes management, a study with Somalis in Ethiopia found that due to poverty, patients struggled to access medical care, refrigerate insulin, and follow dietary recommendations due to chronic food insecurity (Carruth et al. 2020). In Ghana, economic inequality has been shown to influence poor health through a variety of pathways, including malnutrition, inadequate housing, environmental hazards, poor sanitation, low levels of

education and health literacy, and low utilization of, and access to, health services (Adjei and Buor 2012; Weeks et al. 2012). For patients in urban Ghana, the economic burden of diabetes is high, resulting in over half of households experiencing what is called “catastrophic health expenditure” (Pei 2015), defined as out-of-pocket spending for health care that exceeds a certain proportion of a household's income (Ekman 2007). These economic realities interact with the development of diabetes and the conditions around managing it day-to-day.

Gender inequality is another system of power that contributes to poorer diabetes outcomes. Women have been found to have higher diabetes prevalence, risk factors, mortality rate, consequences and complications, and less access to services and support (Hannan 2009; Tang et al. 2003; Ricci-Cabello et al. 2010). Looking at gender in terms of diabetes management adherence, the literature is mixed on whether men or women were more adherent to self-management tasks (Babwah et al. 2006; Fitzgerald et al. 1995; Kalyango et al. 2008; Nau et al. 2007; Rwegerera 2014). In Tunisia, women received poorer quality diabetes primary care than men, despite attending diabetes clinics at much higher rates (Alberti and Alberti 2009). In Ghana, gender inequality exists in several domains including education, wealth creation and ownership, access to resources, health and mental health, and decision-making (Akotia and Anum 2015; Hiscox and Goldstein 2014). These inequalities have tangible effects on how women develop and are able to care for diabetes.

Considering race and diabetes, population based studies in the US have found Black Americans to be more than twice as likely to have diabetes than whites (Gaskin et al. 2013), even after adjusting for age, socioeconomic status, and overweight (Brancati et al. 1996), and have the highest average A1C compared to other ethnic groups (Herman et al. 2007; Saydah et

al. 2007). Social categories of race produce biological consequences on racialized bodies through chronic exposure to frustrating and oppressive social interactions, such as discrimination and lack of access to resources (Gravlee 2009; Gravlee et al. 2005), and influence epigenetic changes that shape health (Kuzawa and Sweet 2009; Benyshek 2007). Although Ghana does not appear to be a racialized society, race plays an important role in Ghana's historical trajectory. Pierre argues categories of blackness and whiteness in Africa that are rooted in the slave trade, colonialism, and global capitalism have supported a race-based political hierarchy and unequal power relations (Pierre 2012). These structures of power have biological health consequences. Populations who were subjected to colonialism often have less maternal capital, which are phenotypic resources enabling investment in the offspring (Wells 2010), and greater stressors related to acculturation that led to lasting increases in glucose levels, glucocorticoid secretion, and adiposity (Szathmary and Ferrell 1990). Biology and culture continually interact and have the capacity to change one another (Lock and Kaufert 2001). Ghana, as a postcolonial society undergoing rapid cultural change, is subject to these biological changes across the population, and Ghanaians as Black Africans experience the racial health disparity of diabetes.

One's race cannot be separated from their gender or poverty status. When an individual inhabits more than one of these disadvantaged identities, scholars argue these inequalities do not simply add together, but rather intersect to compound the effects of different disadvantages (Crenshaw 1991; Cole 2009). For instance, women in poverty have been shown to experience unique and exponential effects of both poverty and gender inequality, including poorer health than men and nonpoor women (Crenshaw 1991). Low socioeconomic position is

associated with a worse profile of diabetes biomarkers for women than men (Kavanagh et al. 2010). In Ghana, women experience higher incidence of and more severe poverty than men, contributing to higher incidence of disease for women (Awumbila 2006).

Studies using an intersectionality lens have described compounded risk and poorer health outcomes for individuals who fall into multiple disadvantaged categories at once. For instance, some studies focused on poverty and gender, finding that low socioeconomic position is more consistently associated with a worse profile of biomarkers for cardiovascular disease and diabetes for women than for men (Kavanagh et al. 2010), and poverty is more consistently a risk factor for diabetes and its complications for women than for men (Robbins et al. 2005; Amin et al. 2014; Tseng et al. 2008). Other studies focused on race and gender, demonstrating that compared to all other combinations of race and gender, black women reported poorer diabetes self-care (Naqvi et al. 2019) and that being black or Mexican and female had deleterious health consequences beyond those already accounted for by race or gender alone (Brown et al. 2016). Considering age, race, and socioeconomic status, black men and women with higher education levels had more rapid health declines with age compared to white men and women with comparable education levels (Brown et al. 2016). These studies illuminate how disadvantages that people experience in society cannot be isolated but are rather experienced together. Separating out the effects of gender and race, for instance, would not be a valid analysis, as people experience life through all their disadvantaged identities simultaneously. This study contributes to the intersectionality literature on diabetes by examining some of the complexities of the ways in which poverty and gender are enmeshed to

influence diabetes outcomes in the context of Ghana. Multiple disadvantage variables will be examined together to understand their impact on diabetes outcomes.

### *Hypotheses*

FBS data are analyzed in relation to age, gender, and poverty to understand how they may individually, together, or interactively relate to diabetes health outcomes. Based on the overall trends in the literature as reviewed above, the expectations for the results of this study are as follows:

1. FBS values will be higher for women than men.
2. FBS values will be higher for patients under the poverty line than patients not under the poverty line.
3. FBS values will be higher for older patients than younger patients.
4. The differences in the above three hypotheses will hold when evaluated simultaneously.
5. The effect of two intersecting conditions will compound:
  - a. Being both a woman and poor will be associated with substantially higher FBS than being a woman and not poor or being a man of either poverty status.
  - b. Being both a woman and older will be associated with substantially higher FBS than being a woman and younger or being a man of any age.

