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# An Exploration of Diabetes Care in Durban, Kwa-Zulu Natal, Suburbs as Seen Through the Work of Diabetes South Africa

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*SIT Study Abroad*

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AN EXPLORATION OF DIABETES CARE IN DURBAN, KWA-ZULU NATAL, SUBURBS AS SEEN  
THROUGH THE WORK OF DIABETES SOUTH AFRICA

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Advisor: Clive Bruzas

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AN EXPLORATION OF DIABETES CARE IN DURBAN, KWA-ZULU NATAL, SUBURBS<sup>1</sup> AS  
SEEN THROUGH THE WORK OF DIABETES SOUTH AFRICA

**Acknowledgements:** I would like to thank Clive Bruzas for advising me on my study and guiding me when I needed directions. I would also like to thank Clive for giving me the push I needed to reflect on my own experiences as a diabetic. I feel like the reflections I have had this semester on my own internal struggle have truly made me grow as a person and as a professional. I would like to thank Mrs. Jenny Russell, Mrs. Natalie Pakiri and the rest of the staff of Diabetes South Africa for allowing me to participate with them and learn all that I can about their role in diabetes treatment and care, and for treating me like one of the DSA family. It truly meant an incredible amount and I will always remember your kindness. Thank you to Dr. Fraser Pirie, Mrs. Kerry Dolloway, Mrs. Julie Peacock, and Mrs. Fikile Serakoeng for sharing your exceptional experiences. I would like to thank Mr. Zed McGladdery for encouraging me to pursue this topic. To my incredible homestay family from Cato Manor who allowed me to stay with them during the process of this study, ngiyabonga kakhulu. You are my true family in South Africa and I have been so blessed to live with you, laugh with you, and cry with you. You have taught me so much about South Africa and my own self that you have honestly changed me forever. Lastly, I would like to thank my family at home in the United States of America for helping me learn to manage my own diabetes and giving me the opportunity to pursue my dreams of helping others with diabetes care abroad.

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<sup>1</sup> I chose to use the term suburb instead of township in this study because there is an apartheid residue linked to the lexis. Nigel Gibson's paper entitled, "The Pitfalls of South Africa's 'Liberation'" discusses the role of this terminology utilized during the Apartheid era and the consequences it has on the development of unity in contemporary South Africa. See: Gibson, Nigel, "The Pitfalls of South Africa's 'Liberation'", *New Political Science* 23(2001): 1-17.

**Abstract:**

This study portrays the lived experiences of diabetics and diabetes caregivers in Durban suburbs through the lens of Diabetes South Africa (DSA), a Non-Governmental Organization (NGO) operating out of Durban. Furthermore, this study also analyzes the progression of the treatment and services offered to diabetics. The specific aim of this study was to understand the situation of diabetic care in the suburbs and the obstacles to improvement. Because diabetes is registered by the World Health Organization (WHO) as a worldwide epidemic and because the rate of diagnosis will be increasing (World Health Organization: Diabetes updated March 2013), it is necessary to comprehend the current state of care in order to cope with the worsening situation as the population of diabetics is increasing.

This study provides a unique perspective on diabetes care facilitated by DSA and others through narrative, triangulating my personal experience and others' personal experiences about being diabetic or offering services to diabetics. Interview was the most significant vehicle for obtaining information, and the interviews are retold in narrative form. Members of DSA, an endocrinologist, two nutritionists, a podiatrist, and a community member have all offered their experiences as aids to understand the situations that face diabetics in Durban. The primary site for the project is DSA and my relative personal experiences while volunteering with DSA as a Type 1 diabetic have also been recounted in this comprehensive report.

Each individual that was interviewed about their experience with diabetes had different experiences in that they each interpreted their involvement and relationship with the disease differently. In this study, I found that my opinion about diabetes care and management in Durban shifted from critical and skeptical to an opinion that is now appreciative with increasing trust in the medical system of South Africa. The services that are currently offered via hospital (public and private) or clinic are not offered effectively to diabetics, but the system is ever-improving. The support system that DSA offers is utilized widely in the Durban suburbs and DSA supplements necessary knowledge to diabetic patients, even from suburbs where public hospitals or clinics are not able to perform on

par. I personally have become inspired by the amount of work that DSA accomplishes with limited staffing and monetary (donation) resources.

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**Helpful Acronyms:**

DSA	Diabetes South Africa
DESSA	Diabetes Education Society of South Africa
KZN	Kwa-Zulu Natal
NGO	Non-Governmental Organization
SEMDSA	Society of Endocrinology, Metabolism, and Diabetes in South Africa
WHO	World Health Organization



## **Introduction:**

I was diagnosed with Type 1 diabetes when I was 17 months old. My mother and father took very good care of me and I enjoyed living a regular life. I woke up, ate cereal for breakfast, went to school, did homework, went to sleep the same as every other little child except that I had to have a shot of insulin twice a day and I had to do blood checks at regular intervals. Truthfully, I had a great experience growing up as a child with diabetes. My parents were extremely involved in training me to care of myself. Every meal was pre-planned. I ate breakfast cereals that were low in sugar, sandwiches that were made with brown bread and lots of meat, and veggies for dinner. Even when my parents divorced, I was able to maintain a healthy lifestyle while living with my mother and father in their respective houses. Only when my mother was diagnosed with gastric cancer did I finally assume complete responsibility for my disease.

The assumption of responsibility for a disease like diabetes is something that I have always found interesting. This is because the nature of the disease requires consistency of treatment, rather than solely visiting the hospital and taking pills or injections. Type 1 diabetes (common in young children and caused by lack of insulin production in the body) and type 2 diabetes (common in the elderly and the result of genetics and a decrease in activity of the insulin receptors in the body) require separate forms of treatment, but both require the same assumption of responsibility from the patient. Diabetes: Greek meaning to flow through or to pass, referring to the excessive urination of diabetic patients. To pass, perhaps that can mean more than just urination. I wonder what the flow of life is for those who are diabetic in Durban. What services are offered to those who wish to not just pass their lives away and wish to fight the onset of complications? In South Africa, I have found that people feel that diabetes tends to fall to the wayside in terms of focus of funding. Because of this, diabetes treatments and education is limited. However, because the numbers of diabetic cases are on the rise, quality and quantity of care and treatment must be improved to accommodate the increasing number of new patients.

Diabetes is an epidemic in Sub-Saharan Africa with direct ties to poverty, urbanization, and social upheaval (Motala and Ramaiya 2010). South Africa has been extremely involved with efforts to maximize diabetes care to the ever increasing population of diabetics. Difficulties have arisen, however, as a result of South Africa's multicultural nature. As understandings of health and wellbeing are tightly entwined with culture, the multitude of cultures and languages has impeded development to optimize resources, especially in rural areas where most diabetics remain undiagnosed (Amod, A. *et. al.*, 2012). Diabetes is a serious multisystem disease where "The insidious and initially asymptomatic nature of the disease result [ing] in patients not seeking early medical attention, so that 30-85% of cases of type 2 diabetes remains undiagnosed. At the time of eventual diagnosis, approximately 20% of patients will already have complications of the disease" (Amod, A. *et. al.*, 2012, 2).

Access to care and diabetes testing are the initial challenges faced by diabetics. Other challenges consist of the financial burden of the disease by needing to purchase insulin, which is an expensive commodity especially in rural South African clinics, in addition to the expensive blood-testing supplies (Fourié, 2005). There is minimal state support in terms of supplying diabetics with monitors at hospitals and clinics; however, although meters will be given to diabetics, the strips for the meters are expensive and difficult to obtain by patients not on medical aid (Dolloway, 2013). Education is also a challenge and in the rural areas that were visited on the SIT program, I noticed that one of the diabetics I encountered believed that eating sugar would safeguard her from the complications of her disease. Diabetic education is necessary to inform patients about the correct ways to take care of their bodies. Although not widely utilized (Pirie, 2013), the International Diabetes Federation created a training manual emphasizing that the, "The person with diabetes is the one who chooses whether to follow a treatment plan and makes decisions about everyday care" (International Diabetes Federation 2006). This emphasis would encourage diabetics to take control of their situation. Aslam Amod, chairperson of the Society of Endocrinology, Metabolism and Diabetes in South Africa (SEMDSA), is hopeful that change in the care and diagnosis of diabetes will result from empowerment (Amod, *et. al.*, 2012). DSA has had a hand in educational processes to empower patients and

encourage them to come to terms with their disease and also to inform them of correct techniques of care.

DSA operates in Durban via lectures and workshops, counseling, support groups, and even a noncompulsory camping trip. DSA has monthly workshops in which diabetic care and good lifestyle choices are reviewed and discussed. It is in this way that DSA encourages diabetics to change their behavior and provides appropriate ways and support to incorporate this change. Pharmaceutical companies also attend these workshops in order to provide free trials of the different foot creams as well as protein-rich shakes that promote stable blood sugars. These workshops are held at parks, clinics, hospitals, and a library to reach a large population of diabetics. At the NGO's headquarters, there is a fully functional podiatry office. In addition to these efforts, DSA also participates in the Global Diabetes Walk on November 14<sup>th</sup> annually and various conferences about diabetes care. Sister Gertie, an employee of DSA, works when she can in the suburbs to explain *isifo ushukela*<sup>2</sup>. In addition, workshops are run by Mrs. Natalie Pakiri and Mrs. Jenny Russell. This study seeks to understand how DSA specifically operates in Durban suburbs.

