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What is Available vs. What is Accessible: An Evaluation of Resources for KwaZulu Natal Diabetics Based on the Data of KwaZulu Natal Experts and Cato Manor Diabetics

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What is Available vs. What is Accessible: An Evaluation of Resources for KwaZulu Natal Diabetics Based on the Data of KwaZulu Natal Experts and Cato Manor Diabetics.

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Fall 2006: SIT Public Health

Independent

Study

Project

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Thanks to Kirthee Pillay, Maria Reynolds, Fiona Prins, and Pilele Dlamini for taking time out of their busy schedules to meet with me and to answer my questions which were very basic to them. Thanks to Christine McGladdery for serving as my

advisor. Thank you to my parents for giving me the opportunity to come to South Africa and for making it possible for me to attend the World Diabetes Congress. I would also like to thank the members of the Cato Manor who were willing to speak with me about their health and their experience with diabetes, particularly Informant 1.

Abstract

The objective of this study was to learn about the resources available to a diabetic and the actual ability of diabetics to access these resources. I found that two ideal paradigms of care were consistently mentioned by experts in KwaZulu Natal and at the World Diabetes Congress (WDC), the international conference on diabetes that I attended in Cape Town. The first is self-management of the disease and a patient centered approach to care. The second is a collaborative team approach to treating diabetics which involves a number of experts besides a physician. These two concepts are connected in that a collaborative team of healthcare professionals is more likely to empower a patient to manage his or her condition.

I examined data from five experts who work in KwaZulu Natal to find out about the resources that should be available to provincial system patients and the realities about access to care. Additionally, I spoke with three informants from the Cato Manor township in Durban to find out what their experience with care was when they were first diagnosed and what it is now. I found that the ideal approaches to care advocated by the experts were representative of the ideal paradigms being presented at the WDC. I also found that the experience of my Cato Manor informants was profoundly negative and did not even begin to approach these ideal models of care. My conclusions are that the state

of diabetes care in South Africa has potential – the personnel is available to help more people than are currently being helped. The overall picture is somewhat bleak in that there does not seem to be any progress to advocate for more prevention or care for diabetics so it seems unlikely these resources will be better organized or more accessible in the near future. There is also no indication that the government is willing to take any action to expand diabetes care or that the ever increasing diabetes burden in South Africa is a major health concern at the current time.

Introduction

Why Diabetes?: The Objectives of My Independent Study Project

“...Poor quality of life is occurring because of poor control of diabetes. Seeing a lot of complications tells that not enough emphasis is being placed on diabetes...”¹

--Kirthee Pillay, Professor of Dietetics and Nutrition

“Everyone forgets about heart disease and diabetes.”²

--Maria Reynolds, Diabetes Nurse Specialist Educator

“There is a major challenge regarding diabetes in this country but it does seem to get the attention it deserves in the public discourse.”³

--Dr. Manto Tsabalala-Msimang, Minister of Health for South Africa

The first two quotations come from two experts on diabetes working in KwaZulu Natal. The last comes from the current South African Minister of Health. Imagine for a moment that these three people were engaging in a dialogue rather than being quoted on a page. Each would say her opinion, all of which indicate that all three women share the

¹Kirthee Pillay, Professor of Dietetics and Nutrition at the University of KwaZulu Natal (UKZN) – Pietermaritzburg, in an interview on November 21, 2006 at the Department of Dietetics and Nutrition, UKZN, Pietermaritzburg, KwaZulu Natal, South Africa. All further citations attributed to Kirthee Pillay refer to the same date and place and will be referenced only with her name.

²Maria Reynolds, Diabetes Nurse Specialist Educator, in an interview on November 22, 2006, at Butcher Block Coffee Shop, Glenwood, Durban, KwaZulu Natal, South Africa. All further citations attributed to Maria Reynolds refer to the same date and place and will be referenced only with her name.

³Dr. Manto Tshabalala- Msimang, South African Minister of Health, in an interview in *Diabetes Focus* magazine. *Diabetes Focus*, Spring 2006, 37.

same point of view – that diabetes is a condition that does not receive enough attention in South Africa. The two experts, I imagine, would then turn to the Minister and say “What are you doing about it?” It is this question – what can be done – that sparked my interest in pursuing a project on diabetes. It is true, however, that my resources and my time were too limited to explore this problem with a great degree of depth. I wanted to learn, at the very least, what the scope of the diabetes problem is in South Africa, what resources are available to fight it, and how these resources are (or are not) being utilized by various segments of the population. Thus, I am seeking to find the answer to the question I imagine being posed to the Minister of Health – what is being done?

Why diabetes? From the data gained from the Public Health Seminar which I took with the School for International Training (SIT), it is evident to me that the public health system in South Africa is overburdened. This reality means that there are many areas that are under-resourced and thus fit to be examined for an independent study project. I chose diabetes because of my personal experiences here in South Africa. For the first month of my stay, I lived in Cato Manor, a Durban township which is mainly populated with Zulu people. I discovered quickly upon arrival to the community that one of the people with whom I was interacting is a Type II diabetic.⁴ It struck me that Informant 1 was taking some steps to control the condition – such as diluting juice or not eating too many bananas – but Informant 1’s information about controlling diabetes was far from complete. In addition, Informant 1’s access to healthcare that could help her to control her condition was limited. The local clinics were cited as unhelpful and the nurses as mean and thus discouraging and Informant 1 has ceased to use the healthcare system.

⁴This person will be known as Informant 1. This person did not want to be identified in this paper so I have taken every precaution to protect this informant’s identity so I will provide no information beyond that this person is a female resident of Cato Manor, Durban and is a Type II diabetic.

Informant 1 has a couple of conditions aside from diabetes (arthritis, an unnamed liver problem) which she seemed to connect with the diagnosis of diabetes at least chronologically.

Talking about diabetes with Informant 1 made me curious about what the options are for diabetics in general in South Africa and for people who are poor and do not have many resources for food or for medicine. I pursued this information through a variety of methods. I volunteered with Diabetes South Africa (DSA), a non profit group dedicated to providing support and information for diabetics. I spoke with experts – a nurse, two diabetes educators, the head of DSA, and a professor. I then returned to Cato Manor, to ask some of the diabetics there whether any of the information I had gathered from the experts was relevant or familiar to them. I also attended the 19th World Diabetes Congress (WDC) sponsored by the International Diabetes Federation (IDF) in Cape Town where leading experts from around the world gathered to discuss the challenges and new developments regarding diabetes.

The objective of this study is to learn as much as I could about the state of diabetes care and access to available resources in South Africa. The methods that I used to obtain this information was that which a newly diagnosed diabetic would have to take – asking experts and searching through secondary sources. Many South African diabetics do not have the opportunity to consult multiple experts or to access books or the internet. My critical evaluation of this information comes from asking about the reality of what the resources are and how they are utilized– from the perspectives of the healthcare providers and recipients.

Methodology

The first part of my paper seeks to define diabetes and to give a brief overview of the condition. The methodology for defining the disease diabetes may seem as though it should be straightforward – take a book or scientific articles and transcribe what the clinical definition of diabetes is, its complications, and its treatments. First, this approach is not possible as there is an ongoing debate on an international scale (mainly between the American Diabetes Association and the WHO) on how to define diabetes clinically.⁵ Second, a comprehensive review of this debate would not be particularly useful for my study. I attended lectures at the WDC that outlined some of these debates and I consulted a clinical text on diabetes, Diana and Richard Guthrie's *Nursing Management of Diabetes Mellitus: A Guide to the Pattern Approach*. What I learned at the lecture and from this text is that the definitions debate is for and among healthcare professionals. It is based around differing opinions about what blood sugar levels should define diabetes. The vocabulary used by experts such as those present at the WDC or in the book is not one that is familiar to me or to most diabetics in South Africa. Since the objective of my project is to assess what should and what does happen when someone is diagnosed with diabetes, it seems outside the scope of the project to include a lot of medical discourse that I nor many of the potential readers of this study can truly understand or apply. I do quote and use parts of the Guthries' text that I understand and feel is relevant to presenting my own understanding of this condition. I also cite facts from the WDC and

⁵Dr. Ayesha Motala, Head of the Department of Diabetes and Endocrinology at Nelson Mandela School of Medicine, UKZN and at Inkosi Albert Luthuli Hospital, Durban, South Africa, in a lecture entitled "Diabetes in Africa: Naught for Your Comfort." Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 4, 2006. Further citations of Dr. Motala refer to this lecture.

from international bodies of experts like the World Health Organization (WHO) and the International Diabetes Federation (IDF) to help me to present what diabetes is.

In seeking to define diabetes as well as in my findings and analysis section, I rely more on the words of the experts that I spent my time with while I was here in South Africa. I do this because this process is what a diabetic would experience. Diabetics rely on experts to interpret their condition and to help them to establish their needs so I have taken this approach as well. Sue Frye is trained as a nurse but now is the head of the Durban branch of DSA. I first interacted with Frye through two interviews that I set up with her to learn about DSA and about her work with diabetics.⁶ She was extremely excited about my interest in diabetes and acted as a gatekeeper, introducing me to other experts including Sisters Pilele Dlamini, Maria Reynolds, and Fiona Prins. I volunteered at her organization for the first phase of my project, so I provide an extended commentary on what I learned and observed during National Diabetes Week at DSA in my findings.

Sister Pilele Dlamini is a nursing sister who works at Inkosi Albert Luthuli Hospital, a tertiary level provincial hospital in Durban. I met with her while she was working at the pediatric endocrinology clinic which meets one time per week. She works generally in pediatrics but she specializes in diabetes. She also gave me access to two Type I diabetic children. I asked the children and Sister Pilele for consent to use what they told me in my paper and both the children and the nurse agreed. I do not use the children's names to protect their privacy though they did not object to me doing so.

⁶I consulted with Sue Frye for data on a number of occasions. The dates on which I interacted with Sue were October 6, 2006, October 27, 2006, November 1, 2006, and November 14-17, 2006. All interactions took place at Diabetes South Africa – Durban which is located in Glenwood, Durban, KwaZulu Natal, South Africa. I do not know which pieces of data came from which interactions, especially since most of it was repeated to me on numerous occasions. All further citations of Sue Frye will just be her name and will refer to data I collected from over the course of these several meetings.

Sister Maria Reynolds is a renal care diabetes specialist who works for National Renal Care and does advocacy and education work around renal care. She is a diabetes specialist, however, and many diabetics suffer renal complications thus she was a very valuable resource concerning diabetes. Sister Fiona Prins is a practicing diabetes educator for Diabetes Educators Society of South Africa (DESSA), the education branch of the Society for Endocrinology, Metabolism, and Diabetes of South Africa (SEMDSA). She meets with clients individually to give them counseling about how to control their diabetes both with diet and with medication. Kirthee Pillay is a professor of Human Nutrition and Dietetics at the University of KwaZulu Natal (UKZN) – Pietermaritzburg and her research interest is diet therapy in Type I children but she was able to provide me with general information about diabetes and diet therapy generally.