### *Methods*

#### *Data Collection*

This study was conducted at the diabetes clinic at Komfo Anokye Teaching Hospital (KATH), an urban public hospital in Kumasi, over 9 months during 2016. A total of 60 patients were recruited and consented to participate, consisting of 40 women and 20 men. Quantitative and qualitative data were collected in order to evaluate lived experiences and health markers and examine differences between groups in diabetes management success and health outcomes. Data collected include recording of health data from patient medical folders, one-on-

one semi-structured interviews with patients and clinicians, and participant observation in the clinic waiting room and at diabetic association meetings. Patient health data were collected for each participant from their medical folder up to 6 of their diabetes clinic visits in the preceding 3 years (early 2014 to late 2016) and included values such as sex, age, and FBS. Because diabetes self-blood sugar test strips are cost prohibitive, most patients in the clinic typically went to a lab for an FBS test on the day of or day before their appointment and brought it to the clinic to be recorded in the patient medical record by a nurse. A doctor would review the value and adjust medications as needed. In medical records, some FBS or other values were missing due to a patient not attending the clinic for an extended period of time or errors in recording.

Qualitative data were collected from the patients who provided their medical record data. The semi-structured interview included questions about patient characteristics, such as monthly income and education levels, as well as open-ended questions related to diabetes management challenges and strategies, economic barriers to health and subsistence, and perceptions about gender roles and relations. Additionally, 6 clinicians participated in semi-structured interviews, where they were asked about trends, challenges, and goals in diabetes care. Interviews were conducted in Twi or English, were audio recorded upon consent, and lasted between 20 to 60 minutes. Interviews were transcribed and translated into English. The participant observation in the clinic has been described in Chapter Two.

### *Data Analysis*

In this study, FBS was a continuous variable used as a diabetes health outcome indicator. The FBS value measured on the day of the interview in late 2016 was defined as *FBS*

*Current.* To allow evaluation of diabetes management success over time, one should evaluate the FBS Current data in light of a prior FBS test; FBS Current should not substantially increase in reference to a prior, baseline FBS. To this end, the oldest FBS value available to this study from patient records in early 2014 was utilized as a baseline FBS value and was defined as *FBS Baseline*.

Annual income was calculated by multiplying participants' typical monthly income estimates by 12. The poverty variable was derived by assigning the value one if annual income was below the 2016 poverty line of 1,315 GHS (Ghana cedis) per adult per year (Cooke et al. 2016), and the value zero was assigned otherwise. Sex and age were collected from patient records and corroborated with the semi-structured interviews. Table 6 summarizes how variables were calculated and coded.

Table 6. Variables

Variables	Description
<b>Income</b>	
Annual Income	Self-reported monthly income multiplied by 12 months.
Poverty	Indicator variable. Coded 1 for individual whose individual's annual income is below the poverty line set at 2016 level of under 1,314 GHS per adult per year. Otherwise coded 0.
<b>FBS</b>	
FBS Current	FBS value on day of interview in mmol/L. Transformed to lognormal distribution.
FBS Baseline	FBS value recorded in early 2014 from patient's medical record.
<b>Sex</b>	
Sex	Coded 0 for female and 1 for male.
<b>Age</b>	
Age	Continuous variable in years.

Semi-structured interviews were coded and analyzed with NVivo qualitative analysis software. The codes were developed in an iterative process and included themes such as

financial challenges with managing diabetes and gender dynamics of diabetes. Pertinent quotes were highlighted in order to illustrate qualitative themes. Analyses such as text queries, coding queries, and compound queries were run to examine themes in context.

All statistical analyses were run in IBM SPSS Statistics software. Descriptive statistics and t-tests were run to examine patterns in the data. Individual cases that did not have data points for all variables were removed from the sample, leaving a sample size of 55, including 39 women and 16 men. A box plot was generated to facilitate visualization of patterns among groups by gender and poverty.

As an additional exploratory analysis, simple and multiple regression analyses were conducted. Due to low sample size, these analyses had low statistical power and cannot be used to generalize about the diabetic population in Ghana but were conducted to understand trends about the patients who participated in the study. Multiple linear regression was utilized in order to consider associations between FBS and sex while holding poverty and age constant. FBS Current values were transformed to lognormal distribution for regression analyses to mitigate skewness. Log-transformed FBS Current was utilized as the outcome variable. Predictors included sex, poverty, and age. The initial models were simple linear regression containing each of the predictors. Using these models as the foundation, the other predictors were systematically added one at a time to examine changes in results. Each hypothesis was tested in models first without and then with adjustment for FBS Baseline. The models with FBS Baseline allowed for evaluation of FBS current's associations with predictors while holding constant the effect of baseline FBS and therefore addressing the hypothesized construct of diabetes management outcome over the two-year timespan. Interactions between a pair of



predictors were tested when there was a statistically significant main effect. Table 7 presents the models and analyses used to test each hypothesis.

