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Emily Applewhite
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Barriers to Prevention and Treatment of Type 2 Diabetes Mellitus: A Qualitative Analysis of
Women in East Sikkim, India

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India: Public Health, Policy Advocacy and Community
Spring 2015

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Abbreviations:

ANC: Antenatal Care

CATCH Sikkim: Chief Minister's Comprehensive Annual and Total Checkup for Health
Sikkim

DM: Diabetes Mellitus

GDM: Gestational Diabetes Mellitus

NCD: Non-communicable diseases

NPCDCS: The National Programme for Cancer, Diabetes, Cardiovascular Disease and Stroke

T2DM: Type 2 Diabetes Mellitus

VHAS: The Volunteer Health Association of Sikkim

WHO: World Health Organization

Abstract:

Diabetes Mellitus is a metabolic disorder that affects more people in India than anywhere else in the world (Ramachandran et. al., 2010). A recent national study concluded that Sikkim, a small northeastern state in the Himalayas, has the highest prevalence of Diabetes Mellitus compared to any other state in India. In order to determine why this is so, this study looks at the barriers women face when attempting to prevent and treat Type 2 Diabetes Mellitus (T2DM) in East Sikkim. Fieldwork for this study was facilitated by The Volunteer Health Association of Sikkim, and took place in Gangtok and a small village near Sikkim's border. Qualitative data for this study was collected through semi-structured interviews and focus group discussions with state health officials, private practicing doctors, and both rural and urban women living with T2DM. It was found that housewives faced barriers not experienced by men, however no other gender-specific barriers were identified. Lack of knowledge surrounding the prevalence of T2DM, lack of knowledge about the causes of the disease, limited doctor-patient interactions, limited access to health services for rural populations, and the inability to seek treatment as a result of socioeconomic standing were all identified as non gender-specific barriers.

Introduction:

What is Diabetes Mellitus?

Diabetes Mellitus (DM) is steadily increasing in prevalence worldwide. Once considered a disease of the West, affluent, and elderly, this metabolic disorder now impacts people in all countries, and across all socioeconomic status and age demographics. The current global prevalence of DM among adults over the age of 18 is 9% (Alwan, 2011). While many diabetic patients are able to control the disease and live healthy and socially integrated lives, The World Health Organization (WHO) projects that DM will be the 7th leading cause of death worldwide by 2030 (Mathers & Loncar, 2006). In many developing countries, rapid urbanization and economic development has lead to the adoption of a “Western” lifestyle, which in turn has lead to an increased consumption of sugar dense foods and limited physical activity. (Mehta, Kashyap, Das, 2009). The lack of knowledge surrounding DM contributes to the high morbidity and mortality rates of the disease, and the International Diabetes Foundation estimates that over 43% of all DM cases go undiagnosed (International Diabetes Foundation, 2014).

When a person has DM, their body is unable to control blood-sugar levels with the hormone insulin. After food enters the stomach, carbohydrates are broken down into glucose, a form of sugar that provides energy to each cell in the body. Glucose first enters the blood stream, which triggers the release of insulin. Insulin then allows glucose to leave the blood stream and enter the cells of the body, which lowers blood-glucose levels (National Institute of Diabetics and Digestive and Kidney Diseases, 2014). If a person has DM, insulin fails to assist glucose in entering the cells of the body and blood-glucose levels remain high, a phenomenon known as hyperglycemia. Continual hyperglycemia can lead to major health complications such as heart disease, stroke, kidney disease, and blindness (Agency for Healthcare Research and Quality,

2012). Therefore, it is important that DM patients stabilize blood sugar levels before these complications can occur.

This paper focuses on Type 2 Diabetes Mellitus (T2DM), as it makes up 90% of all DM cases (Agency for Healthcare Research and Quality, 2012). When a person has T2DM, their body produces insulin, but the hormone is unable to assist glucose in entering the cells, a phenomenon known as insulin resistance. While some people are at a higher risk for T2DM due to their genetic predisposition, it is believed that a diet high in fat and sugar, a low level of physical activity, and high alcohol and tobacco consumption also increases a person's susceptibility to the disease (National Institute of Diabetics and Digestive and Kidney Diseases, 2012). The ways in which a person prevents and treats the disease are very similar, as treating the disease also includes a change in diet and an increase in exercise. In addition, treatment requires daily medications (allopathic or ayurvedic), and more advanced cases require insulin injections. While the focus of this paper T2DM, the phrase "diabetes" will be used throughout this paper, as it is the colloquial term used for T2DM throughout the field study location.

Women have an additional risk factor for T2DM: Gestational Diabetes Mellitus (GDM). GDM is a form of DM that occurs during pregnancy, and the cause is still unknown. Studies have shown that mothers with GDM are seven times more likely to get T2DM compared to those who have not had GDM (Kayal, Anjana, Mohan, 2013). Additionally, the likelihood that the child will develop T2DM also increases. Lifestyle is not directly attributed to be a cause of GDM, and this form of DM is believed to be unpreventable.

Diabetes Mellitus in India:

India is known as "The Diabetes Capital of the World," as more people with DM live in India than anywhere else in the world (Ramachandran et. al., 2010). In 2000, an estimated 63

million people had the disease and the number is projected to reach 79 million by 2030 (Wild et. al., 2004). Along with the worldwide trends of urbanization and the adoption of a Western lifestyle, it is believed that one of the reason behind the high prevalence of DM India is a population-wide genetic predisposition to the disease. Many studies have shown that Asian Indians have a larger genetic susceptibility to developing the disease compared to other ethnic groups due a phenomenon known as the “Asian Indian Phenotype” (Mohan et. al., 2007). Lack of knowledge also contributes to a high prevalence in India, and the estimated number of people with DM who remain undiagnosed ranges from 30-80% (Narayan, Chan, & Mohan, 2011).

Throughout India, women are at a social disadvantage when attempting to prevent and treat the disease due to gender discrimination and differing social roles between men and women. In many parts of the country, women hold a lower social status, which impacts their ability to receive health care (Bajaj et. al, 2013). Because men are typically the head of the family, women must seek approval from their fathers or husbands before they are able to visit a doctor. Many women work as a housewife, which means that many women are unable to pay for treatment without their husbands support. Women are often expected to prioritize the health of their husband and children over their own health, and therefore do not take the necessary steps to prevent the disease. (Harikrishnan, 2013). It should be noted that the highest frequency of GDM cases is among South Asian Women. While the cause of this high frequency is unknown, it means that Indian women are at an increased risk for T2DM (Bajaj et. al., 2013).