While four of my five expert sources are trained as nursing sisters, they are truly multi disciplinary in the roles in which they work – as educators, advocates, and nurses. They are all biased by the fact that they work so closely with diabetes and have devoted their lives to it. They are advocating for patients whom they feel have limited resources and limited options. They are working within a system that they feel is ignoring them and the people with whom they work daily.

The information I was able to record during interviews with these experts was limited due to my note taking ability, questions, and what I deemed important and was able to understand. This limitation will be a crucial methodological concern throughout this paper. My understanding of diabetes and the questions I could formulate, while a limitation, were also important for my paper because what I am able to understand as a person who knew little about diabetes before asking questions is indicative of what a

newly diagnosed patient might be able to understand. I am perhaps able to understand even more than the average patient because I do not suffer a language barrier and I am highly educated.

The secondary sources that I use are the Guthrie book discussed above, \data from the WDC, and the *Chronic Diseases of Lifestyle in South Africa: 1995-2005* report prepared by the South African Medical Research Council (MRC). I also reviewed a number of scientific studies regarding diabetes but did not find them particularly helpful for my study. They were done on small subsets of people and the results from these studies were differing versions of the same finding – diabetes is inadequately cared for in South Africa whether by the patients themselves or healthcare providers. Almost all of these studies are incorporated into the MRC report so I will cite that in the body of paper rather than specific studies.

The MRC report has a lot of information on chronic disease care and is a great reference because it looks at so many studies and data sets. Each chapter is authored by different experts, many of whom authored the studies cited as data in the report. Their conclusions are not different than those of the experts with whom I spoke, but the report was useful to back up the conclusions I was hearing from my interviews. The MRC report mostly outlines guidelines and displays the problems rather than proposing plans of action.

The information from the WDC was aimed at an international audience, but since the Congress was held in South Africa, I was able to gather information on diabetes in South Africa. In addition, many of the general concepts presented at the Congress were

familiar to me as a result of my own research and serve as useful background and additional support for my own data.

During the volunteer phase of my project, my role was one of participant-observer. I helped to collect the admission donation, I wrote receipts for products sold, I made tea (a lot of tea), I washed dishes, and generally helped in whatever way I could. The goal of this phase was to give back to the diabetes community which was providing me with data for my project. I did not take any notes while at the house each day, but rather wrote them from memory when I got home. I conducted no formal interviews – I talked to all of the representatives from various companies who had tables set up and I talked to the Fryes and to their assistant, Sashika. All of these people knew I was going to write a paper.

The space in which I was observing and listening was public – the house was open to anyone that week and no conversations were taking place in a private setting. People were sharing the information about themselves aloud with the hope that they would be helped and arrived with the intent of talking about their disease to people who would listen. Given this environment, I feel that it is ethical to write into this paper the stories I heard during this week. I do not think rewriting what I heard interferes with that open atmosphere in any way. In addition, I am not seeking to identify these people in a way in which their identities could be discovered by anyone reading this paper. I asked for no names and even when a person bought a product or joined the association, thus leaving their name, I did not record it for myself and am not seeking to find it amid the DSA records. I am using the information simply as examples of what diabetics go through and what they came to DSA to find in terms of information and support.

During the Cato Manor section of my study, I spoke with three middle aged Cato Manor women. All of them were in their late 40s to mid 50s. One, Informant 2, spoke very poor English and I was unable to obtain a lot of data from her. I accessed these women through my own connections in Cato Manor and thus it was not a random sample of any sort and was too small to be used to establish any patterns. I asked them as many questions as I could but even the two that spoke English well did not understand the meaning of a lot of my questions. I think these misunderstandings were mainly due to the fact that they do not know that much about their disease so the terminology I was using was unfamiliar to them. For example, I asked them if they had ever seen a dietician and it was not until I rephrased to “a person that helps with food” were they able to answer no. I think it is indicative of the quality of care that they receive that they do not know terms related to their disease. I also went into the Cato Manor interviews with a theory – I did not think that these women were receiving the quality of care to which they are entitled given the information I had been gathering. I had also read a scientific study that looked at a community like Cato Manor in Durban and found many barriers to proper care.⁷ While I was right, I think that this hypothesis probably skewed my questions.

What is Diabetes?

Definition

In order to write properly about a disease, even in a study that is not focused on a deep medically-based understanding of the condition, I must define diabetes and some of the components of treating and controlling it. A clinical definition of diabetes mellitus

⁷Nthangeni, Gladys, et al “Dietary intake and barriers to dietary compliance in black type 2 diabetic patients attending primary health-care services.” *Public Health Nutrition* 5:2, 329-338.

offered by the authors of the chapter on diabetes in the Medical Research Council's report on chronic disease in South Africa is: "Diabetes Mellitus is a diverse group of metabolic disorders with varied clinical characteristics united by hyperglycaemia, the final common biochemical abnormality."⁸ Another way of phrasing this idea is presented by Diana and Richard Guthrie: "Diabetes is...not one disease but many diseases that ultimately cause beta cell failure and/or peripheral insulin resistance."⁹ As noted previously, these clinical definitions are not helpful to laymen – it is not a description that could be given to a patient or his family upon diagnosis of the condition. What is useful about them in the context of this study is that it indicates that diabetes is not a straightforward condition – it is a "diverse" disease and manifests itself with "varied clinical characteristics" meaning that patients need to understand how the disease affects their specific body in order to control their disease. A key lesson I learned over the course of this study that will be repeatedly mentioned throughout this paper is that it is important for people to understand their individual condition and to learn to self regulate in order to attain good control over their disease. Support from family is invaluable to learning and to maintaining this self regulation of diabetes. Support from specialists is essential but should be secondary to self regulation.¹⁰

The definition of diabetes offered in the DSA Beginners' Guide to Diabetes is much more helpful from the perspective of someone trying to learn about the condition. It

⁸Leavitt, Naomi S. and Molleutze, Willie F. in "Diabetes Mellitus and Impaired Glucose Tolerance," Chapter 10 of *Chronic Diseases of Lifestyle in South Africa since 1995 to 2005*, Medical Research Council, 109.

⁹Guthrie, Diana and Guthrie, Richard. *Nursing Management of Diabetes Mellitus: A Guide to Pattern Approach*, 21.

¹⁰These ideas about the self and the role of support for a diabetic come from diabetes experts I spoke with in Durban. Fiona Prins, DESSA Diabetes Educator, in an interview on November 28, 2006, at DESSA offices, Westville, Durban. Further citations attributed to Fiona Prins refer to this interview unless otherwise noted, Sue Frye, and Maria Reynolds. Also attended lectures on it at the WDC. Ideas from these lectures presented in Findings and Analysis section.

says that diabetes is “a condition in which the body cannot produce insulin or cannot use insulin properly. It is characterized by high blood glucose levels.”¹¹ Frye and Sister Pilele describe insulin as the “key that unlocks the cell to let sugar in.”¹² Thus, diabetes is indicated when sugar levels are out of control because the hormone to control it (insulin) is either not present or malfunctioning causing blood glucose (sugar) levels to spiral out of control.

Types of Diabetes

Type I diabetes occurs in younger people (onset is usually before age 30) and with this type of diabetes, the body produces no insulin. Type I diabetics are insulin dependent – they must take insulin in order to survive. Type II diabetes has a later onset, usually after age 35. There is, however, an increasing prevalence of Type II diabetics in people under 35, particularly young children, and thus the age boundary of 35+ is ceasing to be an accurate defining characteristic of Type II diabetes.¹³ Type II diabetes usually develops in people who are overweight and inactive as well as having a family history of the condition. The status of a Type II diabetic’s insulin varies from person to person. In many Type II diabetics, insulin resistance develops and thus insulin treatment will not help their condition. Other Type II diabetics are insulin deficient and this deficiency often increases later in life especially in times of stress so that they require insulin therapy. Type II diabetics are more reliant on diet and exercise to treat their condition and there

¹¹Diabetes South Africa Beginners’ Guide to Diabetes. Taken from the DSA website, www.diabetessa.co.za.

¹²Sue Frye and Sister Pilele Dlamini, Nursing Sister at the Pediatric Endocrinology Unit at Inkosi Albert Luthuli Hospital, November 1, 2006. Further citations attributed to Sister Pilele refer to this date and place unless otherwise noted.

¹³Dr. Ayesha Motala.

are some oral medications that can be taken to lower blood glucose levels by stimulating the pancreas (the organ which is supposed to produce insulin).¹⁴ More on treatment will be included over the course of the findings section of this paper because much of what I learned during the course of my study was how to control diabetes and the challenges of doing so.

There are borderline conditions to diabetes where people have impaired glucose tolerance. It is beyond the scope of this paper to discuss these borderline conditions besides to note that a high prevalence of these conditions is being found in Africa which indicates that diabetes prevalence is on the rise.¹⁵ Also outside the realm of this paper is gestational diabetes which some women develop when they are pregnant.

Etiology

The cause of diabetes remains unknown. Consistent with the clinical definition, the theory is that there are many causes of diabetes just as there are multiple manifestations of the disease. There is definitely a genetic component to diabetes though the inheritance pattern for Type I and Type II diabetes are thought to be entirely different from one another. In research done on the etiology of Type I diabetes, data points to multiple genetic modalities of inheritance and that the environment plays a role in how the inheritance factors are expressed in different family members but this research is still limited and much too complex to explore in depth in this study. The research on the causes of Type II diabetes is even more limited. It is thought to be genetic but unrelated

¹⁴Information for this paragraph comes from Diabetes South Africa Beginners' Guide to Diabetes, www.diabetessa.co.za and from Guthrie, Diana and Guthrie, Richard, *Nursing Management of Diabetes Mellitus: A Guide to Pattern Approach*, 4-5.

¹⁵Dr. Ayesha Motala.

to the immune system. It is also thought to be unrelated to the chromosome on which much of the research on Type I diabetes has been focused. Rather, it is thought that the genetic influence of Type II diabetes is spread across multiple chromosomes and that there is a strong environmental influence on the development of Type II diabetes:

The gene or genes seem to be widespread through the world and in every race and culture. But we see the disease manifest only in developed or developing countries where it is associated with increased caloric intake and decreased caloric expenditure (obesity)...When these [developing] countries begin to industrialize or the people immigrate to more developed countries, there occurs a virtual explosion of diabetes. How this change in lifestyle interacts with the genetic precursor is unknown.¹⁶

The exploration into the cause of diabetes is an area that is still new and exciting for scientific research. For the purpose of this study, what is important to emphasize from the above analysis of potential causes of diabetes are the following two points: First, diabetes emerges in developing countries when they are industrializing and living the lifestyle of those in the “developed world.” 58% of South Africans live in an urban environment and this figure is on the rise.¹⁷ This trend indicates that diabetes prevalence will continue to grow because an industrialized society is highly correlated with a lifestyle that contributes to diabetes.¹⁸ The second point that arises from the above quotation regards this idea of lifestyle choices. If a person is sedentary, overweight, and has a history of diabetes, he or she is more likely to develop Type II diabetes. The science behind this etiology may not be set in stone, but these risk factors are clear.¹⁹

¹⁶Quotation and information leading up to the quotation comes from Guthrie and Guthrie, *Nursing Management*, 21-27. Quotation on 26-27.