Table 7. Linear Regression Models by Study Expectation

Expectation	Models
1. FBS values will be higher for women than men.	1. $FBS = \beta_0 + \beta_1 * sex + error$
2. FBS values will be higher for patients under the poverty line than patients not under the poverty line.	2. $FBS = \beta_0 + \beta_1 * poverty + error$
3. FBS values will be higher for older patients than younger patients.	3. $FBS = \beta_0 + \beta_1 * age + error$
4. The differences in the above three hypotheses will hold when evaluated simultaneously.	4. $FBS = \beta_0 + \beta_1 * sex + \beta_2 * poverty + \beta_3 * age + error$
5. Additionally, the effect of two intersecting conditions will compound: a. Being a woman and poor will be associated with substantially higher FBS than being a woman and not poor or being a man of either poverty status. b. Being a woman and older will be associated with substantially higher FBS than being a woman and younger or being a man of any age.	5a. $FBS = \beta_0 + \beta_1 * sex + \beta_2 * poverty + \beta_3 * age + \beta_4 * sex \times poverty + error$  5b. $FBS = \beta_0 + \beta_1 * sex + \beta_2 * poverty + \beta_3 * age + \beta_4 * sex \times age + error$

## Findings

### *Quantitative Results*

Sample characteristics are summarized in Table 8. The mean age of the patient sample was 57 years of age, with a range of 37 to 79 years. Annual income ranged from 0 to 108,000 GHS with a mean of 7,262 GHS. On average, the patients were overweight, with a mean BMI of 27. Of 59 patients, 44 (75%) were hypertensive (over 129 systolic or over 80 diastolic). The average BP was 141/81, which is in the hypertension stage 2 range (American Heart Association 2020). The mean FBS Current was 10.3, with a range of 4.5 to 28.9. The clinical target range in FBS values is between 4.4 to 7.2 mmol/L (CDC 2019); values over 13.3 mmol/L are considered

dangerously high (Haring et al. 2013). Of the sample patients, 44 of 59 (75%) were above the target range of blood glucose control (having a FBS above 7.2).

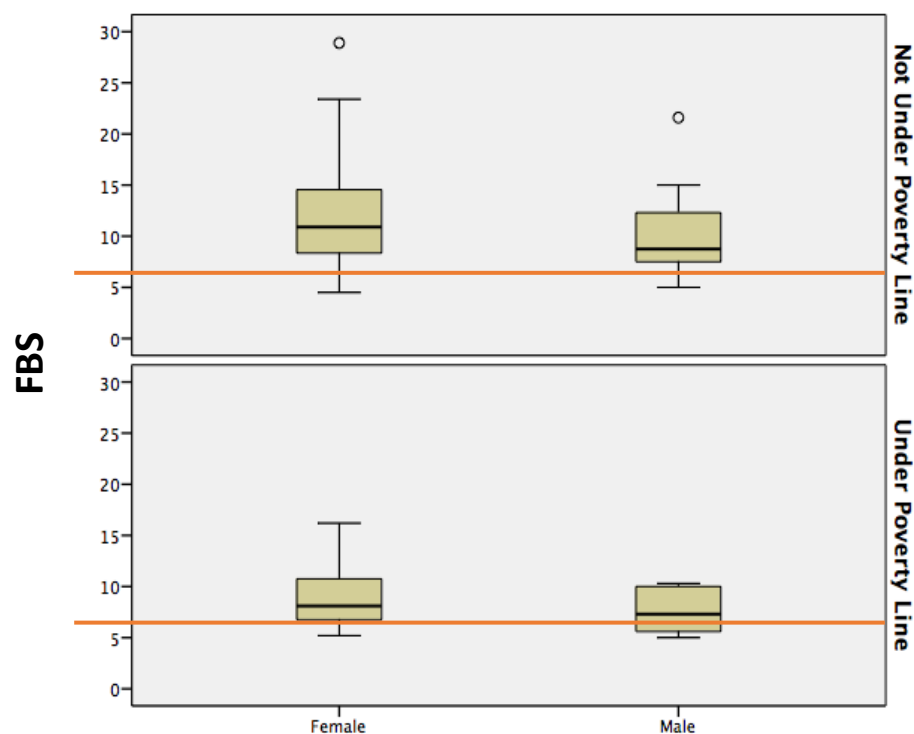
Table 8. Sample Characteristics (n=55)

Variable	Mean $\pm$ SD				
	All	Women	Men	Under Poverty Line	Not Under Poverty Line
Age	56.8 $\pm$ 11.3	57 $\pm$ 11.3	56 $\pm$ 11.5	56 $\pm$ 13.0	57 $\pm$ 11.5
FBS Current	10.4 $\pm$ 4.9	10.9 $\pm$ 5.2	9.3 $\pm$ 4.2	8.5 $\pm$ 2.8	11.7 $\pm$ 5.7
FBS Baseline*	9.9 $\pm$ 4.4	9.9 $\pm$ 4.2	9.9 $\pm$ 4.9	9.1 $\pm$ 3.9	10.5 $\pm$ 4.7
Annual Income in GHS	7,266 $\pm$ 16,976	5,536 $\pm$ 11,306	11,483 $\pm$ 26,209	428 $\pm$ 353	11,824 $\pm$ 20,800
Under Poverty Line	40%	41%	38%		

\*n=48

Figure 1 displays a box plot illustrating FBS Current by gender, stratified by under or over the poverty line. The orange line on each FBS axis represents the cutoff FBS for target

Figure 1. Box Plot of FBS Current by Gender and Poverty



diabetes management (no higher than 7 millimoles per liter). All groups had a mean FBS higher than the FBS management cutoff, regardless of gender and poverty status. Those over the poverty line had higher FBS on average than those under the poverty line, for both sexes. Though poor patients had lower FBS on average, women had higher FBS than men both under and over the poverty line.

Table 9 presents regression models analyzed without FBS Baseline. Table 10 presents models analyzed for each hypothesis including FBS Baseline. In models that did not account for the FBS Baseline value, poverty was significantly associated with *lower* FBS for three models, which was contrary to expectations. This result suggests poverty was associated with more effective diabetes management. When adjusted for FBS Baseline, two models showed male sex was significantly associated with lower FBS, which was aligned with expectations. This result suggests that women's diabetes management was less effective than men's over the two-year time span. No interaction terms were significant; therefore, it cannot be demonstrated that being both woman and in poverty or being both a woman and older is associated with compounding effects on FBS.