To combat the rise of DM and other non-communicable diseases (NCD), the Government of India’s Department of Health and Family Welfare implemented The National Programme for Cancer, Diabetes, Cardiovascular Disease and Stroke (NPCDCS) in 2010. This program now covers 21 of 29 states, and focuses on the health promotion, early detection and management of

NCDs (Kumar & Kaushik, 2013). The 2012 NPCDCS Survey Report revealed that India's northeastern state of Sikkim has the highest prevalence of DM in the country, as over 14% of all patients screened were found to have the disease (Health Department, Govt. of Sikkim, 2012). This perplexes many health officials as the state has some of the most progressive preventative health programs in the country, and the population is traditionally known for having an active lifestyle in the Himalayan Mountains.

Project Goals:

In an attempt to understand why Sikkim has the highest prevalence of DM in India, this study aimed to answer the following question: What barriers do women in East Sikkim face when attempting to prevent and treat Type 2 Diabetes Mellitus? The goal of this study was to understand gender specific and community-wide barriers that lead to a high prevalence in the state. Additionally, this study examined the main causes of T2DM in Sikkim and examined current state government programs related to T2DM.

Field Study Location:

Sikkim is a northeastern state in India's Himalayan region that exists between three international borders: Nepal to the east, Tibet autonomous region to the north, and Bhutan to the west. Geographically, it is India's second smallest state and comprises of four districts, including the North, East, South, and West. The population is around 600,000 people, making it least populous state in India (Census of India, 2011). Among this small population is a vast amount of ethnic, cultural, and religious diversity, as the state is primarily inhabited with people of Lepchas, Bhutais, Tibetan and Nepalese background. This diversity is also seen in the number of languages spoken, despite the small population. These include Nepali, English, Bhutia, Lepcha,

Limbu, Newari, Kulung, Gurung, Magar, Sherpa, Tamang and Sunwar (Census of India, 2011). Sikkim is known for positive health indicators compared to the rest of the country, as the full immunization rate, the literacy rate, and the number of children attending school are all higher than national averages, and the infant and maternal mortality rates are lower than the national averages (Rural Health Statistics, 2012).

Traditionally, women have held a different role in Sikkimese society compared to other Indian states, and are considered some of the most empowered women in the country.¹ Women have participated equally, if not greater than men in agricultural and household activities, and certain societal oppressions such as dowries, sati and female infanticide are rarely seen in the state (Subba, 2014). There are many indicators that point to the empowerment of women within the state; the 76.4% literacy rate, the fact that more women than men are enrolled in higher education and high female turnout rates during recent elections (Census of India, 2011). Despite these indicators, gender inequity still exists in a variety of forms such as domestic violence, child marriage and property inheritance (Subba, 2014). By understanding the specific barriers that women face when attempting to prevent and treat T2DM, this study also tried to examine gender roles within Sikkim to see if these impact a women's ability to prevent and treat T2DM.

Fieldwork for this study occurred in Gangtok and Garamani, which are both located in East Sikkim. Interviews with private doctors, public health officials and urban women with diabetes took place in Gangtok, Sikkim's capital city. This is the largest city in the state, at a population of around 100,000 (Census of India, 2011). One focus group discussion with rural women with diabetes took place in Garamani, a village 65km south of Gangtok and 20km from

¹ For the purpose of this paper, empowerment has the following definition: to feel strength and confidence through realizing individual potential and capabilities (Ghatak; 2004).

the nearest town of Rangpo. The population of this village is recorded at 408 with 82 total households (VHAS, 2015).

Brief Statement of Findings:

The findings of this study indicate that housewives experience barriers in treating T2DM that are not experienced by men. Women are also impacted by non gender specific barriers that include: lack of knowledge surrounding the prevalence of the disease in Sikkim, lack of knowledge surrounding the causes of the disease, limited doctor-patient interactions, access to health services, and socioeconomic status. All information concluded here only applies to specific areas in East Sikkim.

Methods:

In an attempt to answer the above research question, qualitative data was collected through interviews and focus group discussions with doctors, urban women living stably with T2DM, rural women living stably with T2DM, and state public health officials. Interviews took place under the guidance of The Volunteer Health Association of Sikkim (VHAS), an NGO that works to promote health in Sikkim through a variety of programs, particularly in rural areas.

Two semi-structured interviews were conducted with state public health officials. Both of these government employees were also non-practicing doctors and interviews took place in English. An additional seven interviews were conducted with private practicing doctors throughout Gangtok. Due to government regulations, doctors working at government hospitals could not be interviewed. All interviews with doctors took place in the private clinic or hospital where they worked.

All women with T2DM that were interviewed fit specific criteria given to the fieldworker by the SIT LRB Review Board to ensure that they did not undergo emotional or physical stress as a result of the interview process. At the beginning of each interview, all women stated that they were stably living with the disease, meaning that they were not currently facing major health complications or side effects as a result of T2DM. Five interviews were conducted with diabetic women in Gangtok. The women's age ranged from 44 – 67 years old, and they had differing socioeconomic standings, and occupations. Four of these women resided in Gangtok, while one lived slightly outside the city in a more rural area. Women were identified through doctors at Manipal Hospital and through local fieldworker connections. Semi-structured interviews were conducted in Nepali, with a translator. Interviews took place at Manipal Hospital or interviewees homes. One focus group discussion took place in Garamani with four women who had been identified to be living with T2DM by a VHAS fieldworker. This semi-structured focus group took place in the village community center, where the VHAS fieldworker served as a translator. Women participant ages ranged from 44-64, and all worked as housewives. Three of the four women were considered illiterate.

All interviews and focus group discussions occurred during April 18th- May 3rd, 2015. All interviews were approximately 20 minutes and were recorded on a tape recorder. Before each interview, interviewees gave their verbal consent to go through the interview process, and were informed that their answers would remain confidential. To maintain confidentiality, the names of the interviewees, as well as the name of the village where the rural focus group took place have been changed throughout this paper. A list of sample interview questions can be found in the appendix.

