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Why?-abetes: Understanding Diabetes Management in Rural Kwa-Zulu Natal, South Africa

Kyra Wicklund
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Why?-abetes: Understanding Diabetes Management in Rural Kwa-Zulu Natal, South Africa

Kyra Wicklund
Advisor: Dr. Andrew Ross, University of KwaZulu-Natal
SIT advisor: Clive Bruzas

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Abstract

This project will investigate how diabetics, family members, and community members involved with diabetes relate to the disease and its continued management in a rural area of KwaZulu-Natal, South Africa. Although diabetes is an issue worldwide, it has been largely over-looked in sub-Saharan Africa. This study utilized interviews with diabetics, family members of diabetics, and clinic staff as well as personal observations to reveal the strategies, challenges, and stories of diabetes in this area. Conversations with local health experts verified that diabetes is a major issue in the area of this study. Topics of interest were support structures present; education; hardships with diabetes; diabetes management through medication, diet, and exercise; mode of access to health care; checking blood sugar; the use of traditional medicine; attitudes about diabetes; and the questions raised by the interview subjects. Education and support appeared to be the biggest problems for diabetics in this part of rural Kwa-Zulu Natal.

Useful Acronyms

CCG.....community care giver
ISP.....independent study project
KZN.....KwaZulu-Natal
NCD.....non-communicable disease
PHC.....primary health care

Research Question / Objectives / Justification

Diabetes is a chronic disease which is constantly claiming more victims across the globe. “Worldwide, 3.2 million deaths are attributable to diabetes every year” (World Health Organization and International Diabetes Foundation, 2004, p. 4). Yet diabetes is widely under-recognized and misunderstood, especially in South Africa. Dr. Larry Distiller, founder of the Centre for Diabetes and Endocrinology in Johannesburg claims that “Three-and-a-half million South Africans (about 6% of the population) suffer from diabetes and there are many more who are undiagnosed” (health24, 2012). The burden of diabetes is only growing. “The projected growth [in the number of adults with diabetes] for sub-Saharan Africa is 98%, from 12.1 million in 2010 to 23.9 million in 2030” (Mbanya, 2010, p. 2254). Still this threat is not seen. “The burden of premature death from diabetes is similar to that of HIV/AIDS, yet the problem is largely unrecognized” (World Health Organization and International Diabetes Foundation, 2004, p. 9).

Diabetes remains particularly undetected in sub-Saharan Africa, where 62.5% of the estimated 22 million cases of diabetes remained undiagnosed in 2014 (International Diabetes Federation, 2014). This is especially true in rural communities. Although not all diabetics require insulin (World Health Organization and International Diabetes Foundation, 2004, p. 13), there were notable issues of insulin transport to rural areas for those who do need insulin (Beran, 2005, p. 2138). More extensive issues with diabetes management come with the everyday grind of the disease. With that said, my goal for this project was to learn more about holistic diabetic care in rural South Africa. How do victims of diabetes in this rural setting manage their disease? How are the community members and structures supporting neighbors with diabetes?

Context and literature review

This ISP was conducted in a rural community in KZN. The predominant language spoken is isiZulu, but English is common too. Some community members make little income, and government grants are widely used. Subsistence farming is common, with most homes having large, personal vegetable gardens. Homes are connected by red clay roads, which become impassible after heavy rains. Small tuck shops are prevalent and provide the most common food items to community members. There is one local primary health clinic, and traditional healers in the area are often consulted. This project is taking place in a rural South African community where the sense of ubuntu, the act of helping and caring for fellow humanity, is present in many aspects of life. Entering this project, I expected to see family members helping diabetics, but also I wanted to see how the community supports its members with diabetes.

“Diabetes is a chronic condition that occurs when the pancreas does not produce enough insulin or when the body cannot effectively use the insulin it produces” (World Health Organization and International Diabetes Foundation, 2004, p. 7). There are three types of diabetes. Type 1 diabetes occurs when insulin is not produced by the pancreas; Type 2 occurs when the body cannot utilize insulin effectively; and the third type is better known as gestational diabetes mellitus (GDM) occurring during pregnancy (Ibid, p. 7). Type 1 is controlled via daily insulin injections while type 2 often requires other medications (Ibid, p. 7). All types of diabetes are improved by “lifestyle measures such as a healthy diet, physical activity, the avoidance of overweight and obesity, and not smoking” (Ibid, p. 11).

This Independent Study Project focused on the barriers to diabetic patients receiving proper care, which includes everything from infrastructure and drugs to holistic care through community support. A huge part of diabetic care is eating a good diet; however, this becomes a problem when the diabetic cannot really control what they are eating. Typically, African women cook for their men, leaving diabetic husbands little choice in that aspect of their own health; thus, it is “important to give information to the wives, relatives or children of each male patient on how to prepare their food” (Mshunqane, 2012, p. 6) Proper diets may also be hard to afford,

even when the knowledge of healthy eating is present (Ibid, p. 4). People in rural areas get produce affordably by growing personal vegetable gardens. Abundant produce reduces household spending on food, which can then be saved for times when gardens are not ripe. Food is not the only important thing that diabetics put in their bodies; diabetics need medication and/or insulin on a daily basis. “The challenge at primary health care level is to ensure an effective drug distribution system that regularly delivers the prescribed drugs to patients without their daily lives being much disrupted” (South African National Department of Health, 2013, p. 43). Insulin is not always present at health care facilities. In fact, one study of health care facilities in Mozambique, a fellow sub-Saharan African nation, saw insulin present at only one of five hospitals and none of six clinics (Beran, 2005, p. 2138). Rural life can make importing medicines and supplies difficult. Not only do medicines have to be transported by vehicle from outside distributors, but they then have to be transported by foot to patients’ homes. Rural roads complicate both forms of transportation. My classmates have experienced being stuck in a vehicle on a rural road that became too muddy with rain. A prolonged rainstorm could prevent insulin and other medicines from reaching some local clinics. These same roads are the ones used by patients walking to the clinic. Sick patients needing insulin are not likely to be out during heavy rain on washed-out roads. The affordability and availability of insulin from health care centers that provide it can be major barriers to the patient. “The annual cost of purchasing insulin [per person] for the health service in [Mozambique and Zambia] is ~\$56.03. This is ~40 times the annual public sector pharmaceutical spending per patient in these countries” (Ibid, p. 2138). Clearly diabetics lacking knowledge of their disease also hinders receiving the proper care. The World Health Organization has said that “helping people with diabetes to acquire the knowledge and skills to manage their own condition is central to their leading a full and healthy life” (World Health Organization and International Diabetes Foundation, 2004, p. 7). Not only should the diabetic be knowledgeable, but so should their close family and friends be so that they can provide support (Mshunqane, 2012, p. 4). Part of this support must be emotional because people living with diabetes face many battles. One of these battles is combating misperceptions about their illness. For example, many diabetic patients in South Africa, a country historically afflicted by HIV and AIDS, are scared to lose weight to be healthier because weight loss is a

common symptom of HIV. Diabetics go through a lot, so they do not want to defend themselves against a stigma that doesn't even belong to them (Ibid, p. 4). It is crucial to realize that many of these barriers are socially constructed. "The common risk factors and the systems put in place to deal with the conditions in which people live are shaped by social, cultural, behavioural, environmental and economic determinants" (South African Summit on the Prevention and Control of Non-Communicable diseases, 2011, p. 2).