In addition to DSA and their participation in Durban suburbs near Durban, there are two other groups that have published works regarding diabetes in South Africa. These two groups, the Society for Endocrinology, Metabolism, and Diabetes of South Africa (SEMDSA) and the Diabetes Education Society of South Africa (DESSA), work in conjunction with DSA to administer care each through different areas. For example, DSA is directly linked with community members through providing workshops while SEMDSA works on the forefront of policy development (Pirie, 2013) and DESSA works with formal diabetes educators (DESSA, 2013). The role that DSA plays in Durban suburbs is the focus of this study; however, it is necessary to acknowledge the work that SEMDSA and DESSA have conducted to further South African diabetic care. SEMDSA has published regarding the focus of diabetic policy in the health care system and one paper is specifically featured in this study in order to identify the relevant policy.

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<sup>2</sup> *Isifo ushukela* is translated to "the disease of sugar" in isiZulu. While speaking to the largely isiZulu speaking members of the suburbs, it is helpful to utilize this terminology to describe what I am studying and to ask questions of interviewees.

This study extends the knowledge presently documented regarding the current situation of diabetes care in South Africa and it gives a unique perception of diabetes from personal encounters of community members and my own personal experience. This study addresses public health concerns centered on the quality of diabetic treatment and care that is accessible in the Durban suburbs. The situation of diabetes in Durban acts as a microcosm of the international situation. The methodological approach of utilizing narrative to discuss this case-study about DSA in relation to diabetes care and management provides a description about the situation of diabetes care that attempts to minimize bias. Biases will be stated and studied, giving this study a distinctive window with which to see diabetes care and experiences in Durban and the surrounding areas.

## **Methodology:**

This study was conducted via an instrumental case-study of DSA (Stake, 2005), supplemented with various interviews. I worked with DSA for three weeks from 7:30AM to around 2PM when I returned home to Cato Manor. I aided DSA in any way that I could with my experience as a diabetic, be that with organizing databases, speaking at workshops, observing, erecting a wireless internet system, and any other tasks delegated. The unique feature of this study is that while working with DSA, I also have been involved in different aspects of diabetes care through participation in workshops which are held bi-monthly for type 2 diabetics. The support groups were analyzed through my experience to see if they were effective in empowering diabetics. In addition I interviewed Mrs. Kerry Dolloway, nutritionist, Dr. Annette Thompson, podiatrist, Dr. Fraser Pirie, endocrinologist, Mrs. Julie Peacock, nutritionist and type 1 diabetic, Mrs. Jenny Russell, manager of DSA, Natalie Pikiri, secretary of DSA, and Mrs. Fikile Serakoeng, diabetic of Cato Manor suburb, to provide narrative and outside perspectives to diabetes access and care. The interviews have been collected and retold in this study as a narrative of the person who has given the interview. The narratives were then triangulated in the following writing and the cultural implications that my observations has had on the care of diabetes in Durban, South Africa, were explored. The methodologies of treatment in South Africa were compared and contrasted with the methodology of treatment in the USA from my own experience.

The sampling plan of this study was to speak with both women and men<sup>3</sup> about their experience being diagnosed with diabetes and/or their experiences with the challenges that they have endured. The specific aim was to understand the situation of diabetic care in the suburbs of Durban and the obstacles found to improving it. The most effective way of accomplishing this was to organize this study in the form of a narrative that triangulates the interviewees' experiences with my own and prior research. The age

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<sup>3</sup> Although gender was not specified in the sampling plan; I was not able to interview any men other than Dr. Pirie due to time constraints. It must be acknowledged that the lack of equal representation of both women and men in this paper may have caused bias.

group of those being interviewed is from 18-70 years old. Ethnicity is not specified<sup>4</sup> in this study because I am conducting a discussion of another's situation, regardless of ethnic identity. As long as the interviewees have a tie to diabetes in their respective communities, they have been encouraged to interview. This study attempts to be representative of the population of people living in the Durban suburbs, but it must be acknowledged that as a narrative with six interviewees for a qualitatively focused study, it is not possible to ensure that this study is completely representative. The specific procedures that have been utilized to recruit interviewees were to approach via email or in person and discuss the Informed Consent Form. The data collection site is DSA and I was the one recruiting participants and collecting the data. This study reflects the specific stories of a few individuals in the Durban suburbs and it will not be simplified into a general statement about diabetic treatment and care in South Africa.

Data collection instruments consisted of a Blackberry voice recorder if the participants are willing and a notebook and pen. Collection methods consist of asking questions that are outlined in Appendices B and C, and also by asking the interviewees to share their experiences with diabetes. Both participant observation and in-depth interviews were utilized to collect the data for this study.

In addition, I have given back to the community by volunteering for DSA workshops. This has allowed me to be involved in the diabetic community in an invested way where I have built trust with those I interacted with and gained a better understanding of the situation of diabetics in the Durban community. I shared my experiences at the support group and answered any questions that the members had. It must be acknowledged that the period of time for this study was extremely short, thereby making my understanding of the complex situation very limited.

The theoretical questions that this study looks to understand are the following: What is the attitude towards diabetics in Durban? What resources (medications) are easily available to diabetics? What societal or cultural structures impede this access? How does DSA operate in the community and what role does this non-governmental organization

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<sup>4</sup> It must be acknowledged that ethnicity plays an important role in the socioeconomic status of patients. Likewise, depending on socioeconomic class, the access of diabetic care and services will vary.

play? How should diabetes care be expanded into the suburbs? What are the shortcomings of the current primary health care system in regards to diabetic care and prevention? What is the level of education that diabetics receive on how to treat themselves?

These questions have helped to formulate the specific questions asked in the interviews and mentioned on the Informed Consent Forms. The interviewees were informed that qualitative methods are being utilized as they will be the most informative in retelling the lived experiences of diabetics in the Durban suburbs.

Major thematic areas of the data collected in this study are identified where stories are compared and contrasted in the Findings and Analysis section for investigation. Narrative (Alvermann, 2000) analysis interweaves my experience with those collected from interviews. The quality of care in Durban is evaluated from different perspectives to further give insight to the situation that diabetics undergo in Durban. The limitations of this study are the language barrier; however, all of the interviewees that I have talked to speak sufficient English so this barrier was minimized. In total, this study is of benefit to the Durban diabetic community because it will be given to DSA with the potential to help maximize the care it offers.

## Findings and Analysis:

### *A Doctor's Analysis*<sup>5</sup>:

The assignment that inspired me to contact DSA and pursue this study was an interview with my homestay family in Masxha, a Durban suburb next to Chesterville. I chose to interview my 13 year old homestay sister about the status of diabetes and her opinion in Durban. She emphasized that there is not much around to help the Mamas of Cato Manor get diagnosed and learn about their disease. Thus, I contacted Dr. Fraser Pirie from the Nelson R. Mandela School of Medicine to gain better understanding of the current situation in Durban.

Most of the following narratives are compiled in a way that emphasizes the use of narrative techniques. However, my conversation with Dr. Fraser Pirie is being represented in the form of formal interview. The conversation was extremely enlightening, however rushed and it shed light on the direction that this study has taken. His involvement with diabetes research in the Durban community is through a genetics study and study of hypoglycemia in type 2 diabetics. He believes that all of diabetes mellitus, but specifically type 1 diabetes, is managed poorly outside of hospitals<sup>6</sup>. He was familiar with DSA and identified that the lack of educators is a significant contributor to the inefficiency of the health care system in respect to diabetes care.

In regards to education of nurses, there is a course in Cape Town that will be utilized to combat this problem; however, the course duration is listed as one full year, and his confidence in nurses becoming certified is low. He stated that the hardships experienced by diabetics in the suburbs he believes to be dietary problems as well as the stigma of being different, meters being mistaken by thieves for phones and getting stolen, and poor clinic services. The South African Primary Health Care (PHC) system requires that diabetics take responsibility to ask for services and treatment at their clinics; however, this is one area of

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<sup>5</sup> The reason why this piece was put in the beginning was because it was the interview that shaped this study.

<sup>6</sup> Dr. Fraser Pirie further stated that this comment is an impression that he has gotten of the situation from talking to his patients. However, he has not spent much time in clinics to fully be able to analyze the extent to which type 1 diabetes is treated or not treated outside of hospitals.



education to diabetics that has been lacking. His personal opinion on how diabetes is dealt with in relation to PHC is that it is currently, “not good, but improving” (Pirie, 2013). He also acknowledged that the patients that he deals with cannot take control of their situations to assume responsibility for their own diabetic care. I personally resonated with his opinion on empowering diabetics to take charge of their situation and chose to include in further interviews, questions about the extent to which empowerment is considered important when educating diabetics.

Empowerment is difficult to instigate in another person. Truly, it must come from within. Creating the ideal space for diabetics to assume ownership of their disease is a challenge that diabetes organizations are continuously battling (Pakiri, 2013). DSA has been trying to create this space through using support groups that foster the sense of unity to cope. I believe that I would certainly have benefited from a support group such as the ones that DSA run when I assumed responsibility for my blood sugars when I was young.

*Type 1 Diabetes: My Story (Continued):*

My mother was diagnosed with cancer when I was 9. Although we lived in Washington state, my mother flew down to California to have herself checked out for a lump on her stomach. My sister and I followed her out to California shortly after she was diagnosed with gastric cancer. Moving wasn't that big of a deal to my sister and I because we moved around quite a lot and changed schools nearly every year. So in fourth grade in Westwood, CA, I put my blood check (which looked as if it came out of a 1980s “Back to the Future” film) in the back of my classroom. Five minutes before recess, I would quietly sneak to the back table to check my blood. I mutely sat in the back of the room so I didn't disrupt the class while checking.