Current Health Programs Targeting T2DM in Sikkim:

Sikkim has a variety of programs to help citizens prevent and treat non-communicable and other chronic diseases throughout the state, however none of these programs target T2DM specifically. As previously mentioned, The NPCDCS program operates in Sikkim as a way to monitor, prevent, and treat NCDs in the state. The pilot program began in 2009 in East Sikkim, and expanded to include all of the state in 2011 (Govt. of Sikkim, 2012). The specific goals of this program are to prevent and control NCDs by promoting behavioral change, providing early diagnosis of NCDs, and building the capacity of health care centers at all levels to prevent, diagnose and treat NCDs. Since the beginning of this program, two NCD wards have been created at district hospitals in the East and South districts. Additionally this program implemented NCD health camps in rural and urban areas as well as free door-to-door and school check ups (Govt. of Sikkim, 2012).

Sikkim also participates in a national program that aims to detect GDM in pregnant women. The Antenatal Care (ANC) Checkup Programme was created under the National Rural Health Mission's Reproductive and Child Health (RHC) Programme, and aims to decrease maternal mortality rates throughout India (Maternal Health Division, Govt. of India, 2010). Under this program all pregnant women are to receive three ANC checkups that aim to catch and manage any complications that may arise during pregnancy at early stages. These check ups include regular blood tests that test for GDM. Sikkim has been particularly successful in implementing this program as the percentage of women who have received all three ANC checkups has increased from 47% in 2007 to almost 70% in 2012 (Ministry of Health and Welfare, Govt. of India, 2013). An even higher percentage of pregnant women received at least one ANC checkup, and 80% of women in the state received blood testing during pregnancy

(Ministry of Health and Welfare, Govt. of India, 2013). This is the only program that the state participates in that targets DM in women specifically.

In addition to the national NPCDCS screening camps, the state government also implemented the Chief Minister's Comprehensive Annual and Total Checkup for Health Sikkim (CATCH Sikkim) Programme, which guarantees all citizens a full head-to-toe checkup once a year. The goal of this program is to promote community health through preventative care, as well as gain a comprehensive understanding of the state's health status (Health Department, Govt. of Sikkim, 2012). CATCH Sikkim camps occur in remote areas of Sikkim, to ensure that even those citizens residing in villages have access to this program. Health specialists as well as local village doctors serve as staff for these camps, and they provide villages with screening for major health complications (including blood sugar tests for T2DM), referrals to local clinics or hospitals, laboratory investigations of health problems, group and individual counseling, and health education (Health Department, Govt. of Sikkim, 2012). All participants of the CATCH Sikkim program have their health records saved electronically, with the intent that individual and familial health status can be tracked. Through this data, community and statewide health problems can be recognized and then treated through the implementation of additional programs (Health Department, Govt. of Sikkim, 2012).

According to Dr. Navin, a government employee who works closely with the states non-communicable disease programs, the first round of check-ups through the CATCH Sikkim program are finally complete (Personal Interview, 2015). There have been problems trying to implement the program on a yearly basis, but everyone in the state has had at least one recorded check up. It is important to note that Dr. Navin mentioned the limitations of the data collected through these programs. Each CATCH Sikkim and NPCDCS health camps have slightly

different methods for their health screenings, and he stated that in order to verify this data, a statewide survey that checks every person with diabetes using similar methodology would need to be completed. However, despite these limitations, the data from this program is still used to inform Sikkim's government of health trends.

While the CATCH Sikkim program works to “catch” major health complications in their early stages, other preventative programs also exist in the state. Dr. Navin explained that both the Information Education Communication and Behavior Change Communication divisions have radio and local cable network talk shows that discuss NCD prevention and symptoms, and that these shows include information about diabetes (Personal Interview, 2015). The two divisions also work with Primary Health Centers to ensure that education also takes place at the village level. Additionally, the state participates in Village Health Nutrition Days (VHND), a national program that is part of The National Rural Health Mission. This program spreads publicity about the risk factors of certain diseases and other health problems to villages (Ministry of Health and Family Welfare, Govt. of India, 2013).

After a person has been diagnosed, there are a few economic programs that assist individuals in paying for their treatments, however like the other national and state programming, none are specific to T2DM. Government hospitals and clinics provide a free, one time 30-day supply of all medications to patients with chronic ailments when medications are prescribed from a government hospital. However, most diabetic treatments require daily medication throughout life. Patients who are 65 and older, or registered as Below Poverty Line (BPL), receive free medical testing from government hospitals (Health Department, Govt. of Sikkim, 2010). In the event that a major complication arises due to T2DM where specialty services are required, the government provides free health services, medicines, and treatment for

BPL families. The government also provides up to 200,000 INR for non-BPL citizens for treatments outside of the state (Chamling, 2013). The State reimburses all government employee medical expenses, including medications, however all other citizens must pay for their medications directly (Chamling, 2013).

In this study it was found that the above government programs meet some of the needs of diabetic women patients, but not all. A greater analysis of these programs occurs throughout the course of this paper.

Perceived Causes:

India is a large and diverse nation, with a vast number of ethnic groups, cultures, religions, socioeconomic statuses, and languages. While there may be national trends regarding diet and exercise habits, it is important to understand how each risk factor fits into the cultural, political, geographical, and socioeconomic context of a given region. Perceptions surrounding the causes of T2DM varied throughout East Sikkim. Doctors were able to point to causes of the disease, but all of the women with the T2DM were not (a point that will be discussed in greater detail later). Doctors stated that genetic predisposition to the disease, poor food habits, lack of exercise, alcoholism and tobacco, and high stresses were the main risk factors for T2DM. While there was an inconsistency between doctors as to which risk factor was the greatest, all emphasized genetics, diet and level of exercise as the main causes.

Doctors and government officials were unaware that Sikkim has a particularly high prevalence of T2DM when compared with other states, and so few were able to provide risk factors that are specific to Sikkim. However, those that were able identified the following Sikkim specific risk factors: access to cheap and efficient transportation, non-vegetarian diets including a large quantity of rice, and easy access to alcohol.