¹⁷Dr. Naomi Levitt, Professor of Diabetes and Endocrinology at the University of Cape Town, in a lecture entitled “A Collision Course Between Two Epidemics: Lessons from Africa.” Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 5, 2006
Further citations of Dr. Levitt refer to this lecture unless otherwise noted.

¹⁸Dr. Naomi Levitt and Dr. Ayesha Motala.

¹⁹All materials on diabetes will cite these risk factors. Some examples are Sue Frye, *Diabetes South Africa Beginners' Guide to Diabetes*, Guthrie and Guthrie, *Nursing Management*, 26-27, World Health Organization Diabetes Information, www.who.int/diabetes.

Complications

As Sue Frye often says when talking to people about diabetes: “Diabetes isn’t going to kill you, the complications are.”²⁰ Diabetes causes many complications – some examples are, but are definitely not limited to: heart disease, kidney disease, blindness, and neuropathy (nerve damage, particularly common in the feet and hands of diabetics).²¹ The devastating complications of diabetes, such as blindness, kidney failure and heart disease, are imposing a huge burden on healthcare services. It is estimated that diabetes care accounts for between 2.5% and 15% of a nation's health budget and much of this financial burden comes from treating complications.²² An estimated 25% of the world’s nations have not made any specific provision for diabetes care in national health plans.²³

Guidelines exist in South Africa but they are not used.²⁴ The South African Health Minister says that two further sets of guidelines have been made for diabetes care and that “these guidelines are due for publication in due course.”²⁵ The role that diabetic complications play in this study are as a warning and as a reality of what is happening. Complications come up in my data either in the form of happening to people or as a looming threat of what will happen if diabetes is not controlled. So while I will not be discussing the medicine of diabetic complications, they play a huge part in this study because they are what is debilitating about the disease and what increase the need for

²⁰Sue Frye.

²¹Diabetes South Africa Beginners’ Guide to Diabetes. Taken from the DSA website, www.diabetessa.co.za.

²²www.who.int/diabetes and www.idf.org

²³Both facts from the World Health Organization Diabetes Unit - www.who.int/diabetes

²⁴Fiona Prins.

²⁵Dr. Manto Tshabalala-Msimang, interview in *Diabetes Focus*, Spring 2006, 37.

support – complications often take away the ability for a person to self-regulate their condition and the goal of experts is to educate diabetics before a complication occurs.²⁶

Findings and Analysis

Paradigms of Care: Self-Management and the Collaborative Team Approach

The MRC report on chronic diseases of lifestyle highlights the need for collaboration among healthcare professionals and patient empowerment to fight chronic diseases:

The successful treatment of patients with chronic conditions is multifaceted and requires a collaborative approach from all involved. However, in the final analysis, these patients self-manage their conditions...When patients leave the clinic or office, they can and do veto recommendations a health professional makes... An understanding of this principle emphasizes the need that patient empowerment is central to effective care of chronic diseases.²⁷

The MRC findings are consistent with what the experts are saying – patients need to know about their disease and how to control it in order to fight chronic diseases in South Africa. These findings are in step with what was being presented at the WDC which is representative of the most up to date thinking of the international diabetes community.

J. Overland, a nurse from Australia, presented on her experience working in a facility that promoted a collaborative team approach to diabetes management. Her team consists of an endocrinologist, a diabetes educator, a dietician, a psychologist, a podiatrist, an exercise physiologist, and a pharmacist. She described the “traditional” model of care as one in which people make an appointment to see the doctor and wait until they do. In this system, doctors are overburdened and other players – like nurses and

²⁶Sue Frye, Maria Reynolds, Sister Pilele Dlamini, and Kirthee Pillay.

²⁷Krisela Steyn, “Overview and Conclusions: A Perspective on Dealing with Chronic Diseases of Lifestyle in South Africa,” from *Chronic Diseases of Lifestyle in South Africa: 1995-2005*, 260.

dieticians – do only their role as stipulated by the doctor.²⁸ The traditional model is that which exists in South Africa – Pillay complained that people will only go to the dietician if the doctor makes them and monitors that the appointment actually occurred. For many, the doctor is the source of knowledge and any information dispensed by other sources needs to be double checked with a doctor.²⁹

In the collaborative team approach paradigm, each of the team members has substantial knowledge about diabetes generally so that they are able to make an assessment, to take a social and medical history of a patient, and to recognize complications or other findings that should be reported to either a doctor or to another team member. For example, a nurse can assess a patient and recognize a major foot problem and then refer that patient to the podiatrist for treatment. That nurse, however, would be able to explain in detail to the patient what the problem is, what is going to be done about it, and prevention strategies to stop the problem from progressing. Cooperation is essential between team members and less possessiveness over one's specialty area is important. There is an emphasis on blurring professional boundaries so that the patient can receive the same holistic care from all professionals on staff while at the same time having specialists available to help with all facets of care. This system ensures consistency of care, takes pressure off the doctor who can concentrate on more serious complications rather than on basic care, and gives other members of the staff a

²⁸Information on the collaborative team approach from J. Overland, Nurse from Camperdown, Australia, in a lecture entitled "Integrating the team approach into diabetes care." Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 5, 2006. All further citations attributed to J. Overland refer to this lecture.

²⁹Kirthee Pillay

more diverse and interesting work environment which in turn promotes longevity and stability in that workforce.³⁰

The MRC report findings support Overland's system given their analysis of South Africa's current system:

Countries like South Africa, with multiple burdens of disease, actually require a health-care system that caters for both acute and chronic conditions equally. Such countries are called upon to provide both modalities of care with extremely limited resources...Furthermore, comprehensive CDL intervention requires a multidisciplinary, multi-sectoral patient centred approach that goes far beyond the limited medical model that is required for the care of patients with acute conditions, the latter being the model of current health care in South Africa at the primary level.³¹

The other experts with whom I spoke would also support this integrated approach as it would improve the quality of their own jobs and would make them a more valuable and accessible part of the healthcare system.

Is this team approach feasible in South Africa? Overland was asked if her collaborative approach was possible in resource poor settings. She said that the full team might not be able to be hired but that people could train in more than one area – for example, a Chinese doctor trained in diabetic foot care at her clinic in Australia and is now a foot specialist and a doctor in China. Overland's main point regarding resource poor settings is that putting in the extra effort to have a team and to promote that team effort at the beginning of a patient's care would eventually yield cost effectiveness and time efficiency. A patient with a higher quality of care would be less likely to develop complications. It is complications that cause the biggest burden to a healthcare system so it is better to have more output earlier in terms of efficacy.³² I think that the collaborative

³⁰J. Overland

³¹Krisela Steyn, "Overview and Conclusions: A Perspective on Dealing with Chronic Diseases of Lifestyle in South Africa," from *Chronic Diseases of Lifestyle in South Africa: 1995-2005*, 254.

³²J. Overland.

team approach is an important part of improving diabetes care in South Africa. It struck me while listening to this lecture that this approach is what the experts I had spoken to were striving for which is why I have included as one of my two ideal models for care.

The other ideal paradigm for care which is connected to the collaborative approach is that of self-management and patient empowerment. This concept is one that I came across repeatedly while talking to experts in KwaZulu Natal and there were a number of lectures given on it at the WDC. The general message of this strategy for care is that the patient is the final decision maker about his or her care so that advice, dietary adjustments, and lifestyle choices need to be focused around what the patient understands and wants to do. If a patient feels like he can manage diabetes and is taking steps to control it that seem manageable, compliance is likely to be higher in terms of keeping healthy. The collaborative team approach is useful for patient empowerment because it allows different people to be available as support structures and for the patient to have access to holistic healthcare.

Just as a combination of professionals has been found to be an effective type of care, a combination of interventions has been found to be the most helpful to patients. For example, an educator from Michigan ran a patient centered educational course and at the end, she allowed the patients to chose their mode of follow up – a phone call from a nurse or attending a monthly support group. This type of choice allowed patients to let their self-knowledge guide their control of the disease and compliance to the knowledge attained for the course was very high at the time of follow-up.³³ All of the barriers to care that I discuss later on in the findings are also barriers to self-management though

³³M. Funnell in a lecture entitled “Empowering Adults in High Risk Communities,” presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 4, 2006.

paradoxically, the data points to patient empowerment as a mechanism to overcome these barriers.

National Diabetes Week – Volunteering at Diabetes South Africa

I spent four days (November 14-November 17) of the Independent Study Project period volunteering at the Durban branch of DSA. DSA is an organization dedicated to promoting awareness about diabetes and to providing diabetics with the support and the tools necessary to control their disease. In other words, they promote patient empowerment and self-management of diabetes. The “What We Do” section of the DSA website says: “One of Diabetes SA’s most important roles is to be a voice for all people with diabetes in South Africa, to lobby for improved services and the availability of essential medications.”³⁴ This quotation encapsulates much of what I observed DSA trying to do during their opening week but at the same time captures some of the biases inherent in being deeply involved in advocating for a disease that does not get the media or governmental attention that it perhaps deserves. This conflict between wanting to be advocates for a community that is in need of a voice and the frustrations at a lack of funding and a lack of governmental and healthcare infrastructure to deal with the disease was one that I observed repeatedly during my week at DSA.

The Durban branch of DSA used to be an office with one employee to answer the phones during certain hours which is the structure of most branches of DSA.³⁵ With the arrival of new manager Sue Frye in August 2006, the Durban branch of DSA is being transformed into a real center. It is in a house, with a 24 hour helpline for members as

³⁴“What We Do/Activities” section of the Diabetes South Africa website www.diabetessa.co.za

³⁵Sue Frye

well as educational materials and tools to care for the disease (such as glucometers which are machines to test blood glucose levels and the strips that needed to operate them) for sale. Frye and her husband, Bill, have converted their home into this center and it is still very much in the developing phases.³⁶ The grand opening for the new Durban Diabetes Center was on Tuesday November 14 which, purposefully, also was World Diabetes Day. The Minister of Correctional Services, Ngcobo Balfour, was supposed to make the opening speech for the center because he is a diabetic, but his plane was delayed in East London and he sent Trevor Sibaya, the Deputy Commissioner of Correctional Services for KwaZulu Natal instead. Mr. Sibaya also is a diabetic and he discussed his own journey to diagnosis. He spoke of his symptoms such as feeling tired and urinating frequently and of the inability of his doctors to make a diagnosis. He even underwent chemotherapy before being diagnosed as a diabetic.³⁷

Mr. Sibaya's speech was telling on two levels. First, the last minute cancellation by a high ranking official who was going to give some major publicity to the diabetes crisis was typical of the experience of those who work with diabetics in South Africa. Frye, Bill, her assistant Sashika, and the other members of DSA both from Durban and from other branches around the country who had come for the event did not seem surprised that Minister Balfour did not show up. In fact, the general sentiment was one of resignation to the fact that their cause was never going to get the attention it needed. Second, Mr. Sibaya's story was accessible yet horrifying – the idea that a man would be given a toxic treatment like chemotherapy before being diagnosed with diabetes is a shocking condemnation of the South African healthcare system's ability to deal the

³⁶Sue Frye

³⁷Mr. Trevor Sibaya, Deputy Commissioner of Correctional Services for KwaZulu Natal, November 14, 2006 to the public at Diabetes South Africa, 49 Willowvale Rd, Glenwood, Durban.

condition. This man is an employee of the provincial government and must have access to more health services than a vast majority of South Africans yet diabetes was a condition his doctors were unable to diagnose for an extended period of time. Even though the publicity created by his appearance was on a smaller scale than if Minister Balfour had spoken, I imagine it was important for the diabetics who were there to hear of a governmental official who struggled with the same poor resources and lack of information with which they themselves may have struggled.