Being new to elementary school in April (and not in September when the school year started), wearing flood pants (that were about five inches too short), and sporting stylish transition sunglasses (that took at least 10 minutes to lighten up once I entered the classroom) meant that I was obviously the coolest thing that ever met Warner Avenue Elementary School. But all of that—it wasn't enough. I had to be the *diabetic*, flood pant-wearing, visually impaired 4<sup>th</sup> grader that missed the memo and arrived in April. Needless

to say, it was a little tough to make friends. It wasn't too bad, but the sicker my mom got, the more responsibility I assumed in caring for myself and my sister (who was then 8 years old) who also had Type 1 diabetes.

This assumption of responsibility for my own blood sugars is a difficult time to remember because there was a lot of emotional turmoil. My own diabetes in my priority list fell to the wayside. I had no other diabetic to turn to and ask about caring for myself, nor did I have another older diabetic to idolize and model my testing practices after. Mrs. Julie Peacock, a type 1 diabetic, member of DSA, and attendee of the type 1 support group, had similar experiences to mine and she also has relatives with type 1 diabetes.

Julie's story:

I was diagnosed at the age of four. The symptoms were very excessive; I was drinking and urinating constantly. Needless to say, I was basically bedridden in two days. I went to the hospital and [back] in those days it took at least a week to diagnose me. I remember the long lancets that were used to take my blood sugar every two hours. It was indeed a traumatic time, I can remember. It was especially traumatic for my mum. She was worried and stressed and I remember she lost about 5 kilograms while I was in the hospital. I was discharged and went home a diabetic. In those days the glucometers were the size of a brick- they were huge!

Initially [doctors] used the urine dipstick to record my blood sugar [perhaps because the glucometer was too expensive]. My mum was very quick with me from the beginning and her involvement put me in good stead for the rest of my life. She taught me the right way to eat and to live with exercise. My brother was diagnosed also at the age of four. So when he was diagnosed it was quite a lot easier for my mum. Sadly, last month my brother's youngest child, a boy, was diagnosed with type I. Many, many members of my family all have type I diabetes, so it is very prevalent. And those who have diabetes in my family are all type 1.

I had a strict upbringing in terms of food and portion control. My mum made sure to pack lunches for me. Truthfully, I never felt excluded. I almost felt extra-special in school and with my friends and I found that I didn't really want to be "normal". In terms of the

condition, I've never been ashamed of being a type one, although many of my friends have not shared my condition with their families or other friends. It's fairly easy to hide. The only memory I have of deviating from my mum's controlled eating plan was when my mum caught me with Smarties behind my back and she said, "what do you have in your hand" I said, "nothing" she said, "Now why would you do that?" and I answered, "I'm just really tired of being diabetic". Although my mum controlled my blood sugar very intensely, we have had a good relationship. Because I have had type 1 for so long it helped me formulate my career and involvement in diabetes care as a dietician.

My passion is helping others, so I have become a dietician that cares mainly for diabetics; both type 1 and type 2. I do have a great understanding, in my opinion, about how the sugars all work and it's nice because I understand what the diabetics go through. From that point of view I am at an advantage because of this. I do have a lot of type 1 diabetics that come to me as a dietician because I know what they deal with. For example, they can eat the same thing from day one to day two and have totally different readings. And the fact that they should be exercising at the same time every day to keep their sugars under control is also something that is sometimes neglected to be communicated to diabetics, so I make sure I emphasize it.

I did do sports in high school to help with my blood sugar. I played hockey in high school and I am involved with aerobics as an important part of my current lifestyle. It has helped to keep me very healthy and I even have two children, a 9 year old daughter and 12 year old son. I was really nervous to have children but it had always been a dream of mine. And so I controlled it very tightly both before and after my pregnancies. My glucose control throughout the pregnancy was very consistent. I tested 12 times a day on average. My insulin requirements during the pregnancy doubled, but 2 days post-delivery my sugars were back down. With all due respect to the nursing staff I knew more about diabetes than they did. But anyways, I remember the pediatrician said that the children were perfect and if I hadn't been diabetic he would not have known the difference. To be sure, I'm very vigilant of my children's symptoms in case they are to follow the trend of the family and become type 1 (Peacock, 2013).

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After Mrs. Peacock finished speaking, I realized that I thought I couldn't have children. For years, I assumed that because my blood sugars were not well-maintained, that I would not be able to. It was saddening, but I eventually understood it as something that just could not happen. When Julie began talking about her pregnancies and children while also being type 1 diabetic, I was completely floored. I could not remember a time where I met a type 1 diabetic that had a family. My entire world view shifted. No longer was I completely set on just living my life and seeing how it would turn out, I had the possibility of having children. I now had responsibility; a reason to live and to care for my body. I began by checking my sugars every morning while still living in Cato Manor and making sure that I was okay.

This is one example of the nearly immeasurable support that DSA offers to diabetics in the area: there are so many inspiring success stories of diabetics that I would have benefitted from knowing, if I had had access to a support group like the one that Julie participates in. My life has been altered and I know that this is why these support groups are important because someone who doesn't realize it, but is uninformed can be righted by listening to those who are of similar age and of similar status.

*The Importance of Nutrition in Diabetic Care and Management (A Formal Interview):*

Mrs. Kerry Ann Dolloway discussed how one needs to take responsibility for one's own health and responsibility to become empowered and take ownership of the disease. Empowerment and ownership are necessary to make the appropriate lifestyle changes to cope. This conversation is retold in formal interview format to give context to the diabetic situation in Durban from the experience of a well-regarded dietician.

She began, "First off, I am a dietician who originally worked in Soweto in segregated hospitals. I worked with people with no medical aid that were mainly diabetics. Medical aid is becoming more accessible now, though. Now I have a private practice but I also have a passion for community work and talks. Currently all of my patients are still diabetics. I volunteer with child development centers with cooking meals with my church as a

volunteer. I get referred patients by the hospitals because a lot of times HIV drugs mess up the pancreas and give diabetes to HIV positive patients. I have gotten a new focus with my work. My new focus is on integrative (functional) medicine. I am focusing now on Pre-Diabetes and I give talks for DSA.

Now, as to how I am involved in the Durban community, patients come in and they are diagnosed as pre-diabetic and the doctor says to them don't worry. While I was working with government hospitals in diabetic clinics, I also gave talks to groups. Diabetics aren't all recommended to see a dietician. Not many people get the correct diagnosis or know what they should eat at all. The doctors only have 15 minutes with their patients and it is very difficult to teach people about the nature of their disease if you only have 15 minutes with them. Nova Nordisk<sup>7</sup> also employs me to teach about using insulin".

I then asked, what do you think of the primary health care and the use of clinics to access diabetic supplies? And she answered that, "Clinics have limited access to information about diabetes. If the nurses have questions they are usually told to phone a diabetic representative. They don't give meters to people without an insulin prescription if they are on medical aid".

She then continued, "As a dietician, I usually help people record their diets and sugars. Yeah, people who use insulin and go to the private hospitals are in good situations. I have one hour to teach patients that are referred to me which is better than just 15 minutes like most of the doctors have for patients. That just isn't enough time".

Following this, I asked, are diabetics usually utilizing insulin? Or do the doctors prefer to utilize Metformin<sup>8</sup> and/or other pills? and she replied by saying, "If their blood sugars are bad enough they are put on insulin and the insulin can improve the quality of their life. The other tablets that people are on are Glucophage, Metformin, or Glycomin. However, doctors are resistant to giving insulin out to people. I think that the doctors do not usually put their patients on insulin unless their blood sugars are bad enough. General practitioners tend to take care of diabetics themselves instead of sending them to a

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<sup>7</sup> Novo Nordisk is a pharmaceutical company based in Denmark. It manufactures and markets primarily products for diabetes care and management internationally.

<sup>8</sup> Metformin, originally sold as Glucophage, lowers cholesterol levels and decreases glucose in the blood stream. It is the most common form of type 2 diabetes treatment.

specialist. [However], more work needs to be done because diabetes has always been a disease on the wayside. Most people get diagnosed because of complications of the disease. They generally have been eating poorly their entire life and they have very low fruit and vegetable intake. In their diet histories I have found that they might have veggies 1 time per week! So their diets are generally high in fats but very low in fiber.”

I continued, in America, we learn about diabetes in our science classes. Do you know if there is there any involvement of the government to educate children about diabetes in schools? She responded, “Kids in school are in a difficult spot because they go to tuck shops and eat white bread and other such sweets like Coke. The Department of Health supplies the schools but it is not very good. Kids also eat a lot of Coke and Fanta instead of drinking just water at home. They are generally just in a very difficult spot.”

I wanted to pursue this line of thinking and so I asked, is there anything offered by insurances or medical aids or Non-Governmental Organizations (NGOs) that help diabetics cope with their disease? I know we were discussing earlier that education about diabetes is necessary and I began to wonder if there is anything that medical aids and such groups are offering. She said, “Well, Discover Vitality medical aid has a point system where a percent of goods from places like Pick ‘n Pay allow the patient to receive money back if they purchase good foods that are on a certain list maintained by Discover Vitality. This isn’t the only one; there are cheaper life aids that do the same things. Anyone can join and it’s reasonably priced. It’s called a wellness program. Diabetes is one of the biggest killers in South Africa, which was incentive to make these medical aids. Many people remain undiagnosed.”