Despite the reputation that Sikkim is an active population due to their location in the Himalayas, doctors believed most people in Sikkim do not have a habit of participating in physical activities in urban areas. Gangtok is built into a hillside, and to get from one place to another by foot requires walking up or down steep inclines. Despite the metal gate protected sidewalks that line most roads and the many stairways that serve as shortcuts from one area to the next, most doctors believed the citizens of Gangtok do not take advantage of this mountainous terrain. Instead they participate in the city's shared taxi program where an individual rider can get almost anywhere in the city for the sum of 10-30 rupees. Additionally, many urban citizens work office jobs that promote a sedentary lifestyle. A lack of physical activity only applied to the urban population however, and doctors felt that rural populations lead particularly active lifestyles.

The traditional Sikkimese diet of rice and meat, combined with a newly introduced diet of cheap, processed, and sugar dense food are also specific reasons why there is a high prevalence of diabetes in the state. Dr. Sheel, (female) stated that it is common for the people of Sikkim to eat rice for every meal, and that these portions are large and typically cover the entire plate (Personal Interview, 2015). Doctors also explained that the most of the population maintains a "non-veg" (non vegetarian) diet, which is often high in fat and implies a lower vegetable intake compared to "veg" diets. Such a diet differs from the rest of India, as Dr. Akosh estimated that 90% of Sikkim is non-veg, which is a much larger percentage when compared to the rest of the nation (Personal Interview, 2015). These cultural food habits combined with the countrywide trend of consuming processed and sugar dense foods, has a large impact on the prevalence of T2DM in Sikkim.

Many doctors also attribute high levels of alcohol consumption to the rise of the disease. Alcohol in Sikkim is not taxed, and therefore is very cheap. Stores that sell alcohol are present on almost every street. It is estimated that 35% of the population over 21 is considered to be a chronic alcoholic in Sikkim, a much higher average than other parts of India (Das, Balakrishnan, & Vasudevan, 2006) Additionally, the percentage of women alcoholics is also higher than other parts of India, as it is culturally acceptable for women to consume alcohol in Sikkim (Dr. Sheel, Personal Interview, 2015). Understanding specific reasons why prevalence of T2DM is high in Sikkim, along with understanding national risk factors will continue to be important when attempting to implement statewide solutions for preventing and treating the disease.

Diabetes and Gender:

In order to determine if women in Sikkim face gender-specific barriers in attempting to prevent and treat T2DM, interview questions targeted barriers identified in Bajaj et. Al's article, "South Asian Women with Diabetes: Psychosocial challenges and management" (2013). These barriers include: gender discrimination in health care delivery, lack of family and community support, inability to make health decisions, difficulty accessing health care, and financial dependence. Towards the end of each interview, interviewees were asked explicitly if they believe women experience gender-specific barriers in preventing and treating T2DM.

When examining social barriers, women indicated that they had social and financial support from their families or communities. While doctors mentioned that women generally discuss their health with their husbands and that his social support is necessary for receiving care, they did not believe that husbands were likely to withhold support. All women who were interviewed stated that their entire family supported their treatment and healthcare. While many of the women were financially dependent on their husbands, this did not prevent them from

accessing health care. Additionally, women felt that they could speak openly about their condition with their community, and doctors didn't believe that there was social stigma or discrimination surrounding this disease. Rural women even indicated that they form community discussion meetings in order to talk their experiences living with diabetes with others who also have the disease (Focus Group Discussion, 2015).

The role of housewife, held only by women in Sikkimese society, was found to directly impact women's ability to prevent and treat the diabetes. Doctors stated that many women live a more sedentary lifestyle in this role, which is why they may be more prone to the disease. While rural women who work as housewives could not directly comment on their ability to prevent the disease, as they did not know the cause of the disease themselves, they did indicate that this role can make it difficult to treat the disease (Focus Group Discussion, 2015). These women explained it takes a full day to see the doctor, and so they must plan ahead to be able to leave their family and housework. Therefore, if a complication arises unexpectedly, women explained that they unable to see a doctor immediately because they are unable to neglect their housework. Women also stated that men in their village do not face this same problem. Doma, an urban woman who also worked as a housewife, did not indicate that it was difficult to received treatment when needed (Personal Interview, 2015). However, she was of a higher socioeconomic status than the rural women and lived in close proximity to her doctor and had maids.

When gender-specific barriers were explicitly asked about, all interviewees were quick to preface their answers by saying that gender inequality does not exist in Sikkim. Women responded by saying that they did not believe that they were at a particular disadvantage when attempting to treat the disease when compared to men, and doctors also did not believe that women are at a particular disadvantage. Because of this, doctors do not treat diabetes in women

any differently than in men. Doctors had varying opinions about the difference in prevalence of T2DM between men and women. While some believed that prevalence was equal between men and women, others indicated that men were more prone to the disease. Both ayurvedic doctors, explained that most men are the working members of the family and therefore exercise less because they hold desk jobs, and experience more stress and tension as they must provide for their family (Dr. Pawan 1 and Dr. Ranajit 2, Personal Interviews, 2015). In this way, there may be gender-specific barriers for men, however these barriers were not the focus of this study.

From these findings it can be concluded that few gender-specific barriers exist for women in attempting to prevent and treat diabetes. Women do not have an inherently lower social status than men in Sikkim, and therefore do not face discrimination when attempting to treat or prevent the disease. The role of housewife can prevent women from seeking treatment when they need it, particularly in situations of low economic status and limited access to health care. Other barriers were discovered throughout this study, however these barriers have been determined to be community-wide barriers that either directly or indirectly impact a woman's ability to prevent or treat T2DM.

Community-Wide Barriers:

The data for this study was collected through interviews with diabetic patients that were women, however the following barriers are considered to be "community-wide" barriers, as they did not seem to be the result of gender. However, data from interviews with diabetic men would be needed to confirm that these barriers do not only apply to women.

Perceived Prevalence:

All stakeholders were aware that there is a high prevalence of DM in the community, however the extent of this prevalence varied and did not match the current recorded NPCDCS prevalence. Dr. Navin, the non-practicing doctor who works closely with the state's non-communicable disease programs, believed that Sikkim's prevalence of DM was no different than that of the rest of India and estimated that around 3% of the state population had the disease (Personal Interview, 2015). Doctors were aware that there was a high prevalence of T2DM within Gangtok and Sikkim, however when asked about the relative prevalence, most doctors were unaware that Sikkim has a particularly high prevalence of T2DM when compared to other states in India. Most estimated that out of the 40-50 patients they see a day, around 5-6 have T2DM. This however only reveals the number of patients they see with diabetes, and does not reflect population-wide trends.