Providing information about diabetes to diagnosed diabetics is a void that needs to be filled and DSA is working hard to do so. The lack of information given to people upon diagnosis became evident to me simply by being at DSA for their opening week (which continued until Saturday November 18). People would come in for the free blood sugar testing that was available and would have no idea what it meant to have a high sugar level or a low sugar level in relation to their health or their symptoms. They did not know what foods to eat and which were the worst for them – most thought avoiding sugar was the only aspect of a diabetic diet whereas the truth is “it’s the fats that need to be avoided more.”³⁸

One Zulu woman came in who was a Type 1 diabetic meaning that she was insulin dependent. She had a glucometer but no strips with which to use it to test her blood sugar levels. Type 1 diabetics are supposed to receive strips for free from the government but she never received hers. Even when they do receive strips, they do not receive enough to test as frequently as they should.³⁹ The assistant at DSA explained to this woman that she should be receiving free strips and gave her the number of a doctor

³⁸Sue Frye.

³⁹Sue Frye, Fiona Prins, Maria Reynolds.

who would be able to explain her condition more fully and provide her with the strips.⁴⁰ This interaction was only one of many that I observed in which an employee of Diabetes South Africa or one of the experts they had working there during this opening week was able to provide some information to a diabetic who was in the dark about the condition.

The Durban branch of DSA has three full time staff members – the Fryes and Sashika, a 19 year old assistant. There is no way three people can support even a fraction of the entire diabetic community of Durban – they are already overcommitted and Frye only took over four months ago. DSA also receives no government funding and relies entirely on memberships fees, the profits collected from selling diabetic products, and donations.⁴¹ For this reason, the community they can serve is effectively limited to those who can pay the R80 per year to be a member. Once a member, diabetics receive a discount on products like testing strips as well as the quarterly magazine *Diabetes Focus*, access to the 24 hour helpline, and the choice to attend a monthly support group of which there are several that meet in different locations citywide.⁴²

This membership fee is a barrier, however, and most likely the greatest community affected in Durban are Zulus. No one at DSA speaks Zulu and Frye admits that there are not very many Zulu members of DSA but that she would like to reach out to these communities but at this point does not have the resources.⁴³ The most affected community is the Indian community and a majority of the people who walked through the doors of DSA during the opening week were Indian. Frye says that 1 in 3 South African Indians are affected by the disease so her first priority is to get support groups running in

⁴⁰Interaction observed at DSA - Durban, Glenwood, Durban, South Africa, November 16, 2006.

⁴¹Sue Frye

⁴²Sue Frye

⁴³Sue Frye

Indian areas like Chatsworth⁴⁴ though she certainly wants to help as many diabetics as possible. So, while it is duly noted that many diabetics of all races are underserved, looking strictly at DSA, the Zulu community is the most underserved in Durban.

What happened when someone walked through the door during the opening week? Most people were looking for the blood sugar testing as this service was the center of most of DSA's advertising about what was going on for the opening week. Most days there was a nursing sister present to do the test and to explain the results. Most people did not have their sugar at a good level and they were told that they needed to get their disease under control or it could be very dangerous. I observed a few interactions, two of them with Zulus, in which their blood sugar levels were dangerously high. They were told to see a doctor immediately. One woman was a domestic worker who had walked from her employer's house and the nurse gave her the name and number of a doctor and wrote a note to her employer to take her to a doctor immediately.⁴⁵

It was disheartening to see that woman walk away since it was unlikely that she was ever going to get the medical care that she needed but there was little else that could be done for her without first getting her condition under control. The idea of controlling the disease was truly underlined for me during my week at DSA – Frye says to everyone that comes in that the key to diabetes is: “Moderation, moderation, and more moderation and control, control, and more control.”⁴⁶ Some people walk into DSA expecting miracle answers and for the people there to control their disease for them. What DSA is there to do is to help them learn to control their disease themselves and then provide support. Prins emphasizes that diabetes can be controlled on one's own and then educators, DSA,

⁴⁴Sue Frye

⁴⁵Interaction observed at DSA -- Durban, Glenwood, Durban, South Africa, November 15, 2006.

⁴⁶Sue Frye

and medical professionals can act as support structures.⁴⁷ In order for that process to start, however, the disease needs to be medically under control since starting to make lifestyle changes is a gradual process and not one that can occur when a person might go into a coma at any moment. Someone like the Zulu housekeeper may never reach the phase in which she could control her diabetes before she suffers a truly devastating side effect. One of the goals of DSA is to educate people about controlling their disease and to actualize this self-management before they reach a point at which immediate medical intervention must come before self-management.

For the majority of those who came in, their conditions had not reached these extreme measures. Most were given the name of a doctor that would help them to learn to control their diabetes specifically. Often, the name given was the same doctor and I wondered about the capacity of one doctor to see some many referrals. Frye had already mentioned to me how busy this particular doctor was since she ran such a good clinic.⁴⁸ Many of the diabetics were asked what doctors they saw and many of them saw general practitioners. According to Frye, general practitioners are usually not well equipped to handle diabetics⁴⁹ and given the number that came in with uncontrolled diabetes and the descriptions of short visits focused only on insulin prescriptions, this assertion seemed accurate. Frye and Prins have teamed up to offer training courses in diabetes care to medical practitioners in the conference center at DSA and in this way, DSA is hoping to help to address the lack of medical professionals well trained in diabetes care. It may seem as though that all the referrals to a doctor was limiting the opportunity to promote the use of other diabetes specialists. The South African system, however, does not have a

⁴⁷Fiona Prins to a visitor to DSA on November 14, 2006.

⁴⁸Sue Frye

⁴⁹Sue Frye

functioning collaborative approach to diabetes care so doctors are still the frontline for care. As a result, DSA does not have much choice but to refer first to a doctor since the doctors still have all of the medical and referral power. In addition, they did have educators present at their open house and do tell people about them once they have seen a doctor. They are trying to advocate the collaborative approach within the healthcare framework that exists. Furthermore, as aforementioned, there were a number of walk ins whose blood sugar levels were so high that immediate medical attention was essential to ensure that the person did not suffer a complication in the immediate future. In other words, when there is an emergency situation, emergency medical care is what is needed not education or support.

Besides the sugar testing, there were tables set up with diabetic products. Some examples include, but are not limited to – diabetic footwear, socks, jams, vitamin supplements, sugar, cinnamon, and foot cream. It is the complications from diabetes that kill people and cause them to live in extreme discomfort.⁵⁰ Some examples of the representatives present were one man marketing glyconutrients which are vitamin supplements designed from studies about what types of sugars our bodies actually need and which types they receive regularly from diet. Another woman represented a company that made an ointment to reduce foot ulcers and had pictures to show the product's dramatic effect. Bill uses many of these products himself as a diabetic and vouches for their effectiveness.⁵¹

After a day of being at DSA, however, I began to wonder what it would be like to be a diabetic who did not know much about his or her condition and to arrive at a place in

⁵⁰Sue Frye.

⁵¹Bill Frye, Employee of DSA and diabetic, DSA, Glenwood, Durban, November 14-17, 2006.

which there were people providing information, but with products attached. I imagined I would feel as though I would need to buy an assortment of socks and creams in order to get healthy. As aforementioned, the only evidence I managed to gather about these products point to their effectiveness but it made the environment of the house less welcoming to have products being marketed along with every bit of information gained. The money that DSA desperately needs is a factor in this marketing emphasis – the representatives of the various companies paid to have a table at Diabetes week and some of the sales directly benefited DSA. Though I have no doubt that DSA feels these products are effective and helpful for diabetics, I would hypothesize that if DSA had more funding, they would be less aggressive in their marketing of diabetic products. Thus, the need for more funding for diabetes education and work emerges in the form of marketing detracting from the educational efforts that do exist.

Beyond DSA: What Most Diabetics Experience

An Example of Good Care: Inkosi Albert Luthuli

To get an idea of what a clinic that provides care for diabetes is like, I went to Inkosi Albert Luthuli hospital to observe at their Pediatric Endocrinology clinic. Before she sent me there, Frye told me: “Unfortunately, it’s unique because its good.”⁵² She added: “Very few state hospitals can cope with pediatric diabetes and there are 400 kids being treated at Albert Luthuli. The adult clinic is also good.”⁵³ In order to be a patient at Albert Luthuli, a patient must go through referrals from lower level hospitals – as a tertiary level provincial hospital, a patient must have a referral and an appointment – no

⁵²Sue Frye

⁵³Sue Frye

walk ins are taken.⁵⁴ Prins added her own praise of the services at Albert Luthuli: “Albert Luthuli is a rare clinic where a diabetic will be transported to the hospital from whichever hospital they have previously been admitted to. They want to make sure patients will get there who might not make it if they are told to go on their own. A child and his or her caretaker will both be admitted so that they will both understand what to do keep the child healthy.”⁵⁵

Sister Pilele gave me the opportunity to sit with two of her patients. They were a brother and sister who were both Type I diabetics and they were of Zulu origin but spoke excellent English. After some time spent with the kids, Sister Pilele joined us and reviewed with the kids how to control their condition. This interaction was meant to be educational for me but was also serving as review for these kids on how to control their condition.

Since these kids were Type I diabetics, they were on insulin. What type of insulin should be taken and what dosages is a process that needs to be supervised by a doctor according to Sister Pilele: “It’s insulin. It must be ordered by a doctor. Don’t borrow it or buy it on your own. It must be the right type, it must be at the right time, and at the right site. Insulin is dangerous, you can die if you use the wrong amount.”⁵⁶ This point highlights a potential role for a doctor in a collaborative team approach to diabetes healthcare – providing medication. It is not as progressive a model as the Australian model presented at the WDC who said that nurses were involved in prescribing medication and adjusting dosage within the framework of a protocol.⁵⁷ Another point is

⁵⁴Sister Pilele Dlamini

⁵⁵Fiona Prins

⁵⁶Sister Pilele Dlamini in a consult with two pediatric patients.