Speaking of diagnosis, how is diabetes diagnosed in the clinics? Is it the same way that it is diagnosed in the hospitals? Mrs. Dolloway said, “Well there’s a finger prick, glucose tolerance test (most acceptable to diagnose diabetes), and HbA1C<sup>9</sup>. It would be interesting to find the price comparison of the tests to see if there is some way in which the process of diagnosing diabetes could be expedited. In general, it is my opinion that there needs to be more aggressive pretesting protocol. Perhaps making it a pre-requisite for employees when

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<sup>9</sup> This is the average measurement of glucose in the blood stream. The more glucose that is in the blood, the more glycated the hemoglobin becomes. This is the most common test to determine if someone is suffering from diabetes.

they report to their jobs [would help]. And people [nurses and doctors] need to be continuously retrained with all of the new services that are offered. I also think that teaching children in Life Orientation would be a good use of time in school (Dolloway, 2013).

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Talking with Mrs. Dolloway truly showed that nutrition is an extremely important factor when considering the effect of diabetes on the body and ways to care for it. I remember that when I turned nine years old, I truly assumed responsibility for my diabetes and taking care of myself. When I moved in with my father after my mother passed away I did not take good care of my diabetes. I went and met with a nutritionist to talk about my health and eating habits. After a while, I managed to get over my funk of eating poorly and made some additional changes to my diabetic care. I began giving myself insulin every day at school and once I entered 6<sup>th</sup> grade, I was able to go on the Medtronic Insulin Pump. I liked the pump because it gave me the freedom to not have to draw attention to myself when I was giving insulin. However, it was a double edged sword because although I did not draw attention to myself, I would also forget to give insulin and was then subject to higher blood-sugars. I would compensate by overdosing just by a couple of units every time I bolus-ed<sup>10</sup> with the intention of snacking with my friends so that I wouldn't have to check my sugars and bolus in front of them.

Nutrition has always played an important role in my life. When I was in High School, I rowed Crew for about 20 hours per week. During the difficult practices every day where I would return home exhausted, I began to experiment with my blood sugars and the types of things that I would utilize to compensate for my extremely active lifestyle. I began to eat power bars and peanut butter that would help me to maintain consistent blood sugars for longer periods of time. Although this works for me, it does not work for everyone.

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<sup>10</sup> A bolus is a colloquial term for diabetics when they refer to giving a shot of insulin.

*The Critical Role of Diabetes South Africa:*

January of Spring 2013, I left my studies at Muhlenberg College and studied abroad in South Africa. Before I came to South Africa, I had always been averse to a career involved



**Figure 5: Mrs. Jenny Russell, manager of DSA, and Mrs. Natalie Pakiri, personal assistant. Photograph taken by Mallory Bernstein**

with diabetes because I had often said that it would be just, “too much diabetes all the time”. But when I stepped off the plane, something changed in me where I realized that diabetes is something that I do wish to advocate for in my life. And even so, I have recently decided that I will also be applying to podiatry school

following graduating from college which would further increase my involvement with diabetes.

Podiatry in South Africa is a rare profession with only six podiatrists that specialize in diabetes wound care for the entirety of the country<sup>11</sup>. My interest in returning to South Africa as a podiatrist was instantly sparked as I spoke of the difficulties of the podiatric profession with Dr. Annette Thompson, renowned podiatrist that works in conjunction with the diabetes NGOs in Durban.

On April 9<sup>th</sup>, I began working with DSA officially for my study abroad program’s Independent Study Project. The employees of DSA helped me to realize that I do wish to be

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<sup>11</sup> Dr. Annette Thompson’s interview yielded important information regarding the future that my professional career will take. Her story is extremely inspiring and reflects the need for a multifaceted approach to diabetes treatment and care in South Africa and also the obstacles that make these changes difficult. She stated regarding the holistic approach to healing diabetics, “We have the Center for Diabetes and Endocrinology (CDE) program which has worked together with medical aids to foster diabetic treatment. Each patient has an entire team that works with all aspects and complications that diabetics face in Johannesburg. If you are a patient, you have a prescribing doctor, a podiatrist, a renal doctor, and an ophthalmologist. This is the true multidisciplinary approach that the whole of South Africa health care should be working towards. Part of the CDE involvement whereby all disciplines attend a five day CDE course where you revisit the focus areas of what is relevant to treating diabetes. This course culminates in the SEMDSA guidelines (listed in references of this paper) so that each person in the team can become an integrated educator about diabetes” (Thompson, 2013). Dr. Thompson’s experience with the CDE was inspiring for me to return to South Africa to learn about the effectiveness of treating diabetes in a holistic manner and take this modern knowledge and thought process back to the United States of America during our transition to a national health insurance.



involved with diabetes and that I want to return to South Africa after I complete my degree. The employees of DSA are absolutely incredible and truly are invested in helping diabetics control their condition. Diabetes is a special disease, in my opinion. It is because with education about the condition and carefully guided management, it is possible to lead a normal life. Mrs. Jenny Russell, the manager of the Durban branch of DSA does it all; she is involved at almost every level of what occurs at DSA. Jenny has told me her story of why she is passionate about diabetes treatment and support in Durban and surrounding areas.

Jenny's Story:

I remember I was working as the sales and marketing manager for diabetic products of a company when I realized what a terrible state Diabetes South Africa was in. Likewise, I quit my job and volunteered for a year for DSA. It ended up as being around R20, 000 or so in debt. I was involved in community work before. Before I worked in AIDS treatment and before that, I was a teacher. So, you can see that I am a community type of a person.

For 6 years, I ran DSA by myself without anyone except for Sr. Gertie who began helping me in the last two years with the isiZulu-speaking groups. Natalie was my first full time helper. And the fundraising committee was begun in August of last year. My tie to diabetes is that both of my parents, my aunt, my grandfather, and my best friend are diabetics. They all have Type 2. In addition to being the Manager of DSA, I am also the community portfolio compiler for DESSA and DESSA runs courses for nurses, but few and far between are trained. I would say that DESSA educates 30-40 nurses per year.

In my opinion, government hospital care is shocking depending on which hospital or clinic you are talking about. Training for diabetes care is very rare. Private General Practitioners do not have enough knowledge also. They just say don't eat sugar. This is where DSA comes in and provides a more comprehensive training program to empower the individual to take ownership of their disease. The hardships that the general public endures are lack of accessibility to decent health care, education, medicines, and most importantly strips.

For example, they send type I diabetics home with insulin from the hospital with no needles or glucometers. Well what are they supposed to do with that? They can't even give the insulin that they were given! I know that in rural communities, it has been very difficult to treat and teach people about diabetes. Even diagnosing diabetes in the rural communities is difficult because of a complete lack of resources. The dipstick test has been reviewed for rural communities to utilize because they are cheaper, but the government has not officially been very involved with the prevention or treatment of diabetes in South Africa. One of the problems that make it difficult to be diagnosed with diabetes is that one can have a test for sugar in the clinics, but a prescription for insulin cannot be obtained there, so the patient must then go to the hospital to retrieve the script.

There has thus far been no monetary aid from the government for diabetes, but last week at a meeting, there was a member of the government sector that said that home based care givers will give out a survey to diabetics to see if the statistics are really as bad as they seem. It is the first step of a long hike. Diabetes is an elephant of a problem. How do you eat an elephant? Take one bite at a time. People sometimes ask me, why even bother? Well, because if I help at least one person per day, I consider myself to be very successful (Russell, 2013).

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When Mrs. Russell stopped talking, I was absolutely silent. The amount of work that DSA does to train diabetics and spend time with them to help them understand their own disease is impressive. The lack of care identified in Jenny's story necessitated the establishment of DSA and all that they do. This conversation with Jenny made me contemplate whether the work of an NGO should foster discrete results where people change their lifestyle after only one meeting. Truly, what do we expect people to do when we have informed them of new knowledge? What is the amount of involvement of the NGO such that dependency of the diabetic on the NGO is not created?

I had an enlightening conversation with Mrs. Natalie Pakiri, who is Jenny's Personal Assistant and employee of DSA where she discussed in detail the merits of being involved

in DSA and diabetic care and how it has impacted her personal life. Over a course of time the foods that she buys and lifestyle that she leads has been changed because,

“Being involved in diabetes education, I have found that it all that I have [discussed] with patients has naturally become implemented in my current lifestyle. It’s true, you know, when you gather people together and try to sow the seeds of good life management; maintaining less stress, practicing limiting the amounts of foods you can eat, eating healthy foods, these lifestyle suggestions become reflected in your own life. Good health has really become part of my life. My kids are well educated and know about diabetes. My daughters attend the diabetes fairs. Diabetes is very prevalent in our family so my daughters need to know about it. And anyways diabetics when it is genetic, are getting younger and younger in the families when they are diagnosed” (Pakiri, 2013).

Her experience suggests that continuous involvement with diabetes care does have the potential to alter a person’s lifestyle, even someone who is not diabetic but has a predisposition to contract it. The DSA approach is special because the support groups do not foster dependency of the diabetic population on DSA, instead it encourages them to take responsibility for their own disease through discussion. I was surprised to find, from the conversation with Mrs. Pakiri, that her experience with DSA has largely mirrored my own.