Table 9. Regression models for FBS Current (ln-transformed) (n=55)

Variable	Model					
	1. Sex	2. Poverty	3. Age	4. Sex, Poverty & Age	5a. Sex, Poverty, Age & Sex-Poverty interaction	5b. Sex, Poverty, Age & Sex-Age interaction
Sex	-.136 [.125]			-.145 [.121]	-.145 [.122]	-.148 [.122]
Poverty		-.260* [.111]		-.264* [.112]	-.264* [.113]	-.274* [.114]
Age			.001 [.005]	.000 [.005]	.000 [.005]	.000 [.005]
Sex × Poverty					-.007 [.253]	
Sex × Age						-.007 [.011]

\*Significance of  $p < 0.05$

Values in each cell are unstandardized beta with standard error in brackets. In the interest of brevity, constant is not shown. Likewise, intermediate models containing two predictors are not shown.

Table 10. Regression models for FBS Current (ln-transformed) adjusted for FBS Baseline (n=48)

Variable	Model					
	1. Sex	2. Poverty	3. Age	4. Sex, Poverty & Age	5a. Sex, Poverty, Age & Sex-Poverty interaction	5b. Sex, Poverty, Age & Sex-Age interaction
Sex	-.228 [.115]			-.234* [.115]	-.237* [.117]	-.239* [.116]
Poverty		-.144 [.110]		-.126 [.108]	-.124 [.110]	-.113 [.111]
Age			.004 [.005]	.004 [.005]	.004 [.005]	.004 [.005]
FBS Baseline	.003 [.012]	.000 [.013]	.004 [.013]	.002 [.012]	.002 [.013]	.002 [.012]
Sex × Poverty					.079 [.239]	
Sex × Age						.007 [.011]

\*Significance of  $p < 0.05$

Values in each cell are unstandardized beta with standard error in brackets. In the interest of brevity, constant is not shown. Likewise, intermediate models containing two predictors are not shown.

### *Qualitative Findings*

Patient and clinician interviews and participant observation notes on gender, poverty, and age shed light on the quantitative findings. Women and men shared about living with diabetes, which often revealed gendered relational dynamics that impact their ability to adhere to diabetes management activities. Many of these relational dynamics indicated gender inequality in the lives of diabetic patients. Gender roles often placed unequal burden on women's time and energy. One woman patient described some of these burdens: "When you are born as a woman you suffer because all the house chores are yours, coupled with the responsibility of raising the kids. Men don't even wash; you serve them as a woman... So, as women we suffer" (Patient 56). Many male participants shared that their wives help them with their self-management responsibilities, at times even largely taking over the responsibilities, for instance, reminding them to take medications and exercise and shopping for and preparing special foods for them. Men often benefitted from the labor of their wives, daughters, or other female family members who took on some of the share of management responsibility. One male patient shared, "My wife helps me. I tell her all the foods I've been told to eat and she makes sure she feeds me what benefits me. She makes me greens with cabbages and so on. She makes sure the stews are sufficient in my meal" (Patient 46). The typical Ghanaian diet is heavy in starches, so women must go out of their way to purchase more vegetables and cook more stews in order to supplement the reduction of starches in the diet. This may mean spending extra time cooking additional dishes for different family members.

Several women patients described situations where they relied on men for the cash needed for diabetes management. When asked if anyone helps her with her diabetes

management, one patient shared, “Yes, my husband [helps me]. For example, when I come and they prescribe drugs for me and I do not get them from here, I take the prescription form home and he gives me money to buy them. He is the only one” (Patient 6). Other women described the immense stress of not having a reliable partner to help them with diabetes costs. One woman described, “One needs a husband so that when there are no drugs, he can support you in buying them. But my husband who used to support me is dead and there are times when I have no drugs and it affects me” (Patient 8). Another woman was visibly upset as she shared:

Please, I have no one, because ever since my husband passed on...I don't have any child assisting me when it comes to buying my drugs or giving me money for food or cooking food for me. I am the one doing everything, and currently I have lost my job. Things are very hard for me, very hard for me, although you see me appear nicely. So that is how it is. [Patient 20]

Although men did struggle with various aspects of diabetes management, men did not complain over lack of access to cash within their household or lack of control over how their money was spent.

Clinicians also discussed gender as a factor that influences diabetes management success. Doctors and nurses largely were under the impression that men were less compliant with diabetes management directives than women. They described that women were more compliant with taking drugs, modifying their diet, and attending the clinic for review, and that men were more compliant with exercise, and noncompliant with everything else. In the clinic waiting area, it is clear that women are a vast majority of the attendees. Clinicians shared the impression that men cared more about working and making money than taking time to care for their diabetes, while women took their self-management seriously in order to stay alive to be there for their children. One clinician explained:

The males, they don't comply. The females mostly comply because females fear they will die and leave their children. It's not that the males don't fear but... it's like stubbornness or something; they can't comply as the female does. And even the reviews, it's the females who come more than the male as you can see, you've been here for a while, so you know what I'm talking about. [Clinician 6]

A woman patient corroborated this through her description of her motivation to comply, "I choose life so whatever I'm told to do, I do. I don't want to die and leave behind the kids"

(Patient 31). In general, doctors and nurses viewed women as taking their diabetes management more seriously than men.