⁵⁷J. Overland

that while Sister Pilele was emphasizing the doctor's role in controlling insulin dosage, she was also extremely encouraging of these kids to be independent and to know about their disease so that they could lead normal lives: "My work is to make sure you go home, you go to school, you grow up normally, and don't spend nights in the hospital."⁵⁸ She told them to play sports and to educate their friends about their disease so that people would not be afraid and would know how to help them if they got sick.⁵⁹ The take-home message was one of self-management: doctors and other healthcare professionals are needed for support and for review but are not always around so independence is essential.

While sitting with these kids and Sister Pilele, it became clear to me that the process of learning to use insulin is inextricably linked to diet therapy. Sister Pilele would drill the kids on what to do when their blood glucose levels were at certain levels and the correct responses were generally a mix of diet and medication. She explained to me, "10 to 14 is medium high. Anything from 10 is high. Above 15 is very high. Below 4 is low."⁶⁰ Frye told me that between 5-7 is a good sugar reading and that above 7 is not good.⁶¹ These numerical values vary depending on which experts are consulted but the variation does not strike me as a barrier to controlling diabetes.⁶²

Sister Pilele asked her patients: "If your blood sugar is between 10-14, what do you do?" One replied, "Take injection." "No, when between 10-14, no injections. Drink lots of water and exercise. Take a cup of water every 15 minutes. Don't have to sweat –

⁵⁸Sister Pilele Dlamini in a consult with two pediatric patients.

⁵⁹Sister Pilele Dlamini in a consult with two pediatric patients.

⁶⁰Sister Pilele Dlamini in a consult with two pediatric patients.

⁶¹Sue Frye. The unit for blood glucose measure is Mmol/l which is millimols per liter.

⁶²The IDF is involved with a number of other international diabetes bodies in the process of standardizing these values. Professor Pierre Lefebvre, President of IDF, in opening lecture entitled "The diabetes pandemics – What have we done? What shall we do?" Presented at WDC, Cape Town Conference Center, Cape Town, South Africa, December 4, 2006.

putting on music and jiving is exercise.”⁶³ The question posed here was just one of many – she quizzed them on action for every level of blood sugar, high or low and there was a different procedure for each level. A blood sugar level above 15 needed a rapid acting insulin shot. A snack was needed before any type of exercise. In short, there was a lot of information to be learned about using insulin and using diet to control diabetes.

These kids had an excellent grasp on their condition, but they were an unusual case. Their mother was devoted to their care and they had assistance from her employers such as transport and care. They spoke excellent English.⁶⁴ This interaction gave me an example of good diabetes care – Sister Pilele spent half an hour with these kids reviewing their condition but she told me after the kids had left: “[There are] very few people who sit down with kids like me and educate kids.”⁶⁵ If the education and the support did not occur, these kids would not be as knowledgeable about their disease – they still forgot things which underlines the need for support.

The kids recounted how difficult it had been for them to access Albert Luthuli. Both were hospitalized at King Edward, their local provincial hospital, a number of times before they were able to get a referral to Albert Luthuli. Their comments on the care at King Edward were negative: “Most of the nurses at King Edward don’t know anything about diabetes,” the 11 year old told me. “You have to do everything yourself.”⁶⁶ Her brother added, “Most of the nurses when you are asking for help, they are listening to

⁶³Two Zulu Type I diabetic children aged 11 and 15 and Sister Pilele Dlamini, Nursing Sister at Pediatric Endocrinology Clinic, Inkosi Albert Luthuli Hospital, Durban, November 1, 2006.

⁶⁴Two Zulu Type I diabetic children aged 11 and 15 and Sister Pilele Dlamini, Nursing Sister at Pediatric Endocrinology Clinic, Inkosi Albert Luthuli Hospital, Durban, November 1, 2006.

⁶⁵Sister Pilele Dlamini.

⁶⁶11 year old Zulu female Type I diabetic, in conversation on November 1, 2006 at Inkosi Albert Luthuli Hospital, Pediatric Endocrinology clinic, Durban.

music or something.”⁶⁷ My experience at Albert Luthuli occurred early on in my research and what I was to find out later on was that it was definitely an example of good care and most diabetics never received it.

Beyond Albert Luthuli: Barriers to Good Care

As noted, the treatment of these two children at Albert Luthuli was ideal and unusual. While the system at Albert Luthuli is not the fully collaborative team approach advocated at the WDC, these kids had access to a doctor, a nurse who was also a diabetes educator, and a dietician. As a result, these children knew what foods to eat and when as well as how to take their insulin to control their disease. As a result, they are generally healthy in between monthly visits to the clinic and know how to react to acute changes in their condition. This ability to react to acute situations is important for proper self care which was a point emphasized by Reynolds, especially for newly diagnosed diabetics.⁶⁸ Unfortunately, the system that is in place now for diabetes care is not one that can facilitate this goal of self care within a support structure. When a patient comes in and is diagnosed with diabetes, there are a number of obstacles between that patient and the ability to control diabetes.

Time

In order to understand diabetes as a condition and then as one that can be controlled takes a substantial amount of time. Just through my brief interaction at Albert Luthuli, I got a snapshot of how complicated diabetes control is let alone the time needed

⁶⁷15 year old Zulu male Type I diabetic, in conversation on November 1, 2006 at Inkosi Albert Luthuli Hospital, Pediatric Endocrinology clinic, Durban.

⁶⁸Maria Reynolds.

to accept one's condition as chronically ill. When a person is diagnosed with diabetes, they need time to accept that diagnosis and to realize that it is a condition that will affect them for the rest of their lives. Maria Reynolds thinks that psychological support is the most important because the patient needs to be able to begin to accept their condition and to learn to how to respond to acute complications so that their condition does not get worse.⁶⁹ In theory, there are supposed to be a number of support structures available – a dietician, a diabetes educator, and a specialist doctor. On the one hand, seeing them all at the same time would be detrimental according to Maria Reynolds, “You can't have too many people trying to support at once. The most important is psychological support, then dietetics, then a nurse/diabetes specialist, and a specialist doctor.”⁷⁰ The point about how many specialists a patient can handle in one visit is not one that Overland discussed in her presentation on the collaborative approach. I imagine in her clinic, she expects patients to continue to come in for care and with this type of follow up, there would be no need to bombard them with too much information in one visit.

On the other hand, what usually happens is that patients are not allotted sufficient time to use any of these resources nor do they follow up with these specialists. “When a person is diagnosed with diabetes, they are supposed to be admitted to the hospital, dripped, hydrated, and seen by a dietician and a diabetes educator before they are discharged,”⁷¹ said Fiona Prins. She added that this process rarely happens in the public sector. Kirthee Pillay noted that even when a dietician is consulted for a patient, the dietician does not have sufficient time with each patient (half an hour usually one time

⁶⁹Maria Reynolds.

⁷⁰Maria Reynolds.

⁷¹Fiona Prins.

per month at most).⁷² Additionally, as Pillay and Reynolds both told me, the time is also insufficient in that there are rarely enough follow-ups to ensure that the patient's questions are answered or to make changes in the advice given to accommodate new needs of the patient. In other words, they have to treat a consult in the public sectors as a one time shot because they may never see that patient again.⁷³

Another time problem that faces the dietician or any consulting medical professional is the time of the patient. Pillay notes that: "the patient may need to catch a taxi or return a borrowed car so he or she will say 'tell me what I need to know quickly, I only have 5 minutes.'"⁷⁴ The consulting expert cannot give the proper information to a patient in such a limited time span and the patient that is in a rush will not really be listening or absorb what is being said to them. Part of this trouble is a lack of communication – patients are not aware or do not want to be aware of the severity of their condition so they rush through the process of educating themselves. Mainly, it seems that this problem is one of a lack of resources – if more transport was available that was convenient and cheap, patients would probably not be in such a rush to get out of the hospital.

The Doctor

The role of the doctor in diabetes management is controversial. The general opinion among the experts with whom I spoke was that general practitioners in South Africa were, for the most part, ill equipped to handle diabetes patients.⁷⁵ Most of the

⁷²Kirthee Pillay.

⁷³Kirthee Pillay and Maria Reynolds.

⁷⁴Kirthee Pillay

⁷⁵Fiona Prins, Kirthee Pillay, Maria Reynolds, and Sue Frye.

doctors have a poor background in nutrition and it is not advisable for a doctor to give nutritional information. For this part of their treatment, patients need to see a dietician.⁷⁶ Insulin dosage and medical management can be done by a doctor and needs to be, but the patient should be seeing an endocrinologist or a diabetologist.⁷⁷ Reynolds said: “Some GPs think they know all, but they don’t,”⁷⁸ and Pillay agreed that, “A lot of doctors think they know everything from colleagues and will give patients the wrong nutritional information.”⁷⁹ Frye and Prins both noted that doctors are only given six weeks of training on diabetes in medical school and nurses even less so it is not surprising that these professionals are ill equipped to handle this condition.⁸⁰

Doctors also sometimes pose a challenge to the collaborative approach advocated by others in the diabetes field, like Overland. Doctors are supposed to have a dietician on staff and to refer all patients to that dietician as well as seeking out diabetes educator consults for their patients. Patients will often more readily go to an appointment with a dietician if referred by a doctor and if a doctor refers the patient to the dietician, he or she can check to see if the patient has kept the appointment.⁸¹ While Pillay seemed to think that this checks and balances system is effective, Prins and Reynolds thought otherwise. “There is often not a dietician on staff,”⁸² said Prins. Reynolds expanded on this point through an anecdote:

I know of a pediatric endocrinologist who does all his education himself and sometimes that doesn’t do service because the doctor doesn’t have time to do all the education necessary for that patient. There needs to be an educator to refer to within

⁷⁶Kirthee Pillay

⁷⁷Maria Reynolds

⁷⁸Maria Reynolds

⁷⁹Kirthee Pillay

⁸⁰Sue Frye and Fiona Prins

⁸¹Kirthee Pillay

⁸²Fiona Prins

a team, a dietician within a team, and 100% psychological support so that the patient can build rapport with these people and have support.⁸³

What it boils down to, in public system, it is never clear if people are getting proper referrals. The medical unit needs to know what they are doing and a lot of units do not.⁸⁴

The idea of having a unit that is multi disciplinary does seem to exist in South Africa but its implementation is not often not effective. What seems to be the case is that doctors are in need of more training in diabetes because they should be able to know at least the basics of diabetes care. The baseline treatment is completely within reach of general practitioners but this training and the willingness to work with other professionals that could augment their knowledge is often not seen in the public system.