#### Initial Observations of DSA:

I arrived at Entabeni Hospital on February 19<sup>th</sup>, 2013, for the type 2 diabetes support group run by DSA. I was intrigued to find that there were at least 40 members that come to this workshop every other month. It was inspiring to hear the members talk amongst themselves to see if there is anything that they can discuss the best way to care for themselves. It seemed to make the struggle of coping with making the lifestyle changes needed easier. After I attended this support group meeting, I realized that I wanted to be involved with DSA and understand how DSA works to provide support for those who are diagnosed with diabetes.

This study began on April 9<sup>th</sup>, 2013 and on the first day that I worked with DSA, I arrived at Mrs. Jenny Russell's house at 7:45AM to meet the crew that was preparing to



**Figure 6: Mallory with Sr. Gertie Ndlovu, nurse who works with DSA in isiZulu-speaking support groups. Photography taken by Mallory Bernstein.**

leave to go to Umlazi to run a diabetes clinic. DSA does not have an office space and instead they operate out of Mrs. Russell's house. Those who are employed by DSA are Sister Gertie Ndlovu, a nurse who specializes in diabetes and runs the clinics in isiZulu in the surrounding suburbs. Natalie helps with applying for grants and developing proposals for large companies that have agreements with the

South African government to subsidize strips for delivery. Brenda is the secretary and she helps with making sure everything runs smoothly when considering fundraising, clinics, grant proposals, etc. She also is involved with marketing and management so she helps with that front of the programs at DSA as well. Gillian, Litichia, Tracy, and Maria work with fundraising. Jenny coordinates it all.

On this first day, I helped to put the supplies for our day in Umlazi in the company car and then Natalie, Brenda, Sister Gertie, and I set out for Umlazi. The workshop ran from 9:30-11:00AM where Sister Gertie greeted everyone in isiZulu and explained to about 35 patients what diabetes mellitus was, what the possible complications were (amputations and blindness are two significant ones), and what patients need to do in order to prevent the onset of said complications. The first thing that began the workshop was role calling of the registered DSA members to check if they were attending. Then we sang a song about diabetes to a very common tune that most people are familiar with. The song goes:

**Iculo Lempilo *Song of health*  
(Sizothwal Umqhelo Tune)**

Sizotholimpilo uma sidla imifino [we will have health if we eat vegetables](#)

Sizothoimpilo uma siphuza amanzi [we will have health if we drink water](#)

Sinyakazisu umzimba [we must exercise](#)

Singadli amafutha [we will not eat fats \(oil\)](#)

Sinyakazisu umzimba [we must exercise](#)

Singadli amafutha [we will not eat fats \(oil\)](#)

Sister Gertie then discussed with the group the meaning of the song. Throughout the



**Figure 7: Sr. Gertie lecturing to the Marion Hill Support Group. Photograph taken by Mallory Bernstein.**

lecture, she referred to the song lyrics. She was a fantastic lecturer and kept the people engaged with the material of what to eat and how to care for yourself if you are diabetic. Lastly, she distributed packets of sucralose, scone mix, and a 'Diabetes and You' booklet that is produced by DSA. After this, Sister Gertie helped a newly diagnosed patient to buy strips from her (if you're a member of DSA you receive a discount) and also to show her how to test her blood.

While this was going on, I realized that I would have benefited from a support group where diabetes care was reviewed and I was able to find some diabetics my age that were undergoing similar troubles. I remember meeting one of my best friends in middle school. He had type 1 diabetes and was diagnosed in middle school. The middle school years are very difficult in regards to cliques and friend groups, so we truly became friends in high school. Once we began having classes together and learning about each other, I found that many of the same difficulties I had been having with my blood sugar were also experienced by my friend. We developed a game where the person who had a blood sugar reading closer to 100mg/dl would "win" the game. Although immature to an extent, this game was the first time that I felt invested in improving my blood sugar.

Even in college, I have developed very close relations with a few people who are invested in my wellbeing and having consistent blood sugars. Freshman year at Muhlenberg College, I found out that I truly do need to manage my sugars effectively. I play on the Muhlenberg College Women's Rugby team and I found out very quickly that pumps are not ideal for intense contact sports. Nearly every practice (2 times per week), my site was ripped out while rucking or being tackled. My pump site was pulled out so many times that I became bruised all over my stomach and hips which suggested that something needed to change. So I went off the pump and onto the pens. But I did not manage my sugars the day that I switched.

The day that I switched, I woke at 7am and went to Calculus II at 8am. Following that, I was extremely tired and crawled all the way back to my bed. I fell asleep. The next thing I remember, I had missed my Biology 151 class and my roommates were spoon feeding me honey. I was completely incompetent because I had had a mild seizure. Thank goodness my roommates were there when I needed them! They called the Muhlenberg College Emergency Service and a truck came around with a paramedic to check if I was coherent enough. Thanks to my roommates, I was and I was able to just hang out in my dorm room for the rest of the day. So, I donned my fuzzy socks and made some cup-o-noodles and sat in my bed. I missed my classes, but my friends and professors made it easy for me to catch up.

In my college experience, I have made some very close friends that remind me to check my sugars every time I eat. And although I roll my eyes every time they say to do so, they know that my eye-rolling is actually miscommunicated appreciation for their help. According to my friends in college, when my blood sugars are low I am extremely spacey, lethargic, and frankly (to put it in the colloquial wording of my friends) I'm weird. I also tend to refuse to check my sugars when I am low. Why, you ask? I have absolutely no idea. I know that I cannot tell when my sugars are going low and I suspect that it is because I have been diabetic for 20 years already and am not as in touch with noticing when my sugars are high or low. When I am high I tend to be very short with people and also very quiet. My friends have told me multiple times that they really do prefer me when my sugars are normal, and so they help me out with remembering to check and give insulin.

*Coda:*

I do not remember what happened when I was diagnosed with diabetes. I was extremely young and therefore my parents were involved and I grew up with a lifestyle that was conducive to living with diabetes. However, I know that many people do not have the opportunity to ease into this lifestyle and they also must cope without a support group, like those that are supplied by DSA.

Although one can state that giving patients the maximum of information possible about their disease and that is what will help them to cope, sometimes it is also important to learn to understand the disease from the individual's experience. Diabetes is a disease that is unique to each and every person, and learning about the nature of diabetes care is necessary to see through others' lived experiences. The work of DSA has been utilized in certain areas of Durban, but have not expanded into Cato Manor. Understanding the experience of Mrs. Serakoeng, a mother and grandmother in Cato Manor (Masxha) gave me perspective about how she and most likely other women deal with being diagnosed.

Mrs. Serakoeng is a success story with diabetes. I was extremely interested to find out exactly how she came to change her lifestyle completely and still manage to live an enjoyable life where she can eat her favorite foods in moderation. Having looked at real challenges, I'd like to share one more story, one that exemplifies the way that type 2 diabetes can be managed.

*Fikile's Success Story:*

In 2010 I was diagnosed. Something happened that annoyed me. The next day I had a very bad headache. Something happened to tell me to go to the clinic. I could feel the headache was bad. [I] went at 1pm, which is not usual because most people go in the morning. So I was number two in line. I said I had a bad headache and the nurse asked if I had sugar before. I said no. She did a check and my sugar was 28. They told me to go to the hospital straight away; that I should drink water and go by ambulance. I didn't go to the hospital because I was alone with my granddaughter. So I went home and drank a lot of

water. I remember it was a Friday that I was diagnosed. On Monday, I went to a different clinic and did not tell them about my sugar. They did a check and I was 22. King Edward made an appointment for me and so I came home and then went to King Edward Hospital. When I went to King Edward, at 2:10pm they put me on IV drips and I was on them until 11pm! I did not eat a thing until I left! I was 14 when I left. When I left I knew I could control my sugars. I was given Metformin; two Metformin in the morning and two in the afternoon. I was out of danger once I started taking the Metformin.

I get a finger prick once a month to check and I went to a dietician. She was very strict. I'm a person who eats everything I like. I like salt, and tea with sugar. It was hard to change my behavior. She said to drink water and keep flushing it out of my system. Now I am 5-7 in my blood sugars. I had tablets that I took with the Metformin that helped but I stopped taking them. They were herbals. Now I take probiotics and I take it with my Metformin. I usually didn't cook with oil because I boil things till it fries itself. I now use 2% milk.

But really, you can eat everything you like but you can't eat it all the time. Boiling is a lot easier. I was drinking beer when I was diagnosed and the doctor said I must not drink beer but it's okay to drink whiskey. Only take it with tonic water, she [the dietician] said. I also have to eat different fruits every day: pears and bananas 2 times per week, [and] brown bread.

I have headaches when my hypertension is bad. When I have high blood sugar I get thirsty. My husband and mom died of diabetes. My husband's sugars got worse and worse. I remember one time he got low and I gave him sugar water to revive him. He died of low sugar because he was alone. He didn't take care of himself.

At first it was hard to cope with ushukela and work. I [started to] tell people at work, you know, life comes first, then work. This was the first thing I told them. How was I supposed to get my medications? [Well,] I [told] my boss that life is important and there will be days that I won't come early [so I can] go to the clinic to pick up medication. I notice my blood sugar is higher whenever I get sick because the more sensitive because I'm diabetic. All diseases are worse when you're diabetic. I don't know of Diabetes South Africa, but I



would like to know [more about them]. I haven't lost weight because then people will look at you like you have AIDS. Now I am only on one Metformin and am living my life well!

**Reflections:**

Before this study, I believed (albeit immaturely) that I was unable to have children. I believed that the most important facet of diabetes care came out of the policies that the government maintained. I believed that most diabetics were apathetic to caring about themselves. Before my ISP, I saw the world through adolescent eyes and believed wholeheartedly that the world would benefit through the use of maximizing services allocated to diabetics, a utilitarian philosophy which was created by Jeremy Bentham in 1823CE (Bentham, 1823).