It is critical to understand what current prevention methods are used to combat the growing burden of diabetes in South Africa. Here, knowledge is the sharpest of tools. Sadly, many people remain undiagnosed, especially in rural areas of developing countries. While looking for the diabetes prevalence in a rural South African community, one study reported that "Of the cases of diabetes, 84.8% were discovered during the survey" (Motala A, 2008, p. 1783). The estimated prevalence of diabetes in South Africa in 2014 was 8.39% (International Diabetes Federation, 2014), indicating how relevant this growing disease is to the country of South Africa. Already, "There are around 17 million visits at health centres per annum for hypertension and diabetes in South Africa, resulting in significant health care costs and use of human resources" (South African Summit on the Prevention and Control of Non-Communicable disease, 2011, p. 2). Obesity is one risk factor for diabetes, and the World Health Organization suggests amounts of weekly exercise to prevent obesity and promote healthy lifestyles (World Health Organization and International Diabetes Foundation, 2004, p. 14). Although small-scale motivations to exercise are crucial behavior change interventions in preventing diabetes, individual behavior change is not enough. "Informed policy decisions on transport, urban design, and on food pricing and advertising can play an important part in reducing the population-wide risks of developing type 2 diabetes" (Ibid, p. 7). Although this is geared towards urban change, society-wide change especially in food pricing can be adapted to rural communities. This may make healthier food options more affordable to consumers. Another national initiative should be to better train health care workers in recognizing diabetes. The South African National Department of Health said in its "Strategic Plan for the Prevention and Control of Non-communicable Diseases 2013-17" that increased screening for diabetes will happen mainly by "Increase[d] screening of people who are 'at risk' in primary care [facilities and] train[ing] health workers to

identify people at risk” (South African National Department of Health, 2013, p. 54). In order to provide equitable care, it is important that PHC be established and run by the national government. “Healthcare systems at primary health care (PHC) level differ vastly from province to province and even between PHC clinics in the same province” likely because “policy regarding care of non-communicable diseases in South Africa is determined by the national Department of Health while it is up to individual provinces to implement policy” (Mollentze, 2009, p. 50). It is important to understand where diabetics are getting their knowledge about diabetes from. For example, many people in Mozambique and Zambia chose to visit traditional healers before a health care clinic (Beran, 2005, p. 2139). Often these traditional healers could recognize diabetes and send the diseased person to a clinic (Ibid, p. 2139). Ironically, traditional healers welcome the collaboration with health care professionals on matters like diabetes (Ibid, p. 2139). In a community with a deep history of traditional healing, it is important to understand some of the perceptions traditional healing has on chronic diseases like diabetes.

Methods

The people who come to us bring us their stories. They hope they tell them well enough so that we understand the truth of their lives. They hope we know how to interpret their stories correctly. We have to remember that what we hear is their story.

-Robert Coles as cited in Bochner, 2007, p. 131

This qualitative study on diabetes management consisted of interview conversations with diabetic patients as well as those otherwise affected by diabetes within one rural community in KZN. As a part of the narrative presentation, I have included some of my own experiences with diabetes during my time within this community.

Design

“Qualitative research adds [to] understanding a patient’s perspective on reasons for not taking treatment, barriers to diagnosis, the political-economy of infection and treatment...whole-person care needs, the official line vs. what is happening on the ground, gendered dimensions, and highlighting syndemic relationships and need for structural change” (Weinwrith, 2015).

Qualitative research allows for open-ended responses that often bring about more issues than the researcher expected. In a qualitative study of patients with chronic heart failure in New York, issues were raised by the patients which were unexpected by the researcher. “Although the research interviewer did not introduce the subject of death or dying, half of the participants discussed these issues in the context of their heart failure” (Rogers, et al., 2000). I am presenting this ISP as qualitative research because it is important with a chronic disease like diabetes to look at the patient’s whole experience with their disease to see how they manage it. Part of that means looking at the medications they take, part of it looks at the support they receive, and part of that looks at the education they were given about the disease.

Sampling plan

All of the people that I interviewed were black and Zulu-speaking. I did not interview children due to the difficulties in obtaining proper consent from their parents. Diabetes is most prevalent worldwide in the 45-64 year old category, followed by the 65 and older category (King, 1998, p. 1421). Accordingly, all of the people with diabetes that I interviewed fit into one of these categories. I was primarily interested in interviewing people who have diabetes themselves, but I thought it would be valuable to get input from at least one family member of a diabetic because family members experience secondhand the physical and emotional effects that diabetes has on a person. I wanted to interview someone who works in PHC, particularly a nurse, because such an expert has likely seen a variety of the challenges faced by diabetics. Nurses are also the people who are providing knowledge to people diagnosed with diabetes on how to manage their disease so what they are teaching interests me. All of the interview subjects had a direct connection to diabetes. That is, three participants had diabetes, one had a family member with diabetes, and two worked in health care with diabetes patients. Both of the nurses that I interviewed were obviously of working age. In total, I interviewed four females and two males. Because the sample size of this study is six people, this study is in no way generalizable. I was the sole interviewer, but I used a translator for the non-health care worker interviews because the diabetics and the family member of a diabetic spoke only isiZulu. Although the first language of the nurses was isiZulu, they both spoke fluent English so their interviews were conducted in English. I did not choose participants based on the amount of time they have been living with diabetes. I was open to interviewing patients with either type one or two diabetes; however, most of the people with diabetes that I talked to were unaware that different types of diabetes existed. Therefore, I did not collect data about what type of diabetes they had.

I was able to obtain all of my interviews through the snowball method. I started interviewing people known to my host family, and I went off of interview recommendations from that point onward. My host aunt would call a diabetic person she knew to explain who I was and that wanted to talk about. I would then walk to these people's homes with my translator. No nurses were interviewed in healing spaces.