Language

While the most cases of diabetes occur in the South African Indian community (1 in 3 according to Sue Frye),⁸⁵ it is second most prevalent among black Africans. The existence of a language barrier is often a problem in trying to explain to a patient what diabetes is and how to take care of it. For example, in KwaZulu Natal, many dieticians do not speak Zulu and no official translators are provided by hospitals for dieticians. In order to tell patients about their condition and to begin to explain the dietary needs of a diabetic, dieticians rely on unrelated and untrained staff like maintenance workers or receptionists to translate. If no translator is available, the information is conveyed with broken Zulu and English. This lack of communication is likely a cause of noncompliance with the instructions given by the dietician. The university program in human nutrition

⁸³Maria Reynolds

⁸⁴Maria Reynolds

⁸⁵Sue Frye

and dietetics is introducing Zulu at an earlier phase in the degree so as to have more Zulu speaking dieticians, but language is still a major barrier to proper diabetes care.⁸⁶

There are materials published by DSA that are available in Zulu and Afrikaans (they are also published in other African languages in parts of the country where Zulu is not common).⁸⁷ Since most of the Zulu speaking diabetics do not have access to DSA, I do not know how readily these materials are distributed. Generally, according to Sister Pilele, educational materials are not available in languages besides English: “Most are in English. Education is out of reach for Africans who don’t speak English.”⁸⁸

Tailoring Care to Culture

As indicated by the subtitle of this section, the goal of the diabetes educators with whom I spoke is to tailor their care to the culture of the person with whom they are working. If the needs of the person as they lived prior to being a diabetic are not addressed by their healthcare strategy, compliance will probably be low. Of course, there has to be some compromise in this process because change needs to occur in order for a person to control his diabetes. This idea leads back to the idea of self-management – if experts help patients to find a regime of control that works for them, the patient should be able to learn to manage his condition.⁸⁹ While culturally related adjustments to diet, for example, may not lead to the *ideal* diet,⁹⁰ it will lead to some level of control and perhaps

⁸⁶Kirthee Pillay

⁸⁷Sue Frye

⁸⁸Sister Pilele Dlamini.

⁸⁹Fiona Prins, Maria Reynolds, Kirthee Pillay, Eva C Y Kan, Diabetes Nurse Educator, Hong Kong in her lecture entitled “Self Management Education: What are we doing?” Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 4, 2006.

⁹⁰Fiona Prins

more changes could be made later on in the process. Pillay notes that “gradual change is the key.”⁹¹

The best example of this principle comes when dealing with food. The individual history of how a person eats and behaves is a major factor in determining how to teach them to control their diabetes. For example, Zulus eat large amounts of starch along with large amounts of protein and limited portions of vegetables. Zulus also generally eat large portions especially women. Culturally, it’s not bad for women to be overweight, notes Pillay: “it means they are healthy and that they are rich. They intentionally eat bigger portions to get fat.”⁹² The result of being overweight is poor control. The amount of starch eaten must be controlled as a diabetic and more vegetables incorporated into the daily diet. In Indian populations, there is also an emphasis on the starch though for them it comes from rice. The curries and the fried foods in Indian diets are high in fat which is a major problem for diabetics.⁹³

The dietary needs of patients can be met through the foods that they eat regularly. Adjustments can be made based on the person’s normal diet – in fact, Pillay emphasizes that “you can’t be dictatorial in your approach, you need to be clever and manipulate eating patterns...gradual change is the key...if you tell them that they must right away cut down from 8 slices of bread to 2, it’s not gonna happen.”⁹⁴ A dietician will often take a diet history, a process where a patient fills out his or her regular eating habits. The dietician and the patient can go through the foods together and make adjustments based on the foods presented as part of the daily diet. Making simple changes to begin the

⁹¹Kirthee Pillay

⁹²Kirthee Pillay. Concept also discussed in Steyn, N.P. “Big is Beautiful – and unhealthy and confusing?” *South African Journal of Clinical Nutrition* 18:1(April, 2005), 4-5.

⁹³Notes about cultural eating patterns from Kirthee Pillay

⁹⁴Kirthee Pillay

process is the key to achieving compliance – for example, switching from full cream milk to low or nonfat milk or adding soya to foods.⁹⁵ Dieticians and diabetes experts are also able to make adjustments that are specific to cultural eating habits – for example, if mealie meal is prepared and left out over night, then reheated, it is much better for diabetics than if it is eaten immediately.⁹⁶

A major cultural barrier that diabetics often talk about having to overcome is their own family. Many patients say that their families do not want to change what they are eating to what a diabetic needs to eat. Reynolds notes that “there shouldn’t have to have separate pots of food. At the end of the day, you’re making the whole family better by changing to eating habits for a diabetic. Eating with the diabetic makes them feel less isolated. Especially true with children – if everyone else is eating differently they think “I’m the one with the problem, you can do what you want” and feel isolated.”⁹⁷ In other words, it is an essential part of proper management to have one’s family involved in the process. A lack of support will most likely lead to failure. Part of the role of the dietician should be to help families learn to adjust to the needs of the diabetic family member. The dietician needs to talk to the buyer of the food and the person who cooks the food. For these situations, booking an appointment can be more useful than intervening on the spot because multiple people needed to be included in the consultation with the dietician.⁹⁸

In opposition to the idea that the family may not be involved enough in supporting a diabetic is the situations in which families are over-involved. Pillay notes that particularly among Indian families, parents of children with Type I diabetes will often

⁹⁵Kirthee Pillay, Fiona Prins, Sue Frye.

⁹⁶Kirthee Pillay, Fiona Prins, Sue Frye.

⁹⁷Maria Reynolds

⁹⁸Kirthee Pillay

take full responsibility for the child's condition and needs. As a result, children of eight or nine do not have any idea about what they should eat or how to control their diabetes and eventually, they are going to be alone and have to make these decisions without the help of their families.⁹⁹ The role of family in diabetes care is thus a crucial balance between support and letting the patient take responsibility for his own care.

Expenses

There was some disagreement among the experts with whom I spoke about how expensive it is to be a diabetic. Reynolds and Prins both argued that it is expensive, even in terms of diet: "Making cheaper choices with diet is easier with unhealthy foods. Low fat cheese is more expensive as are low fat yogurts. Low glycemic starches are more expensive. All the healthy choices are more expensive than the unhealthy choices."¹⁰⁰ Their position was supported by a presentation at the WDC on the results of a worldwide survey that was sent to dieticians in 150 countries regarding what they told their diabetics to eat. Developing countries advised a much higher level of carbohydrates than did developed countries. When the data was analyzed, this differential was hypothesized to be due to the greater availability of grains in developing countries at an affordable price.¹⁰¹

In contrast, Pillay argues that it doesn't have to cost more trying to find healthier foods. Brown bread is less expensive than white bread. It doesn't cost more to cut fats. A person should use what he has in smaller proportions. Low fat milk is not more expensive

⁹⁹Kirthee Pillay

¹⁰⁰Maria Reynolds

¹⁰¹K. Kapur, India, in a lecture entitled "Eating Preferences – dietary habits and myths from around the world." Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 5, 2006.

than full cream milk. Some reduced fat stuff is more expensive but the general stuff is not more expensive. The dietician needs to be clever about messages sent to the patients because if they think it is going to cost them more to comply with instructions, they will not comply. She insists that it does not have to cost more to eat well as a diabetic – for example, one could advise buying food that is in season since availability will lower the cost of the food. Also, cutting something out of one's diet should mean that there is more money to spend on something else. Eating well is about making choices and those choices can be affordable.¹⁰²

The area in which expense is not a debate is regarding diabetes tools like glucometers and testing strips. Reynolds told me that one needs R300 to get a glucometer. Second hand machines do exist and there is talk of getting international donations to support buying and selling more second hand machines and getting more machines generally. Then there is the long term cost of strips to operate the machines. Strips usually vary between R160 and R190 but can get as high as R380 for a box of strips which only contains 50 strips which does not last for the full month for which it is provided. Government works with Rausch Diagnostics to distribute cost effective strips but patients are not given the machine free of charge. Also they only get one, maybe two packs of strips per month which is not enough. Only insulin dependent diabetics (Type Is) get strips from the government. Therefore, Type II diabetics would have to pay out of pocket each month for strips unless they have a medical aid.¹⁰³ Prins, Pillay, and Frye agreed with this assessment.¹⁰⁴ Frye sells strips and glucometers at a reduced price to her

¹⁰²Kirthee Pillay

¹⁰³Maria Reynolds

¹⁰⁴Fiona Prins, Kirthee Pillay, and Sue Frye.

members and raises money to try to get glucometers for those who cannot afford them, but there is little more that can be done on this issue without a better policy.¹⁰⁵

Cato Manor Study

Three Cato Manor women were interviewed about their diabetes on December 1, 2006. The information that was gotten from these interviews is limited based on the language barrier – one informant’s English was extremely poor and the other two women spoke moderately good English. This language barrier is important because if they were unable to communicate with me about their condition in English it is unlikely they were able to understand or to learn from their healthcare providers.

Virtually none of what the diabetes experts said should happen when a person is diagnosed with diabetes happened with these three women. All three women identified themselves as having “sugar disease” and “blood pressure.” When asked about what happened when they were diagnosed with this disease, Informant 1 described her experience in detail:

My toe hurt, so I asked a nurse, she is my friend, and she said I should go get the sugar testing. I went and it was 24. They gave me treatment to take for two weeks, then told me to come back. I came back and they gave me the test again – it was 19. Then they gave me a medicine to drink and I did, then they gave me the test again. My sugar was 21. They told me I had sugar disease, that it was diabetes.¹⁰⁶

Informant 3 said that they told her she had “sugar disease,” and nothing more about her condition. Informant 2 was unable to answer my question about what information she was given upon diagnosis. None of them saw a dietician. Informant 1 mentioned a nurse

¹⁰⁵Sue Frye

¹⁰⁶Informant 1, Cato Manor, Durban, December 1, 2006. All of the information obtained from Informants 1, 2, and 3 took place in Cato Manor in Durban on December 1, 2006. I went to each woman’s house in Cato Manor to interview each woman. I do not want to disclose the location of the houses for privacy’s sake.

who told her more about her condition, but the other two only cited doctors as the only medical professionals involved in their care.

Informant 1 was told to start attending a different clinic than the one at which she received her diagnosis; she was unsure if this clinic was specifically for diabetics. All the women were told to go to the clinic one time per month which is consistent with what the experts indicated. Informant 1 no longer goes to the clinic though she does still take the oral medications prescribed to her – how she obtains these medications without going to the clinic is unclear. All three women are on oral medications – they all knew that these medications were either for “sugar” or for “blood pressure.” Informant 2 had a large number of oral medications and was also on insulin which she said she took one time per day. Aside from knowing which medications were for “sugar” and which were for “blood pressure,” the women did not seem to know what the medications did.

the monthly visit is the only time at which these women have their blood sugar tested. I assume that all three of these women are Type II diabetics (Informants 1 and 3 definitely are. Informant 2 is on insulin but Informant 1 said that the Informant 2 had only started taking injections recently so I assume she is a Type II diabetic as well). Ideally, Type II diabetics should test themselves two times per day. The oral medications and diet control lose meaning if testing is not done regularly because it is impossible to know their effectiveness.¹⁰⁷ Informants 2 and 3 were able to tell me their last blood sugar reading – 10 and 7 respectively – but they did not know what these numbers meant. They asked me what the meaning of these numbers were, if they were doing well. The communication gap between these women and their healthcare practitioners is clear from

¹⁰⁷Information on testing times and effectiveness of medication from Sue Frye, Fiona Prins, Maria Reynolds, and Sister Pilele.

this point – blood sugar readings are the most basic indicator of diabetes and having no idea what the numbers mean underlines that there is no way for these women to attain effective control.

