



**EXPLORING THE LIVED EXPERIENCES OF YOUNG PEOPLE (18-35 YEARS),
LIVING WITH TYPE 1 DIABETES, ATTENDING AN URBAN DIABETES CLINIC**

BY

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**A dissertation submitted to the Faculty of Humanities in fulfilment of the requirements
for the Degree of Arts in Psychology (MA Psychology) by Coursework and Research
Report**

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

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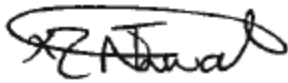
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OCTOBER 2018

DECLARATION

I, Zamokuhle Nokulunga Xolile Thwala declare that this dissertation is my own original work. It is submitted for the degree Master of Arts in Psychology (MA Psychology) by Coursework and Research Report, at the University of the Witwatersrand, Johannesburg. To the best of my knowledge, this work has not been submitted before for any other degree or examination at any other university, or published in any journal, except for where due acknowledgement has been done.

Signature:



Date: 05 October 2018

ACKNOWLEDGEMENTS

To my family who is always behind me, in every situation and decision I make. You believe in me, and I know I always have your support. Thank you very much, God blessed me with you, and may you continue to be the blessing that you are.

To my son Bongani, for understanding that mommy has to study, for understanding that all I do is for you to have a better future. For always being supportive, you surprise me every day, God blessed me with an Angel, there are not many like you...

To my supervisors Prof Claire Penn (may her soul rest in peace) and Jennifer Watermeyer, thank you very much for your support throughout the study. Thank you for believing in me, thank you for the support, guidance and holding my hand through this journey.

I would also like to acknowledge the research assistants who contributed to this research, Sonia Mbowa and Tshogofatso Seabe as well as everyone in the Health Communication Research Unit, thank you very much for your support and assistance.

To the young people who participated in this study, we would not have this information if you did not open up about your life to me, the stranger. I acknowledge and appreciate your bravery and your ability to make the best of your lives.

To my friends and colleagues, I appreciate your support.

I would like to acknowledge Olufemi Ajibola, for the support and guidance, thank you very much for encouraging me and making sure that I do not give up.

To everyone who has contributed into me getting where I am, I cannot list everyone by name, but know that I appreciate you very much and would never be where I am if it was not for you, thank you.

God the Almighty, I am forever grateful for your mercy and blessings, I shall continue to lean on You and not on my own understanding... I give thanks to You for guiding and protecting me throughout my journey, and I know You will continue to stand by my side!

ABSTRACT

Diabetes is an increasing health challenge in South Africa and requires a good understanding and adherence to fairly complex regimes of management. Little is known about barriers to care in the South African context, particularly amongst the younger population and little is known about potential gender difference in this group. A strong need emerges to understand the lived experiences of young people facing this chronic condition. A lot has been documented about gender differences in treatment seeking behaviours from other illnesses, but not much in diabetes care. Most diabetes research is conducted using quantitative method, there is not a lot of research looking at the diabetes patients' lives.

The study explores the lived experiences of young people, aged 18-35 years, living with type 1 diabetes, attending Chris Hani Baragwanath Hospital (CHBH). The study adopted qualitative methods where a phenomenological approach was used in order to enhance the understanding of the lived experiences of young people living with type 1 diabetes. Purposive sampling was used. One focus group discussion with eight young men, as well as 3 in-depth interviews with young women. All participants were accessed through attending the Baragwanath Hospital diabetes clinic, and were interviewed during a diabetes camp. It was a challenge to find patients willing to open up and provide details sought by the researcher. The saturation approach was adopted in which the small sample size was complemented by deep seated conversations held during the group discussion and the in-depth interviews. Data was analysed using thematic analysis.

The findings show that there are challenges with having to enjoy being young and managing the illness. Challenges also include stigma and limited understanding of the illness by people close to the participants. Findings also reveal that there is a positive relationship between patients and diabetes clinic staff as well as peer supporters. This aids patients with coping with the day to day challenges they grapple with as they deal with diabetes. There are some gender issues involved in living with diabetes, whereby young men usually face challenges in their sexual lives, and young women have pregnancy related challenges.

This study shows the importance of a support system in a patient's journey with diabetes. Increased understanding of barriers to care is important for effective management. Therefore, it is recommended that other clinics have a dedicated time or place that is meant for young people. It is also recommended that diabetes awareness is promoted to the general population, to aid in coping with the illness.

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CHAPTER 1

INTRODUCTION

This study focused on lived experiences of young people, aged between 18 and 35 years, who are living with type 1 diabetes, attending an urban diabetes clinic in South Africa. It forms part of a bigger project called ‘Blood Sugars’ conducted by the Health Communication Research Unit (HCRU) together with Drama for Life (DfL) of the University of the Witwatersrand, at Chris Hani Baragwanath Hospital (CHBH).