However, throughout my study with DSA, I have realized that my view about diabetes has been relatively backwards in terms of quantity versus quality of care. I experienced first-hand the value of the support groups that DSA runs when I found out from a fellow diabetic, that diabetics can have children and live normal lives. Working with diabetics themselves is the grass-roots solution to diabetic maladies in this country and it is working wonders, if not better than implementing burdening policies for diabetes care. I learned that diabetics as a whole cannot be generalized because each one is different and holds responsibility for their own disease in differing manners. Diabetics in Durban have an extra obstacle to overcome than those from my hometown: they are not educated about diabetes/ushukela and therefore they do not know the ways that they could have prevented onset of the disease and how they should treat themselves. In reality, before this study, I was a different person. I have so much respect for the NGOs in the area trying to help people with little to no funding, and I respect the use of support groups as a way to manifest good diabetes education and care.

To refer back to the questions that were initially posed in the Methodology section of this paper, the general attitude towards diabetes is that those who suffer from it are different, but there is minimal stigma associated with it. The medications that are available are mainly Metformin, Glucophage, and Glycomin. Insulin is more difficult to get ahold of. The lack of services at clinics impede access to the care that diabetics need. In addition transport is difficult, which is reflected in Fikile's story when she did not return to the hospital on the weekend. DSA is a permanent NGO that does not foster dependency, which truly makes it incredible. The way that diabetes care should be effectively expanded into

the suburbs is via education; however, amidst the current issues burdening the education system, this solution seems very unlikely to be implemented anytime soon. The present state of diabetes education to those diagnosed with the disease seems to me to be minimal at best, depending on socioeconomic class. The current shortcoming of the primary health care system is that there is not enough time that patients spend with the doctors and nurses. However, despite all of these challenges, it must be acknowledged that diabetes care in Durban and the surrounding suburbs is improving.

**Recommendations for Further Study:**

The findings in this study suggest that diabetes care and education is lacking, but improving in Durban and the surrounding suburbs. These documented narratives show that the quality of diabetes care for type 1 and type 2 diabetes fluctuates depending on the demographics of the population interviewed and the location of the population. Further work is recommended on the specifics of access to care in the communities and the training and resources available to nurses. For studies such as this one, an evaluation on the other diabetes groups in the area (DESSA and SEMDSA) would be beneficial to educate the public on the other groups that are working towards providing more policy changes and education about diabetes. The success of the support group as a vehicle of empowerment is also a topic that warrants further study. Once more information is documented on the topic of diabetes care in South Africa, more changes can ensue.

### **Literature Review:**

Alvermann, D. A. Narrative Approaches. (2000). 1 Apr. 2013.  
<http://www.readingonline.org/articles/handbook/alvermann/>.

This literature is essential to the formation of my study because it details the process and goals of using narrative as a vehicle of research. The purpose of the narrative is to tell peoples' experiences in order to understand why people believe what they do and how they understand their own experiences. The theoretical emphasis of this paper is that knowledge is accessed and obtained through peoples' personal experiences and stories. That being said, knowledge is accurate and biased at the same time. The use of narrative is necessary for this study to depict the situation of diabetics in Durban and to compare and contrast their situation with DSA's experience and my personal experience. The natural reflexivity of narrative as well as the attentiveness of the researcher will help to ensure that this study is ethical to the interviewees and accurately describing their points of view. This piece of literature is important to my study because it outlines the goals of narrative and certain aspects of ethics that I wish to emulate in my own writing to provide the best possible qualitative analysis of diabetic care in Durban.

Amod, A. et. al. "The 2012 SEMDSA Guideline for the Management of Type 2 Diabetes (Revised)". *Journal of Endocrinology, Metabolism, and Diabetes of South Africa* 17(2012): S1-S95. Accessed March 20, 2012.

This guideline outlines the most recent policies regarding diabetes that the South African government upholds in the Political Declaration on Non-Communicable Diseases. Policies, such as the protocols of diagnosis of type 2 diabetes in a hospital and clinical setting, are addressed such that it is easily understood by hospitals and clinics to initiate

standardization in regards to diagnostics. This report also formally outlines the systemic approaches to diabetes care including insulin based and non-insulin based management. This article is important to my study because it identifies the most recent policies pertaining to diabetes management. Because my study will focus on the perception and quality of diabetes care and treatment in Durban, the article is a necessary tool with which to do proper research and understand the extent to which diabetic care is accessible (or is supposed to be accessible). This study's method of data collection was to have specialists of certain fields in diabetic care contribute sections of the guideline. This work identifies the current policies, but it neither analyzes the personal challenges faced by diabetics in Durban, nor the extent to which the policies are currently implemented. These shortcomings will be benefitted by my study which will provide insight to the situation endured by diabetics in Durban.

Motala, Ayesha, and Kaushik Ramaiya, editors. *Diabetes: The Hidden Pandemic and its Impact on Sub-Saharan Africa*. Johannesburg: Novo Nordisk, 2010. Online Edition.

This paper is crucial to my study because it contributes much of the background information necessary to begin my study. The most pertinent part of this study, which was prepared for the International Diabetes Forum in 2010 by the reputed Professor Ayesha Motala who teaches at the University of KwaZulu-Natal at the Nelson R. Mandela School of Medicine, are the chapters addressing the economic paradox about offering better diabetic care and offering low-priced insulin and the effects. It is necessary to understand the limits of the economics of diabetes and making necessary drugs available to patients. Because getting treatment to diabetics is difficult, this study identifies why it is difficult and how to provide better treatment in the current hospitals and clinics. This paper is a assemblage of prior research conducted by experts in the field of endocrinology and diabetes. It also details how prevention is the emphasis needed to empower the South African general public to take responsibility for preventing the early onset of type 2 diabetes. This paper provides a good background of objective information about diabetics in South Africa, but

there are ways in which a narrative study such as mine would complement the research done here. In this paper, the theoretical framework of diabetes is identified and solutions are suggested. However, the specific interactions that diabetics have had in the Durban suburbs would be beneficial in forming pragmatic solutions derived from the theoretical solutions discussed in this study to obstacles of diabetes treatment and care.

Stake, Robert, "Qualitative Case Studies". *Handbook of Qualitative Research*. (2000) 17.

This piece of literature from the Handbook of Qualitative Research defines which type of case-study I will be utilizing to analyze the quality of diabetic treatment and care. The "bounded system" (Flood, as reported in Fals Borda, 1998, and Qualitative Case Studies, 2000) that is described in this paper is one of the most difficult parts to organize of a study. Stake suggests that there are three different types of case-studies and the specific type of case-study that I will conduct is an instrumental study where I will be analyzing diabetes and provide awareness of the personal difficulties experienced by diabetics in the Durban province. This piece of literature has organizational value for my research that I will utilize to show how diabetes treatment and care is qualified in Durban suburbs. For example, I will be defining my topic as the quality of diabetic care in Durban suburbs. My study will be formatted as a narrative, and the focus of my study is to tell the experiences of DSA, various diabetics from the DSA workshops, Mrs. Kerry Dolloway (nutritionist), Mrs. Serakoeng (diabetic from Cato Manor), and Dr. Fraser Pirie (expert endocrinologist). The "bounded system" will not include the specifics of quantitative insulin care. My study will focus on a social science perspective that will help non-governmental organizations such as DSA to provide the best care possible to the diabetic community.

*The Diabetes Foundation Report on Insulin-Requiring Diabetes in Sub-Saharan Africa.*  
Bamako: International Diabetes Federation, 2004. Online Edition.

This study focuses on analysis of insulin-dependent diabetes in three countries, Mali, Mozambique, and Zambia. This study evaluates the treatment of diabetes in these three relatively poor countries and found that insulin is difficult to access and that needles are also difficult to access, especially for rural community members. Acknowledging this, the International Diabetes Federation also reported that in these three countries there are no set guidelines that dictate how to standardize diabetes treatment across the country. This is one difference between South Africa and these three other African countries; South Africa has documented guidelines that specify treatment. This paper offers a perspective on concrete actions that are suggested for Mali, Mozambique, and Zambia to implement immediately to improve diabetic care. This study gives perspective on the efforts utilized in South Africa to maximize diabetic care. This study focused on more economically poor countries than South Africa, which is a limitation in my analysis of this study and its relation to my own study. In addition, this paper gives a methodology for analysis of type 1 diabetes in Africa; a difficult topic to research otherwise due to lack of diagnostic data. Since I will be working with DSA as a type 1 diabetic, this paper is instrumental in providing background to what type 1 diabetics in poorer nations in Africa endure. In order to prepare me to comprehend what the type 1 diabetics endure in Durban, this study is helpful, and it will also provide me a perspective of this very different situation than my own experience growing up as a type 1 diabetic in the USA.



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**Primary Sources:**

**Diabetic Narratives**

Mrs. Julie Peacock: April 18, 2013, Nino's at Moses Mabhida Stadium

Mrs. Fikile Serakoeng: April 9, 2013, Residence in Cato Manor

**Diabetes Expert Interviews**

Mrs. Kerry Dolloway: April 8, 2013, Mugg 'n Bean

Mrs. Natalie Pakiri: April 25, 2013, DSA

Dr. Fraser Pirie: April 2, 2013, Nelson R. Mandela School of Medicine

Mrs. Jenny Russell: April 24, 2013, DSA

Dr. Annette Thompson: April 21, 2013, Phone Interview

## **Appendices:**

### **Appendix A:**

As a part of my involvement with DSA, I wrote an article to be featured in the Diabetes Focus magazine which is distributed to all members of DSA across South Africa. The following is the article that I submitted for the magazine, my story of living with diabetes and my experience of working with DSA.