When I asked them about whether they would like to be able to test their blood sugar at home, Informant 1 said yes and asked about the price of a machine. I had to tell her how expensive they were and as a Type II diabetic, that she would have to pay for testing strips as well. These prices were not within her price range to be able to care for herself. Informant 3 was also interested in being able to test at home, though she did not understand what I meant by a machine to test her blood sugar. She is getting medical aid and thus has the potential to get a machine in the future. Informant 2 was aware that she only got tested at the clinic but was unable to understand what I meant by the question.

In terms of dietary instructions, all three women were told primarily not to eat sugar. Informant 1 said, “they said I musn’t eat sugars, fats. I must boil my food. I was fat then – they told me I must diet to be OK. I must do what is in the paper.” The paper to which she referred she identified as a dietary guidelines sheet. She said no one explained it to her and that she followed what the paper said. The process of handing out diet sheets without explanation is taboo – Pillay noted that many practitioners would do this and that it is not helpful because patients cannot understand what they are supposed to do or what the sheet means without a dietary consult. The process also leads to people asking for the sheet and not wanting to see the dietician which furthers patients from help and makes it harder for dieticians to convince patients to use their services.¹⁰⁸ Informant 1 was also told to eat more vegetables and fruits but not all fruits – she said a green apple was given as an example of a good fruit and bananas were given as an example of a bad

¹⁰⁸Kirthee Pillay

fruit. Informants 2 and 3 also cited that they had to start eating lots of vegetables, boiling her food, and not eating fats or sugars. They were told nothing about portion size.

The idea of tailoring a diet to the needs of a specific cultural group was not observed in this group. They were not given any information specific to their eating habits. Besides one woman getting a diet sheet, they were given little guidance about how to eat and why the changes they were told to make needed to be made to control their disease. The experts emphasize explaining the reasons behind changes to patients but this communication has not occurred with these Cato Manor diabetics. There was no lecture given to any of my other informants about moderation – it was all or nothing.

The lack of nuance in explaining diabetic dietary needs to these women reflects itself in a lack of compliance among them. They may boil their food but they still eat a lot of starch. Informant 1 still eats some of the foods that she was told not to – like bananas. Whether or not this information is accurate (Kirthee Pillay said that while bananas may have a greater effect on blood sugar levels than other fruits, they can still be eaten in moderation), the lack of compliance on the part of Informant 1 is indicative of her lack of trust for the people telling her not to eat bananas. Without an explanation of why bananas are bad for her, it is not really feasible to expect her to stop eating them. Informant 3 admits to “being bad” and still putting sugar in her tea. Once again, I hypothesize if she had a better understanding of why this habit has a poor effect on her health, she would be more willing to change.

Another factor that came up regarding compliance was price. Informant 1 said that the foods they told her to eat were more expensive as did Informant 3. As I discuss in my earlier section on expense, there is some disagreement among the experts as how

much the prices of foods for diabetics differ from a normal diet. If the perception exists, however, that a diabetic diet is more expensive, it does not really matter if that idea is true because people will not comply. As Fiona Prins points out, creating a diet based on circumstance is not going to be the ideal diet¹⁰⁹ but at the very least these women need help to learn about a diet that is acceptable to them in terms of content and price that will keep them in a reasonable state of health.

In terms of complications, Informant 1 was told she would die or her feet would have to be amputated if she did not control her diabetes. Informant 3 was told she would have a stroke. Both have problems with their feet – it was actually their feet that caused them to go to the clinic in the first place. Both have also been diagnosed with arthritis – I am unsure as to whether they actually have arthritis or if they have undiagnosed neuropathy in their feet. Either way, both of them should have their feet monitored since foot complications are common with diabetes. Informant 1 said she was given ointment for her feet during her initial two week treatment period but none of the others mentioned foot care as a part of their care after diagnosis. While being told of the complications that can result from diabetes is important, in the context of no other information, it seems to me to be simply a scare tactic rather than a form of information.

Perhaps the most shocking thing about speaking with these women about diabetes is that they don't really know what it is in a biological sense. Informant 1 claimed she knew what diabetes was because "my mother had it," but I am fairly confident given the data I collected from her about food and blood sugar readings that she does not have an understanding of what is going on in her body and how her symptoms relate to her condition and to what she eats. Informant 3 asked me what diabetes was. I explained to

¹⁰⁹Fiona Prins

her about the two types, about the pancreas, and about the role of insulin in her body and she seemed to understand some of what I was saying. She said no one had ever told her any of the information with which I provided her. I left this interview with the question -- how can diabetes possibly be controlled if the patients are not even told details about the condition beyond its name?

Conclusion

The answer to the above question is that diabetes cannot be controlled if those who are afflicted with it are not even told what it means to be a diabetic. My objective was to learn as much as possible about the state of diabetes care and the resources available to diabetics in South Africa. After immersing myself into the Durban diabetes community, I believe that the ideas about how to care for diabetics are present. These educators and nurses have methods and ideas about how to help diabetics and the goals which they hope diabetics would be able to achieve. For example, the mantra of self-management is a universal and modern paradigm – I heard people from Hong Kong, America, Canada, Australia, and Kenya speak about it at the International Diabetes Federation Congress in Capetown. I first heard about it, however, from Fiona Prins, a South African diabetes educator. It is not reaching the people – the women of Cato Manor are managing their disease alone but not in the empowered sense that is encouraged by diabetes experts worldwide.

The experts with whom I met all work together – they all know each other and in fact, the Durban diabetes community seems to be fairly tight knit. They also work with doctors that they feel are committed to good diabetes care. In this sense, the

collaborative team approach is somewhat present in Durban though not necessarily in a single facility (though such a facility may exist of which I am not aware). Whether or not collaboration does exist, it is clear that it is not reaching a lot of diabetics and this is the gap that needs addressing.

The communication gap between the patients and the experts and between the experts themselves was the most obvious failing that I observed during my study. I spoke with five experts who were all nurturing and well informed but there were major limitations on how many patients, especially how many under resourced patients they were able to serve. Even when they did access these types of diabetics, there were huge barriers of time, language, culture, and access to resources that prevent the patient from ever realizing a controlled state of diabetes.

In addition, the women in Cato Manor never saw these experts – they only saw doctors and an occasional nurse. I spoke with no doctors and with the exception of a few who were mentioned repeatedly as “the best,” the experts with whom I spoke did not seem to have a lot of respect for doctors or think that they were doing a good job managing diabetics. Prins and Frye were planning on running programs to educate doctors but even with this example, it seems that there needs to be more interaction between doctors and the other experts in the diabetes community. The result of more communication could be a united healthcare community that could face the problems of their patients together. The experts with whom I spoke and listened to talked about a team approach to diabetes, including the patient but the collaboration needs to start with the healthcare professionals..

In her lecture on Diabetes in Africa at the IDF conference, Dr. Ayesha Motala noted that the number of people with conditions that border on diabetes indicates that Africa is looking at the beginning of an epidemic.¹¹⁰ South Africa is better positioned to cope with this coming crisis than most of the rest of Africa – here, 50% of diabetics know of their condition as oppose to only 15% in other African countries that have been studied (i.e. Tanzania). However, this 50% does not include a recent study that indicates that only 15% of rural South Africans know of their diabetes status which is a statistic that is indicative of South Africa’s lack of preparedness to deal with the potential onslaught of diabetes cases.¹¹¹

I do not know if the South African government can afford to care for all of the diabetics – I was unable to include government officials in my study. While the limitations of the resources are unknown to me, it is probable that they could be doing a better job. They guarantee insulin, strips, and glucometers for all Type I diabetics and I met a Type I diabetic at DSA who did not get her strips regularly. The Health Minister confesses that communicable diseases are overshadowing chronic diseases.¹¹² The Chronic Diseases of Lifestyle paper reports the problems of a healthcare system that cannot care for acute and chronic conditions simultaneously, but many of the solutions proposed are guidelines that should be implemented rather than ideas about actual implementation.

At the WDC, I heard a few experts talk about marrying diabetes care with the care of other diseases like HIV/AIDS and tuberculosis (TB) to ease the burdens on healthcare

¹¹⁰Dr. Ayesha Motala..

¹¹¹Dr. Ayesha Motala.

¹¹²Dr. Manto Tshabalala- Msimang, South African Minister of Health, in an interview in *Diabetes Focus* magazine. *Diabetes Focus*, Spring 2006, 37

systems, but this concept was not one I came across doing primary research. In fact, the common attitude toward HIV by the experts with whom I spoke was one of bitterness and regret that HIV was taking all of the attention away from diabetes.¹¹³ The “What We Do” section of the DSA website mentions HIV/AIDS a few times:

Unlike AIDS, diabetes can be controlled and when educated and motivated, a person with diabetes can live a full, healthy and long life. Diabetes SA aims to assist this process at every level...

The South African government has been criticized for its ambivalent response to the link between AIDS and HIV but less attention has been paid to its inadequate preparation in dealing with country's dramatic increase in diabetic patients...

Around the world it has been shown that patient education and motivation reduce the cost of diabetes care dramatically. Unfortunately our health services are overburden[ed] with the AIDS crisis and diabetes is being pushed aside.¹¹⁴

A more productive attitude toward HIV/AIDS was presented at the WDC conference. Data was presented linking TB and diabetes¹¹⁵ as well as pointing out that diabetes and HIV prevalence are both going to continue to rise so that the care of both should be connected. After all, with the advent of anti-retroviral therapy, HIV is a chronic disease and the HIV doctors have come up with strategies for adherence that could be applied to diabetes. In addition, prevention is the key to both diseases – both are diseases of lifestyle, they just attack different flaws in lifestyle. Diabetes prevention needs to emphasize a healthy diet and exercise while HIV prevention emphasizes safe sex. All of these things are part of a healthy lifestyle for any person so the hope for the future is that these the multiple burdens of disease that South Africa faces can be married rather than in competition with one another.¹¹⁶

¹¹³All the experts with whom I spoke mentioned that diabetes was being overshadowed by HIV.

¹¹⁴Excerpts from “What We Do” section on DSA website www.diabetessa.co.za

¹¹⁵I. Bygbjerg, Professor of International Health, University of Copenhagen, in a lecture entitled “TB, HIV/AIDS, and Diabetes: Emphasis on Type 2 and TB in Africa.” Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 5, 2006.

¹¹⁶Analysis about HIV/AIDS and diabetes from Dr. Naomi Levitt.