Data collection

I utilized structured interviews to gather people's stories. I began each interview with "Tell me a little bit about your experience with diabetes." In a similar study where patients were interviewed for a qualitative study about a chronic heart condition, "interviews started with the open question, 'can you tell me how your heart failure started?'" (Rogers, et al., 2000). Because of respondents' desires for more structured questions, I often utilized my conversation guide¹. I adapted my conversation guide to the culture of the area by adding a question about traditional medicine and dropping my question about exercise. As diabetes education became more of an apparent issue, I asked more questions about that. To allow for open answers, I avoided asking leading questions. However, in some instances, language and word connotations became a barrier, and I had to explain my question further. Because an interview should be a conversation based on trust, I gave everyone that I interviewed the opportunity to ask me questions. Structured interviews allowed me to manage data collection in a comfortable way. I am most comfortable in one-on-one dialogue. More importantly, by giving one person all of my attention, I was better able to learn more about that individual's experience with diabetes. Interviewing one person at a time was more convenient to schedule. With that said, I did not force anyone to answer things they did not want to. When someone chose not to answer a question, I respected their decision and continued on with the interview.

As a researcher, I tried to be a respectful listener, producing as little bias as possible. I asked all participants for permission to record what we talked about. I kept all data confidential, and participants will remain anonymous. I informed every participant of this practice.

Analysis

"Transcripts and notes are the raw data of the research. They provide a descriptive record of the research, but they cannot provide explanations. The researcher has to make sense of the data by sifting and interpreting them" (Pope et al, 2000, p. 114). Such interpretation begins while data collection is going on (Ibid, p. 114). As I said earlier, I added a question about traditional medicine once I realized its relevance during my first diabetic interview. I used a combination of hypothesis testing and grounded theory, where I "identify[ed] analytical

¹ My conversation guide can be found in Annexure 1.

categories as they emerge[d] from the data” in finding themes for this study (Ibid, p. 114). The hypothesis was that this community supported its diabetics. All of the other themes emerged from the data. “Categories are added to reflect as many of the nuances in the data as possible” (Ibid, p. 114). Although two main themes, education and support, were identified, others were included in my analysis to fully represent the data.

I loosely followed the framework approach of qualitative research, where “the objectives of the investigation are typically set in advance” (Pope et al, 2000, p. 116). The five steps of this methodology are familiarization, identifying a thematic framework, indexing, charting, and mapping and interpretation (Ibid, p. 116). I first familiarized myself by journaling about the data I had, creating a narrative of each person’s story. The thematic framework appeared through the questions I had asked about diabetes management. I combined the indexing and charting steps where I charted by question topic. Mapping and interpretation followed, where I recognized the main themes while still including the other topical themes as they related to the narrative of the diabetic. This framework approach recognizes the need to triangulate with quantitative findings as the timescale of such studies is often short (Ibid, p. 116)

Ethics

Individuals giving their consent to participate in my ISP have remained anonymous and the information that they shared with me has remained confidential. I guaranteed privacy in participation by making sure that I was the only person directly reviewing transcripts of interviews. I protected the equipment that data was recorded on with passwords or locks. I never shared information about family members or location of residence. To preserve anonymity, I have used pseudonyms for all participants in this ISP. Only my translator and I know the real names of my participants. This ISP will be available online. It is likely that the people I interviewed will never have access to what I write. However, I will show them respect as if they could access and read what I wrote. Once the ISP report is written and submitted, I will destroy all traces of identity markers in my notebook.

To be fair to all participating, no inducement was offered to anyone whom I interviewed. I did pay my Zulu translator for the four interviews she helped me with. All of my participants were over the age of 18 so that they could give proper, informed consent.

I interviewed both of the nurses outside of the clinic setting while they were not seeing patients. They had both completed four years of nursing education, and they are seen throughout this ISP as experts in their field. I received permission from the clinic coordinator before I began any shadowing. I interviewed diabetics and family members in their homes, where they were familiar with the daily maintenance of diabetes. During the interview, my translator and I would sit where our hosts or cultural cues told us to. For instance, when interviewing an older male in a roundvel, we sat across the room from him on a mat.

I always tried to remain aware and sensitive to the difference in culture between myself and the people that I was interviewing. For example, when I asked about traditional medicine, I would ask “Do you use traditional medicine?” or “Do you know of traditional medicine for diabetes?” instead of “Do you believe in traditional medicine?” The latter has an element of Western medicine superiority that I was trying to avoid.

With the diabetic and family member interviews, my translator often did the introduction for me. She would give the person my name, tell them what school I was from, what I was

studying, and tell them that this was a part of my project on diabetes. Sometimes the participants asked more questions about where I was from. Then I would ask if it was okay if I asked them some questions and recorded their answers. When affirmative, I would then conduct the interview. At the end of all the questions, mine and theirs, I would ask my translator to explain the consent form to them. One interviewee had a grandson read the consent form to him and sign in his place because he was illiterate.

The interviews with nurses went similarly. During a time when they were away from the clinic, I would fully explain my project and ask if they could answer some questions for me. At the end of the questions, they read through the consent form and signed it.

I gave all participants in this study a copy of the consent form with my name, my phone number, my school's name and location, and my academic director's name and contact information. I explained that they were free to contact me at any time about any questions they had pertaining to this study. Sometimes, participants avoided a question, at which point I moved on and asked another. There was never pressure to answer every question. In keeping with this, I made sure that all participants knew that I was first and foremost a student interested in diabetes—I was in no way an expert there to tell them how to do things. However, due to the lack of knowledge about diabetes among patients and family members, I often became an educator in explaining to them the types and causes of diabetes. I only answered questions that had been explained previously to me by health professionals. If I did not feel comfortable answering a question, I said so and would refer them to ask a health professional. Participants benefitted from this study by engaging in good conversation about a health issue pertinent to them.

A local ethics board reviewed this study before any research began.

Presentation of results/findings

It is within the frame of a story that facts gain their importance.

-Bochner, 2007, p. 153

Nurse Zamani works at the local clinic. She is officially a nurse practitioner who specializes (although she would probably consider it generalizing) with chronic care. Over lunch on Wednesday, I learned a bit about her life and nursing career. She has tried out a number of nursing specialties, but she decided that the clinic setting where she could see the biggest variety of people is best for her. After seeing patients one day, I sat down with her in her quaint nurse's apartment to talk about diabetes.

The first thing that I wanted to know about was whether or not there was a diabetes support group in the area. "There might be something like that, but I am new to this area so I don't know." She has not heard of them elsewhere though. I pressed her about who supports diabetics. Definitely their families she told me, "but also here at the clinic." She described how patients are diagnosed with diabetes. "We see the signs," she said. She described how "patients to the clinic get their finger pricked. If sugar is high, it might mean that person is diabetic so they are watched closely. It could also mean that the patient had a big meal right before they came to the clinic. If they are suspected to have diabetes, they will have to come back at a time they have fasted to get a baseline sugar level. After the blood is drawn, the person will be given some sugary solution. After two hours, their blood will be drawn again. After another two hours, their blood is drawn for a final time before all of the samples are sent to the lab where sugar levels can be graphed...We also collect their urine because it has the sugar in it."