Poverty was emphasized by many patients as a major burden to their livelihood and diabetes management. According to participants in interviews, there are several domains of diabetes management impacted by lack of finances. For instance, the National Health Insurance Scheme (NHIS) covers drug and doctor visit costs for a low yearly fee. However, patients and clinicians shared that drug coverages were frequently reduced and that there were several essential drugs that had no coverage at all. Due to tariffs and other political barriers, the out-of-pocket costs for these drugs were unattainable for most of the participants. Additionally, for the extremely poor, even the NHIS fee is out of reach, leaving them with no coverage. One patient explained, "I don't have any job... I am in poverty now. It has always been my prayer that they don't prescribe drugs for me to buy. If it happens, the sickness will kill me" (Patient 3). Another patient lamented, "When you don't have the money to buy [medications and foods], it becomes stress on your head and can knock you down to the point of death" (Patient 25). Financial barriers to diabetes management were of great concern to a majority of participants.

Another essential part of getting care for diabetes at the clinic is getting the FBS test to show the result to the doctor in order to examine the appropriateness of the dosage of drugs. A

patient illustrated that this cost can be prohibitive: “Yesterday for instance, I had no money to go to the lab. I had to beg the person there to take ten cedis because I had no money left. Fortunately, he took it and looked after me and I thanked him” (Patient 27). Without the money for an FBS test and transportation, patients cannot access care despite NHIS coverage of the visit cost.

Additionally, an important element of diabetes management is careful control over diet items, portions, and timing. Patients who worked long hours shared that they eat much later in the day and more infrequently than advised. Those without much access to cash must eat the most inexpensive foods that tend to be the highest in starches, which clinicians urge patients to reduce in quantity. A patient explains the financial challenges in following the diet directives:

African foods are mostly starchy foods. So in reducing [starch], what are you going to eat? But all is what, finance. All is resources. You wish to take good food, but no. Wherever you go, you take in starchy foods. The rice, the banku, the fufu; they are all starchy foods. We can't write it off from our diet. We reduce the quantity. If it's slices of yam, we eat few with plenty vegetables so that it will balance it, so that you will not get the sugary content. So that's how we reduce it. [Patient 36]

Others had to rely on the generosity of others to share meals with them in order to eat, rendering them powerless in determining foods or portion sizes. One patient describes, “Sometimes you don't have money, and someone offers you food with starch in it. You eat it since you are hungry and don't have money to buy your own” (Patient 46). Without access to cash, patients are not in full control of their self-management responsibilities.

Themes around age were less commonly brought up by patients and clinicians compared to topics around gender and poverty. Clinicians explained that older individuals tend to have higher FBS and therefore they follow less stringent targets of blood glucose control for



their older patients. Some elderly patients shared that they have less stress during this stage of life as they do not have to work and are often taken care of by their children who are working. This may reflect a Ghanaian cultural tendency to orient respectfully to elders and to care for and prioritize the wellbeing of their older family members. Older patients also shared that they experienced less of the gendered burdens, such as sexual dysfunction and the pressure that comes with it. In participant observation, Ghanaians shared that older adults typically adhere to a more traditional diet than younger people do, and often eschew “Western” foods that are high in fats, sodium, and sugar. Older Ghanaians also may have been more active for much of their lives than many younger people today who are skewing more toward sedentary jobs.

## Discussion

The findings of this study show that looking at diabetes health outcomes through different lenses alters the findings, and therefore understandings of the intersections of disadvantage and health in the context of Ghana. For instance, when looking at gender, poverty, and age in multiple regression analysis, poverty was associated with lower FBS, albeit still higher than target ranges. However, women tended to have higher FBS than men, regardless of poverty status, as depicted in the box plot in Figure 1. Likewise, when considering sex, poverty, and age in a multiple regression model adjusted for the baseline FBS from 2.5 years earlier in individuals’ self-management journey, male sex was significantly associated with lower FBS values than women, meaning men had better diabetes outcomes. When models included only sex and FBS baseline, sex was not significantly associated with lower FBS; only when viewing FBS through the lens of multiple disadvantage variables did the significance appear.

The patients who participated in this study and whose biological data were analyzed in the preceding section also shared their lived experience, which at times coincided and conflicted with the quantitative results. The first finding, that being male was a significantly associated with better FBS when adjusted for the baseline FBS, is consistent with the qualitative data from participant observation and interviews with patients, but somewhat contested by data from clinicians who viewed men as less adherent to diabetes management. Men having better diabetes outcomes was also largely consistent with the existing literature, where women experience the adverse consequences of poverty and poor health more than men do (Amin et al. 2014; Crenshaw 1991; Kavanagh et al. 2010; Robbins et al. 2005).

One pathway that often explains gender disparities in health is unequal gender roles (Akotia and Anum 2015; Hiscox and Goldstein 2014). Traditional gender roles in Ghana can compromise women's self-management abilities. Common recommendations for diabetes self-management clinicians gave to the patients often did not take into consideration the unequal responsibilities between men and women and the added stress that diabetes care puts on women, such as creating special or separate meals or taking time to exercise. Women are socialized to prioritize the needs of their husband, children, in-laws, and extended family over themselves (Weaver 2014). For instance, Ghanaian men and women explained in interviews and conversation that women are expected to cook meals for the family that are satisfying for the husband, in taste and quantity. The average Ghanaian dish takes hours to prepare, so if a woman is diabetic and is to eat a special diet, this may not be possible due to time or money restraints of cooking separate meals. Additionally, her time is often taken up by her various household responsibilities and looking after children, leaving her no free time to exercise. This

could result in higher FBS levels than desired due to not being able to consume a diabetic diet and exercise, which are important for managing FBS. Men often have an added benefit from their wives that women may not also get from their husbands, especially as these responsibilities traditionally fall under the woman's gender roles. This may contribute to men's lower FBS on average compared to women.