Perspectives surrounding the prevalence of T2DM in rural populations differed between doctors and public health officials and the women living in Garamani. Most doctors and both government health officials interviewed believed that T2DM impacts urban populations and the prevalence is low in rural areas of Sikkim. Conversely, rural women believed that nearly half (50%) of their community had T2DM (Focus Group Discussion, 2015). National estimates on the prevalence of diabetes between rural and urban populations vary between 10-16% of urban populations and 5-8% for rural populations (Chandalia, 2013). However, it is important to note that unreported diabetes cases are much higher in rural areas, and no comprehensive studies have examined the prevalence of T2DM in rural areas at national level. The specific NPCDCS report also does not provide a break down of diabetes prevalence between rural and urban populations. However, throughout Sikkim 75% of the population lives in rural areas while 25% lives in urban

areas (Census of India, 2011). Despite the fact that the prevalence of diabetes in rural populations is lower compared to urban populations, the *estimated* number of people with diabetes is expected to be higher in rural populations in North Eastern States because a significantly higher percentage of the population lives in rural areas. (Kalra et. al., 2013). When looking at the prevalence of T2DM in Garamani alone, we see that a significant percentage of the population has the disease. A VHAS fieldworker identified 24 people with T2DM, out of the total population of 408, which points to an estimated 6% prevalence of the disease in this village (VHAS, 2015).

The lack of knowledge surrounding prevalence about diabetes throughout the state, particularly in rural areas, serves as a barrier for the continual implementation of public health programs that combat diabetes. The state has completed a comprehensive epidemiological study through the CATCH Sikkim and NCSPD programs surrounding diabetes, however doctors and even government health officials are not aware of these studies. While one cannot expect these stakeholders to memorize exact data surrounding prevalence, it does raise concern when a health official that works closely with NCD programs believes that the prevalence is around 3%, a difference of nearly 10%. Without community knowledge surrounding the prevalence of diabetes, targeted and evidence-based policy decisions and NGO programming cannot follow.

Lack of knowledge:

Underlying the Sikkim specific causes of T2DM outlined above, is a lack of awareness from the community surrounding the risk factors of the disease. While a statewide assessment of the knowledge and perceptions surrounding T2DM has not been conducted in Sikkim, all doctors interviewed emphasized that the community engages in risk factors for the disease because they are unaware of their impact. A lack of knowledge about the causes of T2DM was also seen

among women, despite their age, level of education, socioeconomic status, and place of residence.

While both rural and urban women explained that they had changed lifestyle habits after being diagnosed through either exercise or diet, they were unaware that these habits could have also prevented the disease. Despite having the disease for many years, most interviewees responded that they did not know the cause of the disease. Rupa, a 44-year-old woman who lived in Garamani, believed her gall bladder surgery was the primary cause of her diabetes (Focus Group Discussion, 2015). When asked if they were doing anything to prevent the disease among their family, most women stated that because they didn't know the cause, they didn't know what to do for their family. None of the women indicated they knew that T2DM is closely linked to genetics and that having a family member with the disease is also a risk factor.

The women also explained that they did not get checked for T2DM before their diagnosis, and all women came to know that they had diabetes after they experienced major complications with their health. Some of these conditions were symptoms related to the disease such as dizziness, extreme thirst, or vision loss. Other women came to know after a major surgery, such as heart surgery or a gall bladder removal, as it is routine for all patients who are admitted into the hospital to have their blood checked, despite the primary reason that they have been admitted. Many women had never heard of T2DM before their diagnosis, which is one reason why they did not get a health check up as a preventative measure. This points to the fact that a lack of knowledge surrounding the disease not only inhibits preventative behavior change, it also prevents women from receiving early screening check ups that would have allowed them to catch the disease in early stages.

While few studies have been done regarding knowledge and perceptions surrounding diabetes in Sikkim, a study by Pat, et AL, study “Health Education Intervention on Diabetes in Sikkim” (2010), shows the impact that comprehensive education programs can have for both diabetic patients and non-diabetic persons. This study conducted pre and post tests for 189 people that attended a “diabetes awareness camp” at Central Referral Hospital in Gangtok. Of these participants 55% had been previously diagnosed with the disease. Results showed that there was a significant improvement among the population in both knowledge about risk factors, early symptoms and personal precautions, as well as improvements in attitudes surrounding willingness to have annual check ups and blood tests. While unable to give a follow up test after the program, the authors stress the importance of follow up educational programs as they increase the retention rate of the knowledge and perspectives gained. This study points to the fact that an increase in knowledge surrounding T2DM can be achieved by the people of Sikkim through community-based programming.

Community knowledge surrounding the disease is vital for prevention and a decrease in morbidity and mortality for those that have the disease. As mentioned above, preventative screening programs have been implemented in the state such as the CATCH Sikkim program, ANC checkups, and NPCDCS health camps, however none of the women interviewed were diagnosed through these programs. It will take time to see if these programs have lasting effects and are able to prevent the disease from progressing in most patients. It must be recognized however that these programs, while considered preventative, do not provide consistent or lasting educational programs about the risk factors for T2DM. In this way, these programs fail to prevent the disease from occurring in the first place. While Dr. Navin did explain that statewide media campaigns to educate the general population about the risk factors of the disease are in

place, doctors and women with diabetes did not indicate any knowledge about these programs, suggesting that these programs do not reach the majority of the state population (Personal Interview, 2015).

Doctor-Patient Interactions:

Doctor-patient interactions have a large impact on the quality of care that diabetic patients receive, as well as the likelihood that specific lifestyle changes and medication regimens will be followed (Golin, DiMatteo, Gelberg, 1996). Self-management training is crucial for the success of T2DM treatment, which health care professionals can provide. When asked about their interactions with their doctor during diagnosis, women explained that doctors told them nothing more than “the do’s and the don’ts” of the disease. All women were told to decrease their sugar intake, and many women mentioned that they were also instructed to eat fewer potatoes. Urban women were instructed to exercise more, and many women explained that they now go on a morning walk. Rural women however, were given no instructions about an increase in exercise, which is most likely due to their already active lifestyle. While some women initially tried ayurvedic treatment, all women interviewed currently followed allopathic treatments, either through daily medications and or insulin injections. When asked, women stated that their doctor never explained the cause of the disease to them.