"Diabetic patients will often fast before coming to the clinic because they know that eating raises their blood sugar. We don't want people to do that because we want to know that their medications are working... Also, diabetics get very weak and unhealthy when they skip meals." She emphasized that diabetics need to snack.

I asked her when the educating process began. The clinic sisters waste no time here! Between drawing blood samples, patients are informed about good diet. This education was continuous. “We ask them every time that they come in about what they are eating.” She knows that people’s diets impact their health. “Most of the things people eat are starches like mealy meal, rice, and phuthu, but this is bad. They should be eating a variety of food types.”

Diet change "is hard for some people and not as hard for others." "It wasn't hard for my mother because she wasn't one of those 'Oh I want a biscuit...oh I want this sweet'-type of person. But diet is hard for some. My diabetic aunt did not change any of her eating habits because she thought of it as 'Well, I have diabetes so I am going to die anyway.'" While she was pregnant, Zamani explained how "I had to eat every two hours to keep my sugar levels up." Her pregnancy diabetes was controlled via diet. She is a firm believer that "diet really makes a difference in how people feel."

I asked her if it was hard to get people to exercise. She laughed. “When people hear the word exercise, they think they have to go out on the road and run.” I suggested gardening. She shrugged and said it’s all about “doing the small movements. Sweeping even!”

“Diabetics need to drink a lot of water, and they need to pee a lot.” She said that blood sugar levels depend on it. She described one previous patient whose blood sugar dropped immediately after he had gone to the bathroom.

She seemed to imply that diabetics need to eat different things. I’m not sure in what sense she meant this. This was right after she described the rest of households eating big pots of phuthu, etc. She insisted that diabetes is controlled by diet. “Yes, you might take the right medications, but being healthy comes down to food choices.” She implied that people control their level of disease.

I explained to her the perception of fat being associated with healthy as opposed to thin indicating HIV sickness. She explained that fat was an attitude that people had. “It is more like ‘Oh, your family isn’t feeding you well? Shame.’”

She didn’t under-estimate the strain that diabetes puts on a person. When she was hypoglycemic during pregnancy, Zamani said that she "[Felt] sick all of the time. I was miserable." She told me about people who couldn’t come to the clinic themselves so they would

send a family member to pick up their medications for them. "Sometimes when people cannot travel easily, they will send a family member to pick up medications for them." However, Zamani encourages people "to come themselves so that they can be monitored. This might mean having to hire a car to drive them, which is expensive."

Nurse Zamani described people with new diagnoses as "sad." I pressed her for more. "They have it, and it wasn't going away. It was a burden they had to bear."

My first diabetic interview was with a grey-haired man named Ted. Ted met my Zulu interpreter and me in the roundvel at his home. Following Zulu custom, my female translator and I sat on a mat across from him. Then he began to tell us his story:

Ted doesn't know how long he has had diabetes, but "it has been a long time." He does what his is told to—he visits the clinic and he takes the medications like he is supposed to. But does he eat differently? No he eats the same things as before, "even sugary things." He has his blood sugar checked just once a month when he goes to the clinic to get more medications. He goes to the clinic, but he prefers his general practitioner, who "Is a good doctor" in the city. He says that "The doctor checks everything and has more [tools] to check." However, it is hard to get to the city because one has to take multiple minibus taxis to get there. "The government doctor used to come to the clinic once a month...I go to the doctor or clinic when the medication runs out. This might take two months. I go if I am in serious pain."

His family life and support structures have changed. His wife and a couple of his children passed away some time ago, leaving his daughter-in-law to support him. She helps him by cooking and cleaning around the house. During our conversation, he also called on one of his young grandsons to help him with something. He doesn't have outside support. "There is no one. I just go to doctors."

So what was he taught about diabetes? "They didn't teach me. They just gave me the medication, and they told me how to take it." He wants other diabetics to know that "the medication does work."

But that doesn't mean that he feels well all of the time. At first he claimed that "I don't feel any different." However, he used to not be able to walk because his legs were so sore. Even

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now he uses a cane to help him walk. Nala, my interpreter, said that she had known him to be very sick. Towards the end of the interview, he admitted that he "had never been sick until now (that he has diabetes)". He says that "I am sleeping a lot. That is new for me." While we talked, he rubbed his feet, saying that they were hurting.

Just as we were wrapping up our conversation, a friend of his dropped by. The friend asked what we were talking about so Ted explained that we were talking about diabetes. His friend seemed puzzled. He wanted to know what caused diabetes. Ted didn't know either so he turned to me. I explained carefully that there were two types of diabetes. The first type occurs when the body just stops making insulin. The second type usually occurs when a person eats too much sugar so their body stops knowing how to respond to sugar. The two friends nodded, but I am not sure how much I helped them.

He asked if I had brought "anything." According to my translator, "anything" meant medications or traditional teas or things. I took this to mean that he believes in traditional medicine. When I asked Nala about traditional medicine, she said that "If people believe that something is going to help them, it does." Although this is her personal take on traditional medicine, that she said it right after this interview made me think again that Ted believes in traditional medicine.

Ted has accepted his diabetes. "Now that I am old, it is just one of those things that take old people."

Hubert is a graying gentleman with two wives. He only lives with one of them currently because she is sick, and he needs to take care of her. Nala told me after the interview that it is very rare for him to be taking care of her this way. She commented on how much he is doing for her (cooking, cleaning, etc.) which men don't usually do. Part of Hubert's wife's sickness is diabetes, but she is also mentally disturbed. It is unclear at times what is caused by the diabetes and what is caused by mental illness. His wife was present throughout our interview, sitting on the bed. She was twitching and had her eyes closed most of the time. He sat with his back turned to us. He was busy sorting through laundry while we talked.

Right away, Hubert assumed complete responsibility for his wife. "I am her support." And he has been for a while. "I don't know when it started, but it has been a long time. Maybe 2005 or 2006."

What does this good caretaker do? "I go with her to the clinic for medications and injections. She goes when those run out or if she is feeling more sick. She takes medication, but she also gets injected with insulin daily...My daughter-in-law also helps by giving [her] the insulin injection daily." She only gets her blood sugar tested when she goes to the clinic. He also tries to provide her with a healthy diet. "It is hard to eat vegetables because she has no teeth. She eats bananas because they're soft, but I have been told that banana is bad [for her]. Because it's April, it's hard to get the right food, but I am trying." He will not turn to traditional medicine. He explained that "most herbs are expensive. She uses medicines from the clinic. I don't trust traditional medicines because you're not sure what they put in it."

He gets his knowledge from people at the clinic he takes her to. "They do teach sometimes. When she first started medications, they taught a lot." Hubert struggles with her multiple illnesses though. "At the beginning [of her diabetes], she was also mentally disturbed, so I can't tell what is just diabetes." He seemed visibly worn down but persistent.