I was diagnosed with Type 1 diabetes when I was 17 months old. My mother and father took very good care of me and I enjoyed living a regular life. I woke up, ate cereal for breakfast, went to school, did homework, went to sleep the same as every other little child except that I had to have a shot of insulin twice a day and I had to do blood checks at regular intervals. Truthfully, I had a great experience growing up as a child with diabetes. My parents were extremely involved in training me to care of myself. Every meal was pre-planned. I ate breakfast cereals that were low in sugar (putting sugar on corn flakes was unthinkable), sandwiches that were made with brown bread and lots of meat, and veggies for dinner. Even when my parents divorced, I was able to maintain a healthy lifestyle while living with my mother and father in their respective houses. Only when my mother was diagnosed with gastric cancer did I run into trouble with maintaining level blood sugars.

My mother was diagnosed with cancer when I was 9. Although we lived in Washington state, my mother flew down to California to have herself checked out for a lump on her stomach. My sister and I followed her out to California shortly after she was diagnosed with gastric cancer. Moving wasn't that big of a deal to my sister and I because we moved around quite a lot and changed schools nearly every year. So in fourth grade in Westwood, CA, I put my blood check (which looked as if it came out of a 1980s Back to the Future film) in the back of my classroom. Five minutes before recess, I would quietly sneak to the back table to check my blood. I mutely sat in the back of the room so I didn't disrupt the class while checking.

Being new to elementary school in April (and not in September when the school year started), wearing flood pants (yes it was the 90's indeed), and porting stylish

transition sunglasses (that took at least 10 minutes to lighten up once I entered the classroom) meant that I was obviously the coolest thing that ever met Warner Avenue Elementary School. But all of that—it wasn't enough. I had to be the *diabetic*, flood pant-wearing, visually impaired 4<sup>th</sup> grader that missed the memo and arrived in April. Needless to say, it was a little tough to make friends. It wasn't too bad, but the sicker my mom got, the more responsibility I assumed in caring for myself and my sister (who was then 8 years old) who also had Type 1 diabetes.

I began giving myself insulin every day and once I entered 6<sup>th</sup> grade, I was able to go on the Medtronic Insulin Pump. I liked the pump because it gave me the freedom to not have to draw attention to myself when I was giving insulin. However, it was a double edged sword because although I did not draw attention to myself, I would also forget to give insulin and was then subject to higher blood-sugars. I would compensate by overdosing just by a couple of units every time I bolus-ed with the intention of snacking with my friends so that I wouldn't have to check my sugars and bolus in front of them.

Middle school—it happened. And for most Americans, it is considered the most awkward time in your life. It is 6<sup>th</sup>-8<sup>th</sup> grade is when kids are mean—you know, the pre-teen and teeny-bopper age. My mom died in April of 6<sup>th</sup> grade and I moved in with my dad, step-mom, brother, and sister and commenced going to 7<sup>th</sup> grade in Manhattan Beach, CA. I then decided after two weeks of eating by myself in the bathroom, that I would ditch the transition sunglasses and flood-plant look that showed I rocked the '90s (after all, it was 2004). The responsibility for being diabetic finally fell entirely to me. I started thinking, wishing I could fit in, that if I pretended I didn't have diabetes that it wouldn't exist.

Well, as you all probably know (I was a little late in realizing it), life doesn't really work that way. Freshman year at Muhlenberg College, I found out that I really do need to manage my sugars effectively. I play on the Muhlenberg College Women's Rugby team and I found out very quickly that pumps are not ideal for intense contact sports. Nearly every practice (2x/week), my site was ripped out while rucking or being tackled. My pump site was pulled out so many times that I became bruised all over my stomach and hips—something needed to change. So I went off the pump and onto the pens. But I didn't manage my sugars the day that I switched.

The day that I switched, I woke at 7am and went to Calculus II at 8am. Following that, I was extremely tired and crawled all the way back to my bed. I fell asleep. The next thing I remember, I had missed my Biology 151 class and my roommates were spoon feeding me honey. I was completely incompetent because I had had a mild seizure. Thank goodness my roommates were there when I needed them! They called the Muhlenberg College Emergency Service and a truck came around with a paramedic to check if I was coherent enough. Thanks to my roommates, I was and I was able to just hang out in my dorm room for the rest of the day. So, I donned my fuzzy socks and made some cup-o-noodles and sat in my bed. I missed my classes, but my friends and professors made it easy for me to catch up.

In my college experience, I have made some very close friends that remind me to check my sugars every time I eat. And although I roll my eyes every time they say to do so, they know that my eye-rolling is actually miscommunicated appreciation for their help. According to my friends in college, when my blood sugars are low I am extremely spacey, lethargic, and frankly (to put it in the colloquial wording of my friends) I'm weird. I also tend to refuse to check my sugars when I am low. Why, you ask? I have absolutely no idea. I know that I cannot tell when my sugars are going low and I suspect that it is because I have been diabetic for 20 years already and am not as in touch with noticing when my sugars are high or low. When I am high I tend to be very short with people and also very quiet. My friends have told me multiple times that they really do prefer me when my sugars are normal, and so they help me out with remembering to check and give insulin.

January of Spring 2013, I left Muhlenberg College and studied abroad in South Africa. Before I came to South Africa, I had always been averted to a career involved with diabetes because I had often said that it would be just, "too much diabetes all the time". But when I stepped off the plane, something changed in me where I realized that diabetes is something that I do wish to advocate for in my life. And even so, I have found that I will also be going to podiatry school following graduating from college which would further increase my involvement with diabetes. One assignment that I completed was an interview with my homestay family in Masxha, a Durban suburb next to Chesterville. I chose to interview my 13 year old homestay sister about the status of diabetes and her opinion in Durban. She

emphasized that there is not much around to help the Mamas of Cato Manor get diagnosed and learn about their disease. This inspired me to contact DSA.

On April 9<sup>th</sup>, I began working with DSA officially for my study abroad program's Independent Study Project. The employees of DSA helped me to realize that I do wish to be involved with diabetes and that I want to return to South Africa after I complete my degree. The employees of DSA are absolutely incredible and truly are invested in helping diabetics control their condition. Diabetes is a special disease, in my personal opinion. It is because with education about the condition and carefully guided management, it is possible to lead a normal life.



**Figure 8: The Entabeni Support Group with Hulettes scone mix after meeting. Photograph taken by Mallory Bernstein.**

With DSA, I have travelled to Umlazi, Entabeni, Marion Hill, and other support groups to observe what DSA does in practice. I have repeatedly felt that I, myself, have learned so much from attending these support groups even though I have been diabetic for 20 years! Seeing people coping with diabetes on top of poverty and other sicknesses has been extremely inspiring to me and I know that I will forever remember my time working

alongside these wonderful people.

I'll leave you all with one of the most important things that I would tell other diabetics about is to make sure to live a healthy lifestyle. That means to be involved in a sport or active environment and to also make sure that you take responsibility for your disease. As Type 1 or even type 2 diabetics we must consciously think about what our pancreas needs to be doing at every point in the day. Therefore, we just need to stop fighting the system and accept that we will always be giving insulin and checking our blood. It's time to own it—Being diabetic is cool.

It was once I finished and submitted this piece of writing to the editors of Diabetes Focus Magazine that I realized that I have truly loved helping diabetics in Durban and that I

cannot wait to return. My experience writing this piece was extremely relaxed and easy. My experience, I have realized factors in to the experience of South Africa. Although they [the experiences] may be separate strands of the same braid, they have finally come together to weave the same themes of trials and successes. The way that I look at diabetes as a disease and as an ailment has shifted completely. Diabetes is no longer a simple disease where there is a quick and easy fix, it has now become a multi-tiered issue that must be thwarted via a multifaceted approach.

### **Appendix B:**

#### Questions for Interviews of Diabetics:

1. Tell me your story.
2. Can you tell me your experience getting diagnosed? How long have you had diabetes?
3. Can you tell me what being diabetic is?
4. Are you familiar with Diabetes South Africa and their mission to offer services to diabetics in the Durban area?
5. What behaviors did you have to change to accommodate the diabetic lifestyle?
6. What do you feel are certain hardships that you experienced?
7. When you seek diabetic help, who do you go to?
8. Are there any stigmas or stereotypes about being diabetics?
9. Did the clinic educate you about ushukela?
10. How often do you check your blood?
11. Looking to the future, what are your suggestions on solutions to the problems discussed?

### **Appendix C:**

#### Questions for Interviews of Diabetic Specialists:

1. How are you involved with diabetes research and treatment in the Durban community?



2. Do you feel that the hospital medical services offer adequate services for diabetic?  
Do you feel that there are differences between the hospital setting and the clinical setting in relation to diabetes education?
3. Are you familiar with Diabetes South Africa and their mission to offer services to diabetics in the Durban area?
4. Are you aware of any other groups that are operating in Durban to help diabetics adapt to a constructive lifestyle?
5. What do you feel are certain hardships experienced by patients in Durban?
6. What do you feel are certain hardships experienced by diabetics in the suburbs?  
How do services differ in the suburbs versus the area that DSA treats?
7. What are the services available for diabetics in your experience? Do you feel that these services are accessible to the appropriate people? Do you feel that the people that these services are targeting are actually getting the aid or do you feel that those who are targeted are not receiving aid?
8. What is your opinion on how diabetes is dealt with in relation to Primary Health Care?
9. Do you have any suggested literature that would be helpful to enhancing this study?
10. Looking to the future, what are your suggestions on solutions to the problems discussed?
11. Do you feel that the general public is being educated correctly about the nature of diabetes?