In many typical relationships in Ghana, men have more access to cash than women (Tolhurst and Nyongato 2006), which was supported by patient interviews. This can put women at risk of higher blood sugars as cash is an important resource for managing diabetes. Traditionally, Ghanaian men worked outside the home and women did unpaid labor inside the home. In recent decades, women increasingly work outside the home in addition to their household labor (Brown 1996). The husband is expected to give a small amount of cash to the wife and children for the day to be used on obtaining food ingredients or other supplies for the household. If the wife also works in addition to her household responsibilities, the cash she earns is usually spent on children and household needs. Women often do not have the same freedom as men in deciding where cash is spent (Brown 1996). Access to cash is essential for self-management; one often needs a substantial proportion of their income to pay for out-of-pocket costs for diabetes, such as medications, special foods, transportation, laboratory tests, glucose monitor test strips, and more (Pei 2015). If one's husband does not support the use of the household cash to going toward the wife's medical care, then often she must go without (Tolhurst and Nyongato 2006). In a system where women are highly dependent on men for access to cash, women are put at risk when their husbands do not provide, divorce them, or

pass away. This tendency may have contributed to the average FBS being worse off for women in this group.

Clinicians believed that women take their diabetes care responsibilities more seriously than men and were more adherent to most FBS-management tasks, excluding exercise. As described in Chapter Three, female gender expression is congruent with self-care and submitting to the direction of an authority figure, whereas men are socialized to be self-sufficient and tough (Courtenay 2000; Charmaz 1994). These insights shared by clinicians beg the question of why all of women's efforts were not resulting in lower FBS than men. As described in Chapter Two, people were largely on board with the idea of personal responsibility for health and embraced their diabetes self-management tasks, but structural inequalities impacted one's ability to self-manage. As described earlier in this chapter, women tend to experience greater effects of poverty on diabetes outcomes than do men (Amin et al. 2014; Kavanagh et al. 2010; Robbins et al. 2005). Unequal gender roles and barriers to health for women contribute to increased stress and distress, which contributes to high FBS and other poor diabetes outcomes (Mendenhall 2012; Rock 2003; Thapa 2012). Without taking a baseline FBS into account, or stratifying a box plot by gender and poverty, this finding is obscured. It is essential to consider all the disadvantaged categories that people belong to simultaneously.

The second finding, that poverty was significantly associated with lower FBS values, is contradictory to some aspects of the qualitative data and is corroborated by other aspects of the qualitative data. For instance, a majority of the patients described the intense financial pressure they experienced, both as individuals navigating the precarious Ghana economy, and even more so as individuals with additional financial burdens of managing diabetes. They

emphasized the extreme stress and worry they experience at not being able to afford their prescribed diabetes management drugs or insulin, laboratory testing fees, or transportation to see the doctor at the clinic. Similar to a study with Somalis in Ethiopia, due to poverty, some patients struggled to access medical care, refrigerate insulin, and follow dietary recommendations due to chronic food insecurity (Carruth et al. 2020). Often, they painted a picture that the worse off they are economically, the worse their blood sugar gets. Despite NHIS coverage, they struggled to access essential diabetes resources; a study found that income inequalities existed in access to diabetes care even in a country with universal health coverage (Hsu et al. 2012). Additionally, as the literature reviewed earlier in this chapter demonstrated, poverty is commonly associated with worse health outcomes (Chaufan et al. 2011; Connolly et al. 2000; Gaskin et al. 2013; Saydah and Lochner 2010). This brings up the question of why, on average, those participants who were living under the poverty line tended to have lower FBS. Although these challenges with finances have clear impacts on diabetes self-management, there may be other elements of these challenges that happen to result in lower FBS than those not in poverty. For instance, it is possible those living under the poverty line were simply consuming less food due to financial constraints, which led to better glucose control than those above the poverty line. Additionally, the extreme struggles with finances and maintaining one's livelihood and disease management may lead to stress, distress, and depression (Carruth and Mendenhall 2019; Mendenhall 2012; Rock 2003; Thapa 2012), which can also contribute to consuming less food. Of course, poverty-related malnutrition and distress resulting in less calorie consumption is not something to strive for in diabetes management, but rather might explain why elevated FBS was not as high as those above the poverty line. This points to the

limitations of considering only FBS in measuring diabetes management success; individuals may have lower FBS but be unhealthy overall.

Another possible explanation lies in the lifestyles of those living in poverty, namely, more active employment activities and less eating out of the home. Employment activities that lower income individuals tend to partake in, such as farming and hawking goods, consist of more bodily movement and are more physically demanding than sedentary jobs that higher income individuals may have, such as banking or other desk jobs. They may also walk longer distances to save money on bus and taxi fares. This would contribute to better blood glucose management. Additionally, observations of conversations in the clinic and in Ghana in general indicate that those with less income tend to eat at home and eat more traditional foods, such as fruits, plantain, green leafy vegetables, fish, fermented maize products and palm oil, than those with more expendable income, who often eat outside of the home and consume high-fat, calorie dense foods that are sold on the street and in restaurants such as fried rice, pastries, and sugary beverages (Frank et al. 2014). Those working in the low wage informal sector may have more flexibility in their working hours to attend the clinic regularly compared to those who work during business hours and cannot take time away from their workplace. More frequent attendance may lead to better care, increased patient education, and enhanced solidarity with other patients.

On the other hand, this sample of patients who were at the diabetes clinic might have excluded those diabetics who were even poorer and could not afford to attend the clinic in the first place. Those who were too poor to attend likely could not afford to pay for NHIS (which would cover their office visit fee), their transportation costs to attend, or the required FBS test.