So what does his wife think of all of this? "She had to accept it and take the medication. She asked [people at the clinic] what she could do. They suggested medications. But sometimes she's angry." And she doesn't enjoy talking about her illness. "There is no support group. Even if there was one, she does not like to talk about her personal life, even before she got sick."

Hubert had to step in and start taking care of his wife when she was defaulting on her medications. "The medications are helping now because when she was taking them herself, she might not have been taking them the right way. With my help, it's working." Hubert cares for his wife, and he only wants her to feel better. At the end of my questions, he asked me if bananas were good for her to eat. He also wanted to know what was causing her diabetes.

My next interview was with MaSamu. She seems to be the most educated diabetic whom I have spoken to. Part of that may be due to her job as a Red Cross worker so she is in the health care

field. However, I think a large part of it has to do with her son Samu's influence. A couple of times throughout the interview he interjected his own thoughts about her disease.

"It has been about five years now." Hers has not been an easy journey. "I inject myself twice a day, and I take tablets too...The hardest moment was when I was diagnosed, and they told me that I must inject myself with insulin. I had to get over that fear."

Education on her disease has helped her cope. "When I was diagnosed, I was taught mostly about diet and eating healthy. I was told to eat more fruit and less starch. I should also mix more vegetables into my diet. I was told that I must exercise." For her, this meant "working and playing with grandchildren."

MaSamu wants to know more though. She is somewhat aware of how her blood sugar levels make her feel, and she asked about how to fix both high and low sugar levels. As of now, she only checks her blood sugar once per month at the clinic. However, she is looking into getting a blood sugar meter soon so that she can monitor it herself. "It's better to check more often."

"I go to the clinic because it is closer [than a doctor]. Since I have been going there, I have been satisfied." But she doesn't go there for the support. She doesn't use a support group now because there aren't any in the area currently. However, she said that there used to be. "We used to meet at the clinic. It wasn't a discussion. The nurses would teach us things." She gets the support she needs elsewhere. She smiled and looked at her grown son. "My family is my support." This is when Samu interjected "They don't call me a gentleman for nothing."

I raised a question about traditional medicine and started a conversation, which MaSamu, her son, and my interpreter all agreeing that traditional medicine is not the way to go. MaSamu said, "I have never tried anything like that."

Diabetes has been a journey for MaSamu. "When I was diagnosed, I was angry. I was very stressed out because I did not want to inject myself. I was afraid of injections, and I didn't inject myself for the first month. But then I thought about my life and what I had to live for so I started injecting myself with insulin." She has now accepted diabetes as a part of her life, and she is "okay with it", albeit still very inquisitive about how to feel better.

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One day I got the opportunity to talk to Nurse Tia. She often does things like setting up outreach clinics outside local trading posts and going on rounds to patients' homes. She really enjoys her job. Her passion for being a nurse comes from seeing the need for nurses firsthand. In her family alone, she says "We have buried ten people since 2000."

I began by asking about her experience with diabetes. As an outreach nurse who sees chronic patients often, I thought she might know something about the elusive diabetic clubs. "Clubs?...No we don't have those. It's hard for people in rural areas to get together, and they don't see why it's important. They aren't educated enough [about diabetes] to see how talking to other people would help them."

Because she has always been an outreach nurse, she has never been a part of the diagnosis process. "We refer them to the clinic if we suspect something like diabetes or hypertension, and they do the diagnosis." However, she did check the blood sugar level of every diabetic that came to the outreach clinic distribution, a monthly event.

The clinic also does the educating. "Diabetic patients even in rural areas know what sugar and starch do to them, and they know that they're bad." At a different point in our conversation, she said "education was about the right way to take medications. It was also about diet." She never mentioned exercise.

She attributed part of the lack of diabetes knowledge to the age of the diabetic. "There are young diabetics too. Maybe we can teach the young ones something. The older patients will say they know what you're talking about, but they really don't."

Nurse Tia described the variety of attitudes about a diabetes diagnosis. "It is a mixture. Some are okay with it. Some are in denial like 'I can't have that sugar disease.'" But "acceptance comes with education."

People seem to go to the closest clinic to them. Obviously, we saw many people at the outreach clinic, which was meant to get as close as possible to people's homes. She went on to talk about immunization and the problems with the way the municipality wards are drawn up. "Because one of the [clinic's] wards is closer to another clinic managed by a different district, that district is stealing numbers from this clinic district. Even when we work so hard, it looks like we are under-performing." Although she was talking about immunization, if residents of

that outer ward are going to a closer clinic for immunizations, they are probably going there for their other needs too.

“Why are you doing this project about diabetes?” I told her I thought it was a growing issue in South Africa. At another point in our conversation, she seemed to share my opinion. I asked about the common ailments she saw with her traveling job. "It's hypertension and diabetes for the older people."

I visited a last diabetic named Gertrude in the roundvel at her home. She was living alone since her kids had moved out some time ago. She was very chatty but not when it came to talking about her diabetes. At that point, many of her answers became short replies to the questions posed.

Diabetes is nothing new for Gertrude. "It has been a long time. I don't know when it started." Knowing that she lives alone, I wanted to know who supported her with her diabetes. She smiled as if I had told a joke. "Nobody helps me. I do everything by myself, but it's not hard at all." Did she utilize support groups in the area? "I meet other diabetics when I go to the clinic, but there is no club." Gertrude goes to the clinic to get more medication when her supply runs out. She was diagnosed on a visit to the clinic. "When I was diagnosed, they checked my blood sugar. They told me about the medications I needed to take." I pressed her about diet. "They said nothing about diet."

She finds some relief in her medications. "There's a difference since I started to take the medication... I started to feel better when I took the medication and ate differently." Gertrude doesn't vary from her clinic medications either. "No, I don't believe in those [traditional remedies]... I take medications that I get from the clinic."

I asked her if she knew what causes diabetes. She simply said "No." She didn't ask me to embellish. But she did ask me how to help her high blood pressure and diabetes. From what I know about high blood pressure, I told her that cutting down on salt is a good idea. I told her that controlling diabetes has a lot to do with a varied diet. She just nodded.

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From watching her answer all of my questions, I saw that nothing seemed to phase her. I wanted to know how she felt about diabetes. "I was confused at first. I didn't know what this disease was. But I started to feel better when I took the medication and ate differently."

Throughout my time in this rural community, there were random moments when my work with diabetes within that community became relevant outside of my one-on-one interviews with people. It was these moments that confirmed for me how big of an issue diabetes is in this part of KZN, South Africa.