Kirthee Pillay said: ““The rural woman with two grandchildren, where is she supposed to go for help?””¹¹⁷ I do not have an answer but I did learn that it is a question that needs to be taken much more seriously here. I sat in a Cape Town restaurant looking at my schedule for the diabetes conference and one of the waiters asked me what I was doing and I explained. He had no idea that the conference was in town. If a crowd of 12,000 people cannot attract people’s attention, even for a few days, I am not sure what will. I think the personnel exist in South Africa to begin to make some serious progress toward better control of this disease. Most diabetics do not need insulin – the provision of it will not be the major expense. They do need glucometers and strips to test their blood sugar. They do need the education to know what foods to eat and what their blood sugar readings mean. They do need support to work through the challenges of having a chronic disease because that’s the reality – diabetics are going to be diabetics forever. The women in Cato Manor are not receiving adequate baseline care let alone the comprehensive, ongoing care that they need to control their disease and live healthily. The provincial healthcare system is guaranteeing a higher standard of care than they are providing and this needs to change. Furthermore, South Africa cannot afford to take care of more diabetics – the WHO cites that between 2.5% and 15% of a nation’s annual healthcare budget often goes to fighting diabetes complications.¹¹⁸ Preventative campaigns are thus important so that this burden does not increase. The prevention of diabetes comes from the promotion of a healthy lifestyle which would be a boon to South Africa in and of itself.

¹¹⁷Kirthee Pillay

¹¹⁸www.who.int/diabetes; <http://www.idf.org/home/index.cfm?unode=3B9691D3-C026-2FD3-87B7FA0B63432BA3>

Limitations and Recommendations for Further Study

My limitations on this study were countless. I only spoke with five experts out of the many that existed in Durban and around South Africa. I only interviewed three diabetics in Cato Manor to find out about the implementation of the resources that I heard about from experts. While volunteering at Diabetes South Africa, I interacted with diabetics but I did not have formal conversations with many diabetics which would have added data to my project. Diabetes South Africa only reaches a limited population and the diabetics whom I met there and the services they were able to access were unusual. I did not have a lot of knowledge about diabetes going into this project and thus was not able to form particularly profound or well informed questions for the people with whom I was speaking. I also did not examine scientific studies that have been done in South Africa with a great deal of care. I focused this project on verbal data and while I skimmed a number of scientific studies, I did not incorporate them directly into the paper but only insofar as they were mentioned by an expert.

I would recommend that if someone were to pursue this project further, they would talk to some doctors. I would talk to diabetes specialists and general practitioners – I would ask general practitioners if they felt ill equipped to deal with diabetes. I would ask the specialists if they feel as pessimistic about the situation of diabetes in South Africa as the nurses and educators with whom I spoke do. I would speak with many more patients to get more of a sense of the range of care received. Another possible angle is comparing the public and the private sector – I was told by Prins, Reynolds, and Frye that that the private sector is a completely different world. Patients are seen by a dietician and an educator before leaving the hospital upon first admission and can follow

up with the educator or dietician as often as they need to after release from the hospital.¹¹⁹ A source for further study would be how the private model of care could possibly be implemented in the public sector and how it relates to collaborative team models internationally.

Annotated Bibliography and List of Sources

Experts

Sister Pilele Dlamini, Nursing Sister and Diabetes Educator, Inkosi Albert Luthuli Hospital, Durban, South Africa, November 1, 2006.

Sue Frye, Manager of Diabetes South Africa – Durban, South Africa, October 6 and 27, 2006, November 1 and 14-17, 2006.

Professor Kirthee Pillay, Professor of Dietetics and Nutrition at the University of KwaZulu Natal (UKZN) – Pietermaritzburg, Pietermaritzburg, South Africa, November 21, 2006.

Sister Fiona Prins, DESSA Diabetes Educator, Durban, South Africa, November 14 and November 28, 2006.

Sister Maria Reynolds, Diabetes Nurse Specialist Educator, National Renal Care, Durban, South Africa, November 22, 2006.

Cato Manor Diabetics

Informant 1, Cato Manor, Durban, South Africa, December 1, 2006.

Informant 2, Cato Manor, Durban, South Africa, December 1, 2006.

Informant 3, Cato Manor, Durban, South Africa, December 1, 2006.

Other Diabetics

Bill Frye, white, middle aged male, DSA employee and husband of Sue Frye, head of DSA. Was diagnosed with Type 2 diabetes three years ago.

Trevor Sibaya, black (probably Zulu) man. Deputy Commissioner of Correctional Services for KwaZulu Natal, November 14, 2006 to the public at Diabetes South Africa, 49 Willowvale Rd, Glenwood, Durban

Zulu Girl, Age 11, diagnosed with Type I diabetes at 8 months.

Zulu Boy, Age 15, diagnosed with Type I diabetes at age 4 years.

¹¹⁹Fiona Prins

WDC Experts

Professor I. Bygbjerg, Professor of International Health, University of Copenhagen. Lecture Cited: “TB, HIV/AIDS, and Diabetes: Emphasis on Type 2 and TB in Africa.” Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 5, 2006

M. Funnell, Diabetes Educator, United States. Lecture Cited: “Empowerment of Adults in High Risk Communities.” Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 4, 2006.

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Professor Pierre Lefebvre, President of International Diabetes Federation, Belgium. LECTURED CITED: “The diabetes pandemics – What have we done? What shall we do?” Presented at WDC, Cape Town Conference Center, Cape Town, South Africa, December 4, 2006.

Dr. Naomi Levitt, Professor of Diabetes and Endocrinology at the University of Cape Town. Lecture Cited: “A Collision Course Between Two Epidemics: Lessons from Africa.” Presented at the WDC, Cape Town Convention Center, Cape Town, South Africa, December 5, 2006

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Secondary Sources

Dr. Manto Tshabalala- Msimang, South African Minister of Health, in an interview in *Diabetes Focus* magazine. *Diabetes Focus*, Spring 2006, 37.

Interview with the Health Minister in *Diabetes Focus* magazine which is the magazine published by Diabetes South Africa. s

Steyn, Krisela, Fourie, Jean, and Temple Norman (eds) *Chronic Diseases of Lifestyle in South Africa: 1995-200*. Medical Research Council Technical Report, May 2006.

The MRC report is divided into chapters, each of which are authored by different experts on the topic of that section. I used the chapters on diabetes, health services research, and the conclusion most heavily in this study though I also examined the chapters on obesity and nutrition. This report was essential secondary source data because, as far as I can tell, it is the resource on chronic diseases in South Africa. It cover studies that have been done and guidelines for care. While the plans for implementations are not a strong part of the report, it was still a valuable resource for this paper. It is correlated with the findings in my paper that this report only became

available in 2006 – it does not seem to be that another comprehensive resource on chronic disease was available before this time.

Guthrie, Diana and Guthrie, Richard. *Nursing Management of Diabetes Mellitus: A Guide to The Pattern Approach*. New York: Springer Publishing Company, Inc ©2002.

This book is a clinical text on diabetes management meant for nurses and other healthcare professionals. I used it for information on defining diabetes and the etiology of the disease, but it includes extensive information on these topics and much more that is beyond the scope of this paper. It is a great source for anyone who wants to learn about the medicine of diabetes care.

I read a number of scientific studies which I will list below. I did not cite all of them in the body of my paper but they did help guide me in terms of getting a sense of what kind of data was being collected and what sorts of hypotheses I should be making for my own study.

Blaauw, Renee, “Healthy benefits of the glycaemic index.” *South African Journal of Clinical Nutrition* 16:1 (February, 2003), 7-8.

Editorial discussing the idea of the glycaemic index and how it can be applied to chronic conditions like diabetes and whether it is the appropriate nutritional tool to use with these diseases.

Erasmus, R.T. et al, “Importance of family history in Type 2 black South African diabetes patients.” *Postgraduate Medical Journal* 77(2001), 323-325.

Gave me information on diabetes risk factors and which ones were important in the South African context.

Levitt, N and Bradshaw, D. “The impact of HIV/AIDS on Type 2 diabetes prevalence and diabetes healthcare needs in South Africa: projections for 2010.” *Diabetic Medicine* 23 (2006), 103-106.

This letter was formulated around the same data that Dr. Levitt presented at the WDC. Though I reference her talk in my section on HIV and diabetes, I read the information in this article first but gained an understanding of it from her talk.

Motala, A.A. “High Incidence of Type 2 diabetes among South African Indians: a 10 year follow up study.” *Diabetic Medicine* 20 (2002), 23-30.

This study gave me an idea how hard hit the South African Indian community is by diabetes.

Nthangeni, Gladys, et al “Dietary intake and barriers to dietary compliance in black type 2 diabetic patients attending primary health-care services.” *Public Health Nutrition* 5:2, 329-338.

This study gave me background on what to expect in my Cato Manor interviews.

Steyn, N.P. “Big is Beautiful – and unhealthy and confusing?” *South African Journal of Clinical Nutrition* 18:1(April, 2005), 4-5.

An editorial on a study that looked at the body image of black urban women to examine the phenomenon of a positive correlation between weight and health.

Appendix A: Interview Questions

I did not ask each of these questions to every person I interviewed, but these are comprehensive lists of the questions I asked to my expert sources and to my Cato Manor diabetics.

For the Experts

What got you interested in diabetes specifically?
What communities do you see as the most affected?
What does the public health system have available to help diabetics?
What parts of these support structures work? What parts do not? Is there any hope for improvement?
What do you do in your job? What are the roles of various specialists?
What needs to be stressed in treating diabetics – what are the most important things for them to know given the limited time you often have to advise them?
What should be done to improve healthcare for diabetics?
How well do patients respond to the need to control their disease?
What problems do you see with compliance?
What frustrations do you face as a non doctor?
Do you think general practitioners are equipped to handle diabetics?
Are doctors and nurses properly trained in diabetes care?
How does diabetes affect different communities here – are any complications more common in a specific community?
How manageable is the disease on a limited budget? Is it possible to be a poor person and have controlled diabetes?
Ideally, what would the process be for managing the disease?
Do you think that diabetes is overshadowed by communicable diseases like HIV/AIDS?
What are the biggest challenges of living as a diabetic in South Africa? Of working with them?
How does the prevalence here compare to the rest of the world?

For Cato Manor

Why did you go to the clinic?
What did the doctor tell you?
Did he tell you what diabetes is?
Did he tell you what it means to have diabetes?
Did you talk to anyone else at the clinic besides the doctor?
Did you talk to a dietician (a person who talks about food)?
Did they give you anything to read?
What did they tell you to eat?
Did they tell you to stop eating anything?
Did they give you any medicines?
Were they nice to you?
How often did they tell you to come back?
Did they tell you to test your blood sugar?
Did they ask you about your feet?
Did they ask you about your heart?
Did they tell you what might happen if diabetes is not controlled?
Are the foods they told you to eat expensive?
What do you need to help you with diabetes?