This sample of patients living in poverty include only those who had the means to make it to the clinic. Therefore, they had some baseline amount of resources to be able to attend. This even poorer group may have had different trends in FBS values.

Other potential protective factors for those in poverty include qualitative data that often very poor patients and older patients with no income were being supported financially by their working children. Several patients described their children or extended family providing them with money for their drugs and transportation and expressed that they never worry about their diabetes self-management costs. The patients with little to no income may not have counted these contributions in their monthly income estimates. These supports may contribute to increased self-management participation and therefore lower FBS values on average.

The last finding was that age was not significantly associated with higher FBS, contrary to what has been reported in many other populations (Chia Chee et al. 2018; Ko et al. 2006; Maneatis et al. 1982). This also contradicts the experience and opinions of the clinicians in this study, who believed that older individuals had higher FBS. Some possible explanations for this contradiction include that older Ghanaians typically adhere to a more traditional diet rather than high-fat Western foods, which may lead to lower FBS. The consumption of traditional foods may not necessarily prevent diabetes; a study found that traditional diets were associated with increased odds for developing diabetes (Frank et al. 2014). Older patients have also been more active throughout their lives compared to younger Ghanaians who may be increasingly sedentary (Abubakari and Bhopal 2008; Muthuri et al. 2014). Because elderly patients shared that they have less stress during this stage of life, this may contribute to lower blood pressure and diabetes complications, as described above.

The results highlight the importance of considering multiple layers of disadvantage in understanding health outcomes and diabetes self-management, as analyzing more than one variable simultaneously revealed different outcomes than looking at only one. When analyzing only sex, sex was not significantly associated with better FBS outcomes, but when analyzing poverty, age, and baseline FBS, the significant association of male sex and better outcomes appeared. Additionally, poverty was associated with better FBS outcomes, but when considering their FBS management over time, this poverty effect was diluted and was no longer significant. This is congruent with the theory of intersectionality, which claims that when you look at only one disadvantaged identity, the additional inequalities experienced by those who inhabit more than one disadvantaged identity are obscured. However, the findings in this study did not support intersectionality theory, which argues that the consequences of experiencing multiple disadvantages would compound the negative effects. As shown in Tables 9 and 10, the interaction terms were not statistically significant, meaning there was not enough evidence to support that there was a compounding effect.

This study also illuminates the importance of utilizing both qualitative and quantitative data when coming to understandings about diabetes, inequality, and health outcomes. Though the quantitative analysis pointed to those in poverty having better outcomes, the qualitative data often contradicted this. Those in poverty might have somewhat better FBS control, but this may not necessarily mean they are healthier in terms of stress, mental health, cardiovascular health, nutrition, and other areas. The local biology (Lock and Kaufert 2001), or the unique bodily and social experience of diabetes in Ghana, is shaped through “dialectical interactions among social inequalities, livelihoods, food security, nutrition, and illness”



(Leatherman and Goodman 2011). The results from this study contribute to the literature on intersectionality, gender and chronic illness, and diabetes, gender, and poverty in Ghana, by providing a biocultural analysis, intertwining the knowledge of people who grapple with diabetes every day and the differences in diabetes self-management outcomes that are revealed in biomarkers.

### *Limitations*

There are some limitations of this study. The poverty variable was calculated based on self-report income estimates, which may have been under- or over-reported, and may have impacted the results showing that lower income individuals have lower blood sugar, when in fact some of these individuals may have had access to cash or resources beyond their technical income level. These additional resources may have contributed to lower FBS levels. Future studies can collect additional variables to compute a composite socioeconomic status score, including income, monetary support from other sources, expenses, dependents, education level, and marital status. Additionally, as mentioned above, the poorest patients who could not afford NHIS, drugs, or laboratory tests would likely not attend the clinic and thus are not included in the sample, which may compromise the generalizability of the observed association between poverty and FBS outcomes. Future studies may seek to include diabetic patients who are not engaged in specialist diabetes clinical care.

Another limitation is the use of FBS as a diabetes outcome variable. FBS values can vary widely within an individual from day to day due to a range of external factors, therefore requiring the use of two readings to confirm diabetes diagnosis. Two FBS readings are considered accurate in diagnosis, but HbA1c is generally recommended over FBS for monitoring

blood glucose control in individuals who are already diagnosed with diabetes (Ghazanfari et al. 2010). HbA1c provides a clearer picture of blood glucose over the preceding three months and is not as sensitive to the environmental factors that can cause a temporary spike in FBS. In high-income countries, HbA1c is typically used for self-management monitoring, but in Ghana, the cost of this test is high and prohibitive for most patients. For this reason, at the time of this study, the diabetes clinic utilized only FBS tests. Future studies can utilize HbA1c values in evaluating the relationships between groups. Lastly, due to small sample size, the regression analyses had low statistical power and results cannot be used to generalize about diabetics in Ghana.

## Conclusions

This study sought to understand the impact of multiple identities of disadvantage, including poverty, female sex, and older age, on diabetes management and health outcomes. When looking at multiple identities in this group of patients, poverty was associated with better FBS levels, but analyzing only poverty would have concealed the pattern that women had higher FBS than men regardless of income group. Qualitative results demonstrate that women had additional and unique financial and role-based challenges that impacted their ability to manage diabetes. The results paint a picture of how certain disadvantaged identities experience challenges in diabetes management for this group of patients in Ghana and the importance of examining disadvantage through multiple lenses. The findings contribute to understandings of intersectionality, the anthropology of gender and chronic illness, and clinical diabetes care in West Africa, by examining both qualitative and quantitative data in uncovering how social structures and patterns impact bodily health and diabetes health outcomes.