One morning I was set to shadow a CCG on her rounds throughout the community. She, a couple of Red Cross workers, and three clinic sisters ended up putting on an outreach clinic and one of the local trading stores that day, as they do once per month. As a group of 20-25 patients were gathered waiting for the clinic to be set up, the Red Cross workers, who spoke English, encouraged me to ask some questions of the diabetics within the crowd². Their questions for me were perhaps more interesting though. No one in that small crowd knew or was willing to speak up about the causes and types of diabetes. Using my knowledge from my previous education in the United States and from health professionals in Durban, I explained the two major types of diabetes and simplistically what caused them. They asked me questions that I could not answer pertaining to drug combinations for different conditions. And they asked me how they could feel better when they were already reportedly doing all of the right things. That was a tough question to answer. They didn't tell me what exactly they were doing to help themselves currently. I preached, again from my previous knowledge, that diabetic care is a combination of taking the right medications correctly, eating a varied diet, and exercising. The translation of my words was met with a sea of nodding heads. I will never know if or how much I helped those people, but I know that having an open conversation about their disease could not have hurt them.

² I was unprepared for this impromptu question and answer session, and I was unable to obtain proper consent from individuals who participated in that conversation. However, I think that it is still appropriate to share some of the questions they asked me, as these indicate holes in their diabetes education without me taking personal information from them.

Another day I was set to attend an imbizo³ that my host aunt had helped to put together for the municipality. My translator and I had met one of the municipality workers before people were even seated, and she was very interested in me and why I was there. She was so interested that she asked me to speak at the beginning of the meeting to explain myself to the assembly. What does diabetes have to do with a municipality budget? However, some people were intrigued by my story, and after four hours of budget talks, a question about diabetes came up from a member of the audience. The question was about the cause of diabetes. This was not a new question for me, but I was very surprised by the setting it came out of this time. This experience led me to believe that diabetes is relevant to more parts of the community than I had thought about.

A large part of eating healthy with diabetes is about controlling the amount of starch that is consumed. As a guest of the house, I felt that it was rude to turn up my nose at any meal that my host family served me. They served me a lot of starch though! I ate excessive amounts of phuthu⁴ and white bread to resent those foods for any foreseeable future. Those are exactly the kind of foods that are unhealthy for diabetics in large quantities (Desmond, 2012, p. 19). In my opinion, they're unhealthy for anyone to eat in large quantities because I often felt sick after meals. The reality is that those foods are cheap and easy to find in a rural setting, making the masses of people prone to eating them and in large quantities. That cannot be good for diabetes.

³ An imbizo is a community meeting about a current community issue. This particular imbizo was held around the topic of the budget for the next fiscal year.

⁴ Phuthu is ground corn meal, cooked in boiling water, and it resembles porridge.

Analysis/reflection

Looking back at all of my experiences with diabetics in this part of KZN, I realize that their questions about diabetes were the defining parts of this study. Regardless of the topic, there was always an underlying “Why?”

Why⁵ do I Need Support?

One of the aims of this ISP was to find sources of community support for diabetics, but I have found little evidence of such support. Instead, diabetics rely on family. Gertrude, who lived alone, cited no one as support (Gertrude, 2015). All of the other diabetics only credited family members (Ted, 2015; Hubert, 2015; MaSamu, 2015). Family support is imperative, and this study saw that especially in how Hubert was taking care of his wife (Hubert, 2015). In Zulu practices, it is rare and special for a man with two wives to devote all of his time to caring for a sick wife (Nala, 2015). While Nurse Zamani is supporting a family member with diabetes, she insisted that the clinic was supportive also (Zamani, 2015).

But family support is not enough, and I believe that these diabetics would benefit from a diabetic club within the community where they could learn from each other about coping with symptoms, eating habits, exercise habits, etc. In all six of my interviews, no one cited community or neighbors as support, and no one had known of any diabetic clubs currently operating, defeating my hypothesis that community support would be critical in a small community like this one. Nurse Tia confirmed this by saying “It's hard for people in rural areas to get together, and they don't see why it's important (Tia, 2015). They aren't educated enough [about diabetes] to see how talking to other people would help them.” However, one diabetic, Gertrude, may see the need, especially because she lives alone. “I meet other diabetics when I go to the clinic, but there is no club” (Gertrude, 2015). Dr. Marilyn Ritholz, a psychologist the Joslin Diabetes Center, believes that “sometimes a person with diabetes can feel very alone and “different.” Support groups are important and helpful to people with diabetes, because they provide a venue to meet others who share similar medical and psychosocial concerns” (Joslin

⁵ Throughout the Analysis section, I explain my title “Why-abetes” through these questions. I am trying to emphasize the number of questions that diabetics in the area of study still have about their disease.

Diabetes Center, 2015). Others see the need for community support groups. One branch of Diabetes South Africa, an NGO supporting diabetes needs within the country, explains “as part of our outreach project we motivate, manage and finance community support groups: we have over 30 support groups, many in underprivileged areas, a critical element in good diabetes management” (Diabetes South Africa, 2014). “A diabetes strategy for (South) Africa: regaining momentum,” a review on diabetes strategies in South Africa, proclaimed that “A need exists for a patient advocacy group similar to the Treatment Action Campaign for HIV/AIDS” (Mollentze, 2009, p. 51).

The bottom line is that this part of rural KZN currently lacks community support, structured or unstructured.

Education—Why Do I Have Diabetes?

I discovered that the biggest issue facing diabetics in this rural community is the lack of education about the disease. When asked how diabetics were educated, both nurses initially referred only to the education received upon diagnosis with diabetes. All of the diabetics⁶ confirmed that they were taught when they were diagnosed, but none of them said anything about current, ongoing education (Ted, 2015; Hubert, 2015; MaSamu, 2015; and Gertrude, 2015). So what were they taught? Three of the four diabetics were only educated on how to take their medication (Ted, 2015; Hubert, 2015; and Gertrude, 2015), with the fourth diabetic also getting some education on diet and exercise (MaSamu, 2015). However, Nurse Tia believes “Diabetic patients even in rural areas know what sugar and starch do to them, and they know that they're bad” (Tia, 2015). Do they really? When were they educated about this if it did not come during their diagnosis education? MaSamu explained that at the out-dated support group, “the nurses would teach us things” (MaSamu, 2015). Nurse Zamani claims “We ask [diabetics] every time that they come in about what they are eating” (Zamani, 2015).

One of the four diabetics was interested in checking her blood sugar herself (MaSamu, 2015), but none of the six people I met with spoke about the consequences and complications of poor blood sugar control, a crucial part to diabetes management (Desmond, 2012, p. 6).

⁶ Although Hubert was not a diabetic himself, I group him in with the diabetics for simplicity. I do this because he is speaking on behalf of his wife.

According to the article “What the primary healthcare worker needs to know about the management of type 2 diabetes,” “diabetes patient care flow sheets, care objectives and patient information leaflets are freely available” (Mollentze, 2012, p. S20). But are they widely distributed and used?