Dr. Raj explained that there is a relatively short interaction with diabetic patients during and after their diagnosis (Personal Interview, 2015). Once patients are diagnosed, they are prescribed medicines and then sent home. After that, it is up to the patients to follow their treatment or not. Besides support from family and friends, patients do not receive any assistance in self-managing their condition. The women interviewed for this study were stable, and therefore had been successful in adjusting their lifestyle and adhering to their medication

regiments. However, it took each patient months or years to reach stability as most patients struggle to comply with the needed behavior changes to treat the disease.

Limited interactions with physicians may point to the reason why some women find it challenging to follow through with their treatment plan after diagnosis. Doctor-patient interactions have had a huge impact on patient's willingness and ability to adhere to their treatment plan, and while no study has examined diabetic patient-doctor relations in India specifically, Mocherla, Raman, and Holens's study "Expression of Equity: Imbalances in the Patient – Clinician Interaction" (2011), closely examined doctor-patient interactions regarding glaucoma treatments in Hyderabad. This study found that when patients understood the causes of the disease, as well as learned of the justification of their treatment, they were more likely to follow through with said treatment. A larger explanation surrounding the cause and reason for treatment of diabetes was not provided to any of the women interviewed, therefore current doctor-patient interactions serve as a barrier for women when attempting to treat the disease.

In addition, doctor-patient interactions aim to simply decrease health complications of the patients, and no further action is taken to combat the high prevalence of diabetes among the community through these interactions. Because doctor-patient interactions contribute to women patients' lack of knowledge surrounding the causes of their condition, it perpetuates the inability for women to prevent the disease among their family members and the larger community. Around half of the women interviewed were housewives, and therefore act as the primary caregivers for their family. They have a strong influence on their family's lifestyle, particularly their family's diet. In India 75% of all T2DM patients have a family history of diabetes, and because T2DM has a particularly strong genetic component, and it is likely that the children of these women are genetically predisposed to the disease (Davey et. al., 2000). Women with

diabetes are unable to prevent the disease in their children without knowing the primary causes them. Doctors believed that the community has a responsibility to combat diabetes by increasing awareness about its causes, however this study indicates that doctors themselves do little to combat T2DM on a community-wide level during interactions with patients.

Access to Health Services:

After a patient has been diagnosed with T2DM, patients require daily medications and routine doctor visits for blood testing (Mehta, Kashyap, & Das, 2009). Therefore, access to health care is extremely important to minimize morbidity for diabetes patients. When considering access to diabetic health services, this study considered location of services, availability of nurses and doctors and the availability different types of medical services. While socioeconomic status is clearly linked to access, it is discussed extensively in the following section.

Within Gangtok, a variety of types of doctors and medicines are available to diabetic patients. While no diabetes specialists currently work in Gangtok, general practitioners are able to serve diabetic patients. Most patients in the city follow allopathic treatments, however AYUSH and Amchi doctors are also available to patients.² All of these treatments are available through both government and private practices, and with the exception of inpatient care, doctor consultations can occur at hospitals or smaller OPD clinics. These facilities are physically accessible, due to the relatively small size of the city and the readily available local transportation systems and walkways. Notably, Gangtok is home to STNM Hospital, Sikkim's state hospital. STNM is centrally located and offers allopathic, ayurvedic and amchi medical

² Allopathic medicine refers to "Western" medicine, AYUSH refers to 5 traditional forms of Indian medicine; Ayurvedic, Yoga and Naturopathy, Unani, Siddha and Homeopathy, and Amchi medicine is traditional Tibetan medicine.

services. Manipal General Reference Hospital, a private hospital, is also easily accessible as it is only a few minutes outside of Gangtok by taxi.

All doctors interviewed believed that it was easy to access medical consultation for diabetes throughout Gangtok, and women in urban areas also agreed that it was relatively simple to receive care. While Lakpa, an urban women with T2DM, chooses to travel to Siliguri, a town four hours south in West Bengal to receive her treatments, all other women felt that it was relatively easy to see a private practicing doctor (Personal Interview, 2015). However, government health care may not be as accessible as Lakpa mentioned that she chooses not to receive government care because of long wait times (Personal Interview, 2015). All women also agreed that buying their medications was hassle free.

Accessibility to health care is vastly different for Sikkim's rural population. As part of the Government of India's National Rural Health Mission Scheme, a hierarchy of health centers is in place for rural communities. Not only does the state have a small shortfall of Sub-Centers and Community Health Centers, but Sikkim's rural areas health centers are often far away from villages and wait times at these clinics can be long (Ministry of Health and Family Welfare, Govt. of India, 2015). The state has a low road density, which can make it challenging for rural populations to get to a doctor or chemist (Kalra et al., 2013). Extreme weather conditions, such as snow storms and monsoons, often physically block the already limited access to health care through snow and mudslides (Kalra et al., 2013). The interviewees in the rural focus group echoed this, and shared that it was difficult to see a doctor when they needed to, and that they had few options regarding the type of treatment they received and where they could receive it.

During the focus group discussion (2015), rural women explained the lengthy and often difficult process of seeing a doctor or buying medicines. To see a doctor at a Primary Health

Center or to refill their medicines, these women must travel nearly 20 km to Rangpo, the nearest town. Women can reach Rangpo for 40 INR in a shared taxi, and while the drive takes 20-30 minutes, women explained that it takes an entire day to see a doctor due to wait times. Women shared that they try to regularly see the doctor once a month, however if they are feeling particularly healthy they will go two to three months without a visit to avoid spending time away from their housework. If medicines are not in stock in Rangpo or they need specialized treatment at a District Hospital, women must travel 30km to Singtam. Traditional folk healers are not common in this area, and while one woman expressed that she had met with an ayurvedic doctor before, most people in the village seek out allopathic care.