Diabetes continues to grow as a major global health concern. Further studies can investigate what exactly about being in poverty and being male in Ghana may support better FBS maintenance and use the findings to support people with diabetes in self-management success, keeping in mind the stories that participants shared that highlighted the additional burdens that women and those in poverty must navigate to take on their diabetes management responsibilities.

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## Chapter 5: Conclusion

This dissertation interrogates the lived experience of diabetes in a context of a highly gendered society that is also grappling with income insecurity. The setting of Kumasi, Ghana, provides insights on how sociocultural systems of disadvantage impact health; namely, that systems generate and reproduce inequalities that impact individuals' susceptibility to and outcomes of diabetes. For instance, when controlling for poverty, age, and a baseline FBS measure, female gender was associated with higher FBS than male gender, despite their active participation in diabetes management. This research also highlights how women and men with diabetes exercise agency to accept, challenge, or negotiate these structural barriers to health. For example, patients struggled to fulfill the shared ideal of personal responsibility for health due to inability to access cash for health expenditures such as medications, insulin, transportation to the doctor, FBS testing, and diabetic-friendly foods. Consequently, many patients and clinicians looked to the government to supply the basic necessities in order to self-manage diabetes. Some were involved in petitions, rallies, and media outreach to demand further NHIS coverage of drugs and decreased tariffs on imported medications, increased public prevention messaging, and regulation of pesticide use on food crops. Other examples of agency include women indirectly explaining the negative impact of sexual dysfunction on their relationships and sense of self despite the strong cultural discouragement to discuss sexual matters in public. Qualitative interviews with women revealed their tenacity to overcome the limitations placed on them by societal expectations of men to control the household cash and to find ways to support themselves and their families financially, including funding their diabetes care.

The approach, design, and interpretation of this study utilized chronicity theory, which considers these disadvantages, gender inequality and poverty, as chronic conditions that have their own health consequences and intertwine with diabetes, leading to a more stressful management experience and worse health outcomes (Manderson and Smith-Morris 2010). It considered the interaction of social, psychological, and physical aspects of diabetes (Weaver and Mendenhall 2014), while highlighting how chronic conditions cause changes in identity for patients (Estroff 1993). By looking at diabetes from two vantage points, the individual and the macrosocial, the results point to the connection between structural conditions and physical embodiment of disadvantage (Weaver and Mendenhall 2014). Patients shared both their subjective experience and their health data, which allowed for analysis of how these chronic conditions are both social and biological (Manderson and Smith-Morris 2010). Their stories revealed the ways in which global assemblages impact their ability to manage their illness amidst insecure incomes, rising costs of drugs, food, and transportation, and gender hierarchies that favor men.

In resource poor contexts, the experience of poverty, diabetes, and other comorbidities can trigger a “recursive cascade” of increasing ill health and economic struggle (Manderson and Warren 2016). In Chapters Two and Three, patients illustrated the extreme distress they experienced at not being able to afford their diabetes care and daily subsistence, as well as the pressure lack of finances, energy, and sexual function and how that impacted their gender expression and self-perceived value as a woman or man. Often, being poor led to decreased ability to care for diabetes, and diabetes led to increased poverty. Failing in gendered expectations for work and sexuality impacted marriages and therefore financial security,

especially for women. Furthermore, women were less likely to have their sexual dysfunction treated due to social and cultural attitudes toward women and sexuality. In Chapter Four, women shared about the difficulties stemming from a system where men are largely in control of women's access to cash. In both Chapters Two and Four, women were shown to more diligently take on their personal responsibility for self-management, yet women still tended to have higher FBS than men, signaling that structural inequalities might have more of an impact than personal behaviors. Using an intersectional approach to consider all of the chronic conditions simultaneously experienced by these patients, including poverty, gender, and diabetes, reveals the importance of examining the health consequences of multiple layers of disadvantage; some trends were obscured when just looking at one area. Additionally, listening to people living with diabetes is key to determining the health consequences that might not be revealed in FBS values.

This study has implications for clinical practice, health care policy, and global health. As a widespread global health concern, enhancing conditions for clinicians and patients and their families to treat diabetes is essential. The patients at the diabetes clinic shed light upon what is needed to care for diabetes: access to drugs, insulin, testing, balanced foods, spaces to exercise, and transportation. While these resources are costly for public resources and health systems, they will help to reduce costs overall, including costs of complications, inpatient care, and lost productivity (American Diabetes Association 2018). This is especially pertinent today with infectious diseases like COVID-19 and people with diabetes being at higher risk for hospitalization and death (Muniyappa and Gubbi 2020); ensuring people can maintain their health with diabetes is crucial for surviving such pandemics. Previous research shows that

individuals have much less control over their health outcomes than generally thought, and that creating policy and structures that establish “healthier defaults” encourage positive behavior without relying on self-control (Brownell et al. 2010). Health research and policy should elicit lived experiences and target areas that patients themselves find important, drug costs, help with sexual dysfunction, and special supports for women, in order to find a synthesis between personal responsibility and social responsibility. One such healthier default in the diabetes clinic would be to establish universal, confidential screening of sexual dysfunction for both men and women in order to bypass the strong social discouragement to discuss these issues in public and reduce the amount of emotional and relational suffering that may exacerbate diabetes. Health practitioners should likewise acknowledge the psychological and emotional elements of diabetes that are often overlooked, build respectful and trusting relationships with patients, and offer support and resources for coping, all of which will lead to better self-care and diabetes outcomes (Mendenhall et al. 2019). Diabetes care strategies that take into consideration the stressors and desires of these patients will generate successful diabetes management and overall health.

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