At my interviews with Ted and Hubert, I asked how they thought that diabetics should be educated about diabetes, and they both avoided the question (Ted, 2015; Hubert, 2015). Is the lack of education and under-recognition of the need for education due the age of the majority of the diabetic population? Nurse Tia said, "There are young diabetics too. Maybe we can teach the young ones something. The older patients will say they know what you're talking about, but they really don't" (Tia, 2015). Regardless of why these diabetics did not know about their disease, health illiteracy is a problem. The South African Summit on the Prevention and Control of Non-Communicable disease states “Unequal development including poverty and health illiteracy is strongly associated with increased NCD morbidity and mortality” (South African Summit on the Prevention and Control of Non-Communicable diseases, 2011, p. 2).

Prolonged education should improve a diabetic’s quality of life. Community support should fill the holes in diabetic education, but there is no such community support. I believe that a diabetic club in the area would be a step in the right direction. Because of the low level of current education⁷, I think that some education from clinic nursing staff about diet, exercise, medication, and general knowledge about diabetes may be necessary to get the group going. However, this educator would need to be correctly educated⁸ and be teaching correct principles. One barrier to a diabetic support group in this rural area of KZN currently is the reality of getting everyone together. One of the diabetics I interviewed has had some trouble walking (Ted, 2015). The same realities that keep people from traveling far for medical advice apply to traveling in general. "Sometimes when people cannot travel easily, they will send a family member to pick up medications for them" (Zamani, 2015). If diabetic patients cannot even travel to obtain their medication, how would they be able to travel to a diabetic club?

⁷ This is a personal belief.

⁸ Each clinic is supposed to have a list of diabetes guidelines, which each nurse should follow from the diagnosis checklist onwards. These guidelines would contain how diabetics should be educated about the disease.

Why Is Diabetes So Hard?

When diabetics were asked about the largest struggle with the disease was, they all had different responses. Ted spoke of a complication due to diabetes (Ted, 2015), Hubert talked about how getting the proper diet was hard (Hubert, 2015), and MaSamu told me about her fears of injecting herself with insulin (MaSamu, 2015). Nurse Zamani explained how it was hard to properly monitor diabetics when they fast before coming to the clinic. “We don't want people to do that because we want to know that their medications are working” (Zamani, 2015). Because diabetics faced a list of issues, I think that talking to other diabetics in the area who face similar issues would benefit everyone involved. For instance, if one diabetic struggled with diet while another struggled with exercise, the two could share what was and was not working for them, giving new ideas to both sufferers.

No one in my study brought up the misconception that losing weight implied that the person was HIV-positive. I asked one of the nurses about it, and she laughed. She explained to me that “fat is an attitude that people had. It was more like ‘Oh, your family isn’t feeding you well? Shame.’” So being larger apparently indicates that one’s family cares about them.

Why Should I Use the Clinic vs. the Doctor?

All four diabetics in this study used primarily the clinic to get their medications (Ted, 2015; Hubert, 2015; MaSamu, 2015; and Gertrude, 2015), although Ted preferred the doctor (Ted, 2015). A nurse from the area seconded that people go to the clinic nearest them (Tia, 2015). Another nurse claimed that transporting some individuals is so much of an issue that some just send family members to pick up their medications (Zamani, 2015). All four diabetics informed me that they are currently only getting their blood sugar checked once a month when they visit the clinic (Ted, 2015; Hubert, 2015; MaSamu, 2015; and Gertrude, 2015). When patients with diabetes cannot make it to the clinic, they are missing out on their only blood sugar monitoring opportunity that month. Sometimes this monthly blood sugar testing is cause for concern. “Diabetic patients will often fast before coming to the clinic because they know that eating raises their blood sugar” (Zamani, 2015). Are diabetics afraid of the authority that is the clinic sisters when their blood sugar appears too high? If so, what can be done to make this environment more supportive to diabetics seeking treatment?

Rural realities differ from the ideal professional diabetic management involved. According to a “Diabetes Education Booklet for Patients” that a dietician in Durban gave me, diabetic patients should be seeing a doctor/specialist diabetic doctor, a specialist diabetes nurse educator, a dietician, and ophthalmologist⁹, a podiatrist¹⁰, a dentist, and a pharmacist (Desmond, 2012, pp. 2-3). One of the diabetic patients told me “The government doctor used to come to the clinic once a month” (Ted, 2015). In this reality, how can one doctor see all of the diabetic patients in addition to the other conditions needing his attention in that one day a month? And a doctor is only one of the seven health professionals which are recommended for diabetics to see (Desmond, 2012, pp. 2-3). In order for diabetics to be monitored, they must visit a clinic or an outreach clinic, and transportation even within the community is not easy for some. “This might mean having to hire a car to drive them, which is expensive” (Tia, 2015). Neither of the diabetics interviewed who injected with insulin reported any trouble in obtaining enough insulin.

Diagnosis of diabetes occurs at clinics. A nurse from the clinic informed me that the blood sugar is checked of every patient admitted to the clinic (Zamani, 2015). Is this a part of a screening process? The head of the KZN Department of Health Dr. Sibongile Zungu encourages annual health check-ups to screen for things like diabetes (Government of South Africa, 2014, n.p). Perhaps this is the clinic’s way of screening for diabetes, especially if people are not already coming in for the suggested yearly checkup.

Why Should I Use Traditional Medicine?

All of the diabetics that I interviewed were on medication from the clinic, with two of them also taking insulin injections daily (Ted, 2015; Hubert, 2015; MaSamu, 2015; and Gertrude, 2015). Only Ted said that he used traditional medicine for his diabetes (Ted, 2015). The other three diabetics did not use traditional medicine, calling it expensive and untrustworthy (Hubert, 2015; MaSamu, 2015; and Gertrude, 2015). Thus, traditional medicine was present but not popular amongst this older population in the community.

⁹ Eye doctor

¹⁰ Foot doctor

Why Am I Okay with My Diabetes?

Although the overwhelming response to diabetes currently among the four diabetics interviewed in rural KZN was acceptance (Ted, 2015; Hubert, 2015; MaSamu, 2015; and Gertrude, 2015), it had not always been such. Two were angry and confused at the time of their diagnosis (MaSamu, 2015; and Gertrude, 2015). A nurse who diagnoses patients said “Some are okay with it. Some are in denial like 'I can't have that sugar disease' ...[but] acceptance comes with education” (Tia, 2015).

Age seems to have some impact on acceptance as well. One diabetic felt that "Now that I am old, it is one of those things that take old people" (Ted, 2015). One nurse agreed with this sense of fatalism, saying "They have it, and it's not going away. It is a burden they have to bear" (Zamani, 2015). Perhaps these patients were not seeing ways in which they could feel better in the future.