Clearly, access to health care is completely dependent on the location of the diabetic patient, and serves as a huge barrier to treatment for rural populations. While the CATCH Sikkim program and NPCDCS health camps do meet communities' needs in providing preventative health screenings, it does not meet the specific needs of many diabetic patients. It is difficult for rural women to receive necessary monthly checkups, which is why they avoid them if they are not facing any health complications. In Gangtok, women do not face the same accessibility problems, as facilities and doctors are readily available. However, all of the urban women with diabetes that were interviewed received care from private practicing physicians. Therefore, an analysis of the accessibility of government health facilities in Gangtok and facilities cannot follow.

Socioeconomic Barriers:

Socioeconomic status has a huge impact on an individual's ability to access T2DM treatments. For a person of low socioeconomic status, T2DM treatment can account for 25% of their income (Mehta, Kashyap, & Das, 2009). Doctor visits, medications, and lifestyle

changes all contribute to the economic burden of the disease. The price of doctor visits vary, depending on the type of treatment received. Registration costs at government hospitals is 10 INR, and most tests related to diabetes are 15 INR (Department of Health Care, Human Services & Family Welfare, Government of Sikkim, 2010). For private consultation, the price can range from 60-400 INR depending on the clinic. Price of medications varies depending on treatments. Daily medications (both allopathic and ayurvedic) can cost as little as 300 INR a month, while insulin injections can cost up to 30,000 INR a month (Dr. Deepan, Personal Interview, 2015). While most doctors estimated that the price of medications for diabetic patients costs 300-500 INR a month, both rural and urban women stated that they pay 1,500 – 2,000 INR a month to treat T2DM.

All women interviewed paid for their medications out of pocket, however opinions differed between women about the financial burden of the disease. Rural women explained that the cost of medicines is the largest barrier they face when attempting to treat their diabetes (Focus Group Discussion, 2015). The average monthly income of these women's families was around 4,500 INR, making the cost of these medicines approximately 25% of their current earnings (VHAS, 2015). Urban women had differing opinions about the impact of the price of medicines, as the socioeconomic status and the type of medications they were taking varied between women. Those who found paying for medications difficult were of a lower socioeconomic status and indicated that the financial burden of paying for treatment caused stress and tension. Stress and tension have been identified as risk factors for the disease, and it is recommended that all patients with T2DM reduce their levels of stress as a method of treatment. Therefore, it is difficult for patients of lower socioeconomic status to properly treat the disease when concerned about the cost of treatment.

Low socioeconomic status not only affected women's ability to pay for their medications, but also directly impacted their ability to participate in necessary life style changes, specifically exercise and monthly doctor visits. Tshering, an urban woman who works an office job, explained that because she paying for medications is a huge financial burden, she is unable to take time away from her job to do her necessary exercises (Personal Interview, 2015). For many other women, time spent at the doctor for monthly checkups means time spent away from work. This is particularly true for women who seek treatment at government facilities as most government OPD clinics operate during business hours (Lapka, Personal Interview, 2015). This means that in order for working women to see a government doctor, they have to miss work and therefore face a decrease in their salary. Private OPD clinics in Gangtok often have later hours and are open on Sundays, however this option is only available to those patients who can afford seeing a private practicing doctor.

While government programs are available to assist patients in paying for their medications, none of the women interviewed for this study who were eligible for these programs utilized them. Lapka, a woman living in Gangtok, worked as a government employee and therefore could have all of her medications reimbursed by the government (Personal Interview, 2015). She explained however, that in order to utilize this program, she would have to see a government doctor. As stated above, the operational hours of the local government makes it close to impossible for her to seek treatment from a government doctor. She also explained that the hassle of the completing the required paperwork was not worth the reimbursement. Doma, whose son is a government employee, could have her medications reimbursed, but also explained that this process is too complicated to utilize (Personal Interview, 2015). Therefore, while the state has implemented a program to ensure that government employees are able to pay for their

medications, they have made the process complicated and conditional, and many employees may not actually benefit from this program. Additionally, the program benefits people who by nature have a source of income to pay for their medications, and therefore does not target patients of a lower socioeconomic status who may have the greatest need for such a program.

All of the women interviewed for this study were stably living with diabetes, and therefore did have the ability to pay for their medications, despite the financial burden that some families faced. It must be noted however that there may be women who are unable to pay for their medications at all because no long-term medication payment programs exist for non-government employees. However, further studies that focus solely on diabetic patients of a low socioeconomic status would have to be completed to fully determine if this is so.

Conclusions:

This study sought to understand the barriers that women in East Sikkim face when attempting to prevent and treat T2DM. While gender-specific barriers could only be identified for women who work as housewives, the study was able to identify non gender-specific barriers that impact both women and the entire community. The people of Sikkim pride themselves on the lack of inequality that exists throughout the state, and it was clear that gender has little impact on a women's ability to prevent and treat T2DM. Some women who work as housewives however are at a particular disadvantage when attempting to treat T2DM due to the fact that they are unable to immediately seek care if a health complication arises. The extent of this barrier however, heavily depends on the socioeconomic status of the individual and the proximity of health care facilities. Other barriers were identified that could not be closely linked to gender, however they still have a large impact on women's ability to prevent and treat the disease.

Lack of knowledge surrounding the prevalence of T2DM within the community and the main risk factors of the disease were identified as major barriers to prevention for both the women interviewed and the entire community. Effective community action aimed to decrease the prevalence of T2DM cannot occur without comprehensive knowledge surrounding the problem at hand. In the same way, individuals cannot prevent the disease without sufficient understanding of its causes. Abbreviated doctor-patient interactions contributed to women's lack knowledge about the disease, even after being diagnosed. This impacts women's ability to follow their treatment, and fails to inform them about how the disease can be prevented among their family.

Limited access to health care and the high price of medications also serve as barriers to treatment of T2DM in Sikkim. For rural women, the large distance between their homes and health clinics impacts their ability to receive medications and monthly doctor consultations. Many women expressed that financial burden of living with T2DM, due to the high price of medications and treatments, often leads to stress which is important to reduce when treating T2DM. While all women in this study were able to pay for their medications, there are no government programs that assist BPL patients pay for their medications long term. Therefore, this study found that a women's socio-economic status greatly impacts her ability to treat T2DM.