**Ethical Clearance Forms:**

**Name:** Mallory Bernstein

**Program:** SFH Durban Social Policy and Community Health

**Student Phone:** 083-700-1328

**Title of ISP:** An Exploration of Diabetes Care in KwaZulu-Natal Suburbs as seen through the Work of Diabetes South Africa

**Site of ISP:** Diabetes South Africa

**Funding Source, if any:** R200 daily from the School for International Training Stipend

**ISP Advisor Name, Title, and Contact Telephone:** Clive Bruzas, Dr, 0823957243

**Brief description of the purpose of the study:** Because diabetes incidence is increasing in South Africa (Motala and Ramaiya 2010), I am ultimately utilizing this study to see how multicultural societal structure and other relevant factors of South African culture pose challenges for DSA in terms of increasing access to diabetes treatment and care. This study more specifically seeks to understand diabetes in the context of Durban suburbs and observe how DSA functions, while also identifying multiple sources that give perspective concerning the different challenges that currently inhibit access to diabetic services.

**Brief description of procedures relating to human subjects' participation:**

- a. **How are participants recruited? And is an inducement offered?** Participants are recruited through contact by email and in person and there is no inducement offered.
- b. **What is the age range of the participants?** 18-70 years
- c. **What is the gender breakdown of the participants?** The genders of interviewees are both male and female.
- d. **What are other relevant characteristics of subjects, including (but not limited to) institutional affiliation if any?** The interviewees are from a variety of

institutional affiliations. These specific institutions are Diabetes South Africa, the Nelson R Mandela School of Medicine, and independent entities.

- e. **What is the number of participants?** The number of participants is initially 4 interviewees; however, the total number of participants cannot be identified at this moment in time because the specific number of Diabetes South Africa workshop members that will be interviewed have not been able to be estimated. The maximum number of participants will be limited to 15 interviews total.
- f. **If there is a cooperative institution, how was their permission obtained?** N/A
- g. **What will subjects be asked to do, and/or what information will be gathered?**  
The interviewees will be asked to answer questions that I will ask, to the best of their abilities. The information that will be gathered and questions that will be asked will be featured in the Informed Consent Forms.
- h. **If subjects are interviewed, who are the interviewers?** The interviewers are limited to Mallory Bernstein. Translation from isiZulu to English is not foreseen as an issue.
- i. **In what language(s) will you interview participants? How will interpreters be paid?** The language that interviewees will be interviewed is in English. Interpreters are not expected to be utilized.
- j. **How will the interviewers be trained and paid?** The interviewer is Mallory Bernstein and has been trained by the School for International Training and interview questions have been reviewed by Clive Bruzas as well as Zed McGladdery, professors of the School for International Training. Interviewer will not be paid.

**Protection of human subjects. Before completing this section, you must read and agree to comply with both the SIT Study Abroad Statement of Ethics, SIT Human Subjects Policy, and the program's additional Human Subject Research Guidelines.**

- a. **Have you read and do you agree to comply with the SIT Study Abroad Statement of Ethics, SIT Human Subjects Policy, and the Human Subject Research Guidelines in the SCRHM course and handbook? Yes**

- b. Do subjects risk any stress or harm by participating in this research? If so, why is this necessary? How will these issues be addressed? What safeguards will minimize the risks?** Possible informants consist of experts used to being quoted, free to give interviews, partners of the SIT program. (Mrs. Jenny Russell, Sr. Gertie, Mrs. Fikile Serakoeng, Mrs. Kerry Dolloway, Dr. Fraser Pirie) and persons accessing public services in the proposed research space All informants are adults freely able to give or withdraw informed consent, no possibility of harm. This project will inform the work of Diabetes South Africa, a prominent NGO in diabetes advocacy. This study would help them to provide information and diabetic resources to suburbs and other areas. The payment that will be given to the participants is a handwritten thank you card and a copy of the published work with them correctly cited. I understand the extra effort that this will take; however, I would like to possibly return to South Africa to work with DSA and others and I would like to make my paper completely transparent and prove that I am trustworthy to all interviewees to promote good relations when I would return. The following groups have been identified and will be protected in the following ways:
- a. DSA:** I will write my observations and interpretation of the situation and then I will show it to DSA three days before it is submitted to SIT in order to have it reviewed in a timely manner. I will ask if it is appropriate to be published with informed consent. Anonymity and confidentiality will be maintained in the strictest sense.
  - b. Mrs. Serakoeng:** I will also write my observations and show it to her before it is submitted with informed consent. I will also talk to her regarding the context of the interview and where I will be inserting her narrative. I will show her the final draft and she will be able to tell me if she thinks that this is a safe way for her to discuss her experience as a diabetic. I will ask if she is in accordance of it being published. Anonymity and confidentiality will be maintained in the strictest sense.
  - c. Mrs. Dolloway:** I will also write my observations and show it to her before it is submitted with informed consent. She will be given a final copy and I will

also make sure that the context for her opinion is correct. She will be consulted if the paper is appropriate to be published. Anonymity and confidentiality will be maintained in the strictest sense.

- d. Dr. Pirie:** I will also write my observations and show it to him before it is submitted with informed consent. I will ask if he is in accordance of it being published. Anonymity and confidentiality will be maintained in the strictest sense.
- c. How will you explain the research to subjects and obtain their informed consent to participate?** The research will be explained to subjects via the Informed Consent Form which will be reviewed closely with the subject before the subject is interviewed. The consent form is appended on pages 17-19.
- d. If subjects are minors or not competent to provide consent, how will it be obtained?** All interviewees will be of legal age.
- e. How will subjects be informed that they can refuse to participate in aspects of the study or may terminate participation whenever they please?** Interviewees will be informed that they can refuse participation in verbal and written form on the informed consent form reviewed prior to the interview.
- f. If subjects are students or clients or program partners, how will you protect them from feeling coerced due to the (if only perceived) power differential?** In order to protect program partners, such as Mrs. Kerry Dolloway, I will state that at any point she can withdraw her statement.
- g. How might participation in this study benefit subjects?** This study should be pursued because it would aid in providing better and more diabetic care to those in need. In the transition to the National Health Insurance Plan, this is a perfect time to analyze the shortcomings of the current system in order to improve them in the new system of health. This paper's specific focus on diabetes care would give DSA insight into how the NGO has been working and how to expand into a larger area. For these reasons, the potential harm from this study weighs lighter than the potential benefit to diabetic communities. This study will inform DSA a prominent NGO in diabetes advocacy. This study would help DSA to provide information and diabetic resources

to suburbs and other areas. Subjects will benefit because they will be aiding DSA cater to the current diabetic population's needs.

**h. Will participants receive a summary of results or other educational material?**

**Specify who will receive what.** Some participants will receive a summary of results.

- a. DSA:** In thank you, I will give the report to this expert operating body. DSA will be able to determine if my results should be reproduced to diabetics in the Durban community.
- b. Mrs. Dolloway:** I will give the report to this operating body and she will be able to determine the value of the report and whether it is useful to distribute among colleagues or patients.
- c. Dr. Pirie:** I will give the report to him and he will be able to determine the value of the report and whether it is useful to distribute among colleagues or patients.

**How will the following be protected?**

**a. Privacy:**

- a. DSA:** I will write my observations and interpretation of the situation and then I will show it to DSA three days before it is submitted to SIT in order to have it reviewed in a timely manner. I will ask if it is appropriate to be published with informed consent.
- b. Mrs. Serakoeng:** I will also write my observations and show it to her before it is submitted with informed consent such that she can review the narrative and ensure that her privacy is looked after. I will also talk to her regarding the context of the interview and where I will be inserting her narrative. I will show her the final draft and she will be able to tell me if she thinks that this is a safe way for her to discuss her experience as a diabetic.
- c. Mrs. Dolloway:** I will also write my observations and show it to her before it is submitted with informed consent. She will be given a final copy and I will also make sure that the context for her opinion is correct. She will be

consulted to determine if the paper is appropriate to be published and her privacy is not compromised.

- d. Dr. Pirie:** I will also write my observations and show it to him before it is submitted with informed consent so as to not infringe on his privacy. I will ask if he is in accordance of it being published.
- b. Anonymity:** Interviewee names will not be attached to the data, unless subject chooses to be identified. They will be asked this question when the Informed Consent Form is reviewed. There is a section that allows the interviewee to sign if they would prefer to remain anonymous. This will be accomplished for each of the interviewees individually.
- c. Confidentiality:** Access to data will be held in confidence between me, the interviewee, and my advisor (Clive Bruzas). In addition, coding will be utilized during the interview, but the coding shorthand will make it difficult for others to understand what the interviewees are discussing with me. Coding will be one of the vehicles of keeping the interviewees separate from the information obtained. Data will be stored on paper and input onto a computer Word file and once the study is complete, the data will be destroyed. The data utilized for this study will not be utilized for any other study unless the interviewee approves. Permission for further use will be obtained via a written consent form. The need of this consent form will be discussed in the study.

**Are there any other details or procedures of the study that should be known by the ISP Ethics Review Committee, and if so, discuss. No.**