“There is [a] need to fully integrate non-communicable diseases into the re-engineering of Primary Health care in South Africa with the view to increasing community based prevention, screening, self management, care (including rehabilitation and palliative care) and referral according to the WHO innovative model for chronic care” (South African Summit on the Prevention and Control of Non-Communicable diseases, 2011, p. 3). These fatalistic diabetics do not realize what complications poor management of the disease is setting them up for. “Patient education and self-care is central to the prevention of acute complications, and that of chronic macro- and microvascular complication” (Mollentze, 2012, p. S22). Diabetics living within rural KZN need to realize the responsibility they have in their managing their diabetes.

Why Should I Diet and Exercise?

One aim of this ISP was to discover how diabetics in one area of rural KZN are managing their disease, partly through diet and exercise habits. I received different responses about the variety within the diets of diabetics of the area. One diabetic ate the same as always (Ted, 2015), two eat more variety (Hubert, 2015; MaSamu, 2015), and one ate “differently” than before she was diagnosed (Gertrude, 2015). One of the nurses insisted that diabetics were aware of the

dangers of starch (Tia, 2015). The “Diabetes Education Booklet for Patients” suggests “The amount of starchy/carbohydrate rich foods is most important as these are the foods that have the biggest impact on your blood sugar levels” (Desmond, 2012, p. 9). Diet change is not always easy, and one of the nurses acknowledged that “this is hard for some people and not as hard for others” (Zamani, 2015). Tuck shops which feed the community sell mainly non-perishable food items that are in constant demand. If healthier options, perhaps those lower in sugar and starch, were more widely promoted and sold in tuck shops, consumers would buy more of them, creating a healthier diet in the process. One man added that “because of the season it was hard to get the right food” (Hubert, 2015). When some foods like vegetables are out of season, they are more expensive to buy. There seems to be an understanding that healthy food is expensive. Locally-applicable advice from a health professional could address some of these economic concerns of individuals.

Only one of the diabetics brought up exercise during the four diabetic interviews (Ted, 2015; Hubert, 2015; MaSamu, 2015; and Gertrude, 2015). There seems to be an aversion to exercise. One of the nurses explained that people “think they have to go out on the road and run” when it’s really about doing the small, everyday movements (Zamani, 2015). Diabetics in this community have misconceptions about the amount and types of exercise that would benefit themselves.

Why?

One of the diabetics interviewed had a question for me about managing her blood sugar. “What can I do when I have high blood sugar?” (MaSamu, 2015). The fact that she recognized how her blood sugar level made her feel was unique among the diabetics that I interviewed. Yet this should be taught among other things to a diabetic when he or she is diagnosed (Desmond, 2012, p. 5).

However, the most frequent question I got was about the cause of diabetes. I was shocked that this question came up with diabetics during one-on-one interviews. Coming from a paradigm where people know too much about their diseases because of resources like WebMD, I was surprised that diabetics in this part of rural KZN were unaware of the basics of a disease

they had been living with for a number of years. I was surprised that people at a community budget meeting wanted to know about the cause of diabetes. If people were unaware of the cause of diabetes, they were unaware that there are multiple causes of diabetes because there are multiple types of diabetes. I had intended to ask each diabetic interviewee which type of diabetes they had, but as at least three of the four were unaware of the cause of diabetes, I presumed that they did not know of the multiple types (Ted, 2015; Hubert, 2015; MaSamu, 2015; Gertrude, 2015).

I had intended to ask all of my interviewees about diabetes prevention and education, but when I realized that these people with diabetes had no idea what was causing it, I knew that prevention methods were not being utilized in the area. Grade 7 learners are supposed to spend three class hours in their Life Orientation course in weeks 3-5 learning about common diseases, including “tuberculosis, diabetes, epilepsy, obesity, anorexia, HIV and AIDS” (Republic of South Africa, 2011, p. 15). Is that enough time to really learn about diabetes type II prevention? Were older generations given any such education? More than one of my interviewees was admittedly illiterate, meaning they would not have attended formal schooling. Prevention and knowledge about diabetes are seriously lacking in this part of KZN.

Conclusions

People with diabetes in one area of KZN have strength to deal with their disease, but they lack the knowledge to make their disease more manageable. Family support is currently the only really support that these diabetics are getting. A diabetic support group would help educate people with diabetes in an environment conducive to support. However, there are some barriers to the formation of such a club. Transportation, particularly for those who cannot walk very well, is an issue in getting participants together. The recognition that such a group would help diabetics learn from others with the same disease living in similar conditions is still unknown. Education seems to come primarily and almost exclusively upon diagnosis with the disease. In order to maintain healthy habits, education must be prolonged. Diabetics struggled most with different aspects of the disease so learning from others in a collective, supportive setting would allow diabetics to give and take from other people with similar issues. The diabetics in this community utilize the local clinic because it is the easiest form of access to medications. Traditional medicine, even among older people with diabetes in this rural community, is not common. Diabetics in this part of KZN are typically accepting of their disease. Part of this acceptance and fatalism could be due to their advanced age. Diabetics need a varied diet, but this is sometimes hard to achieve in this rural setting. The importance of exercise is overlooked, and there are misunderstandings about the types of exercise that older diabetics should be doing. Overwhelmingly, people's largest remaining question about diabetes was what was causing it. This made me believe that people in the community are not aware that different types of diabetes exist. Education about diabetes currently begins in grade school, but this education has not reached older generations. However, education upon diagnosis must still be expanded to completely cover medications, diet, exercise, and general knowledge about the disease.

In the future, studies on this topic could continue in a few directions. I discovered that a lack of education about diabetes in rural KZN was an issue, and further study could facilitate some sort of learning space, noting what diabetics were gaining as completely new knowledge. This study could be tried in another rural community in South Africa. This study only considered the Zulu population, but perhaps another of South Africa's populations might show

different results. Another study could look at how people identify with their diabetes, noting what parts of themselves feel sick. This would make for an interesting body mapping exercise.

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Annexure 1: List of questions

The following questions were used as a guide during one-on-one interviews:

1. What is your story with diabetes?
2. How long have you had diabetes?
3. What does diabetes mean to you? What is your attitude about it?
4. How does diabetes make you feel?
5. How do you take care of yourself because you have diabetes?
6. Do you go to the clinic or the doctor?
7. Do you take pills or inject insulin?
8. Who supports you? How?
9. Is there a sort of support group in the community?
10. How often do you check your blood sugar? How often do you go to the clinic?
11. How did you change your diet once you were diagnosed with diabetes?
12. Do you exercise?
13. What were you taught about diabetes?
14. What is the biggest challenge about having diabetes?
15. Do you know anything about traditional medicine for diabetes?
16. Do you have any questions for me?