These findings point to many ways that the state of Sikkim can continue to prevent and treat T2DM by removing these barriers. The government has already taken steps to "catch" cases of T2DM in their early stages through the CATCH Sikkim program, ANC checkups, and NPCDCS health camps. Hopefully, these programs will continue to decrease the number of individuals that face further complications with T2DM. There is still more that the government, grassroots organizations, and NGOs can do to target the specific causes of T2DM in the state. For example, such organizations should educate its citizens about the disease, before it can

develop. By requiring mandatory nutrition and health education that specifically focuses on NCD like diabetes, children can grow up knowing how to live a life that prevents T2DM. In addition, mothers should be educated about the causes and risk factors for the disease through community programming and media campaigns and a special emphasis should be placed on educating mothers who have T2DM themselves, due to the genetic components of the disease. Doctors should receive training on how to maximize patient visits, to ensure that women with diabetes fully understand the reason behind their treatments, and how to prevent the disease in their families. Despite the fact that prevention and treatment of T2DM depends on the choices and lifestyle of the individual, the high prevalence of this disease is a statewide issue and therefore the community has a responsibility to respond.

Limitations:

While this study succeeds in identifying some of the barriers that women in East Sikkim face when attempting to prevent and treat T2DM, it has many limitations. The first is a small sample size of nine women, seven private practicing doctors and two public health officials. While the findings here accurately portray the information provided from these stakeholders, one should use caution in generalizing these findings to a larger population because this study only drew from two locations in East Sikkim. Government doctors were not interviewed and only four of the nine women sought government funded care, so a larger analysis regarding the impacts of government health care services could not occur.

Another important barrier is that women who were facing major health complications could not be interviewed for this study. All of the women interviewed for this study were stably living with diabetes, and therefore could only provide perspectives on times when they had difficulty stabilizing their condition. Women who are currently undergoing complications may

be able to provide the best perspective on the barriers women face when attempting to treat T2DM, however this may not be considered ethical in many contexts.

It is also crucial to recognize the language and cultural barriers that existed between the fieldworker and all interviewees. While a translator was used for all interviews conducted in Nepali, it cannot be guaranteed that all translations truly conveyed the intent of the interviewee. Even interviews that were conducted in English are prone to language and cultural misunderstandings.

Suggestions for further studies:

In order to expand on the works of this study, interviews with government doctors and a larger sample of diabetic women who seek care from government hospitals would shed light on how these service support women with diabetes. This would be important for a comprehensive analysis of how government facilities are targeting barriers that women face when attempting to treat T2DM. It would also be important to interview men in order to compare the barriers that they face with those of women. This could point to more gender specific barriers that could not be identified in this study that only interviewed women. Additionally, because of the rich and diverse cultures that exist in Sikkim, a larger study surrounding specific cultural practices in Sikkim and how these relate to T2DM would also be important to understanding why the state has a significantly high prevalence of the disease.

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Appendix:

Sample Interview Questions for Health Officials:

1. How long have you worked in this position?
2. Please describe your role, specifically how it relates to NCD and diabetes?
3. What factors lead to the high prevalence of diabetes in Sikkim?
4. What is being done on a government level to combat these factors?
5. Do more people have T1DM or T2DM?
6. What barriers do you believe that women face when attempting to prevent diabetes?
7. After a woman has been diagnosed with diabetes, what barriers do they face when trying to stabilize and treat the disease?
8. Do you feel that some women are more susceptible to the disease than others?
 - a. Which ones and why?
9. How are these challenges different for urban vs. rural women?
10. What different treatment options can women receive?
11. Are women more likely to want a specific type of treatment?
12. In your opinion, are all treatments equally effective?

Sample Interview Questions for Allopathic and Ayurvedic Doctors:

1. How long have you been working in Gangtok?
2. How many patients do you have that have diabetes?
3. What factors lead to the high prevalence of diabetes in Sikkim specifically?
4. Do more people have T1DM or T2DM?
5. What barriers do you believe that all people face when attempting to prevent and treat diabetes?
 - a. Why it is hard for people to prevent and treat diabetes?)
6. What stops women from preventing the disease?
 - a. What stops women from treating the disease?
7. How do most women come to find out that they have diabetes?
8. After a woman has been diagnosed with diabetes, what barriers do they face when trying to stabilize and treat the disease?
9. Why would a woman not do her treatment?
10. Do you feel that some women are more likely to get to the disease than others?
 - a. Which ones and why?
11. How are these challenges different for urban vs. rural women?
12. What different treatment options can women receive?
13. How much do these treatments cost?
14. It is easy for women to receive treatments and access their medicines?
15. Are women more likely to want a specific type of treatment?
16. Do you think allopathy and ayurveda can work together?
17. What needs to be done to decrease diabetes prevalence in Sikkim?
18. What needs to be done for women specifically to decrease prevalence of diabetes in Sikkim?

19. Does the community or do individuals have a greater responsibility to combat T2DM?

Sample Interview Questions for Women with T2DM

- 1) Are you stabling living with DM?
 - a. Are you currently having side effects or complications with the disease?
- 2) How long have you lived here?
- 3) Do you work? What do you do?
- 4) Do you have a family?
 - a. Who is in your family?
- 5) How did you come to know that you have diabetes?
- 6) How do you treat the disease?
- 7) What is the hardest thing about having diabetes?
- 8) What barriers do you face when trying to treat the disease?
 - a. What makes it hard to do your treatments?
- 9) Where do you go to the doctor?
 - a. How long does it take to get there?
- 10) Where do you get your medicines?
- 11) When you were diagnosed what was the interaction with the doctor like?
- 12) Does your husband and family support your treatments?
- 13) Can you talk with other members in the community about your condition?
- 14) How has your lifestyle changed since diagnosis?
- 15) Do you know what causes T2DM
- 16) Do you feel that it is easier for men to prevent and treat the disease?
- 17) Is it difficult to prevent and treat the disease as a woman?
- 18) What could the government do to help you prevent and treat the disease?
- 19) What kind of treatments have you tried?
- 20) How many people of you think have diabetes in this community?
 - a. How many people do you know with diabetes?
- 21) What does it mean to live healthily with diabetes?