1.1 BACKGROUND

‘Blood Sugars’ is a three-year project – funded by a Wellcome Trust International Engagement Grant – which aims to improve understanding of types 1 and 2 diabetes in an urban South African context, by creating a healthier dialogue between patients, healthcare and research professionals, and a broader ‘at-risk’ public. It is a collaboration between the Health Communication Unit and Drama for Life (both at the University of the Witwatersrand) and Chris Hani Baragwanath Hospital’s diabetes clinic. The project uses both drama therapy and applied drama. Drama therapy is a psychotherapeutically based, HSPCA-accredited practice. This study falls under PHASE 4 of the Blood Sugars project, which looks at the barriers and facilitators to care experienced by types 1 and 2 diabetes patients and healthcare professionals in Soweto and Johannesburg, South Africa. This study used qualitative method to examine specifically the experience of young people, living with diabetes type 1.

There are a few qualitative studies which have been conducted by the HCRU, looking at different issues in patient care in the Chris Hani Baragwanath Hospital diabetes clinic. One of the studies is Burkett (2015), who conducted a study exploring the practice and perceptions of nurses and patients regarding communication at an urban gestational diabetes mellitus clinic in South Africa. This study found that there are challenges to treatment of gestational diabetes mellitus, given the diverse linguistic and cultural backgrounds of patients (Burkett, 2015), which is typical of most urban communities in South Africa. This may then result in communication barriers in interactions, such as limited understanding of the information given to patients by health care providers.

Another study conducted in the HCRU is by Diab (2015), and it explored the role of the doctor-patient relationship in the management of diabetes in South Africa. It looked specifically at the influence of language and communication in this relationship. Research has found that patients and their health care professionals in South Africa are unlikely to share the same language and even more unlikely to share the same cultural beliefs, ideas and values, given the language and cultural diversity (Diab, 2015 and Watermeyer & Penn, 2009). It was also found that some doctors choose to conduct consultations in the language of choice of patients, even though that might not be their home language, which helps patients to be able to talk freely in their own languages (Diab, 2015). This study therefore looked at a different angle, taking into consideration the results found from the previous studies as well as literature, with a particular focus on exploring the gender influences in the understanding and management of diabetes.

Rationale

Diabetes is an increasing problem, especially in South Africa. The researcher is aware of the gender differences in treatment seeking behaviours from other illnesses (Moodley, 2013; Leichliter et al, 2011; &Smith et al, 2006), but we do not know a lot about gender differences in diabetes care, and some evidence suggests there are some gender differences (Siddiqui, 2013, Hilawe et al, 2013 & Gebel, 2011). It is also important to note that most research on diabetes is conducted using a quantitative method, which is why this study is looking into understanding young people's experiences of living with diabetes, qualitatively.

The researcher has always had an interest in understanding health issues affecting the community of South Africa and this has presented an opportunity to observe how communicable diseases like diabetes have increasingly become a challenge for South Africa's younger generation. The researcher has also observed young persons having to grapple with the day to day challenges related to diabetes. The researcher also has come across some myths in the community regarding the illness. This motivated the researcher to engage in understanding the illness and to investigate how patients especially the younger persons cope with it. This study will therefore also help the community have more understanding on the illness. This research will not only add to the body of knowledge (or literature), but it will also benefit the hospital in order for them to know what issues they are dealing with regarding young patients.

1.3 Research Problem

Diabetes is a global challenge, mostly in developing countries. Research shows mainly medical challenges caused by the illness. There are also some studies on different interventions to improve wellbeing of people living with diabetes, as well as interventions of adherence to treatment. However, there is little evidence on the actual experiences of people living with the condition, taking into account how the condition may affect the patients' social and psychological well beings. It is also important to note that most of the research conducted on this subject is quantitative research, which mainly shows statistics on the problem but does not go deeper into people's experiences in living with this condition.

It follows that literature has mostly remained statistical and focused on aspects such as diabetes prevalence in Sub-Saharan Africa with figures for South Africa between 1999-2011 standing at 32%, Quantitative data has also been provided on diabetes outcomes (chronic diabetes complications, infections, and mortality), access to diabetes diagnosis and care, and the economic burden caused by diabetes. Economic costs of diabetes have also been quantified. A South African study investigated the cost of hyperglycaemic emergency admissions in South Africa over a two month period in 2005 and reported an average cost R5309, equivalent to US\$712, per admission. Other scholars have focused on management strategies but mainly presenting quantified data (Mudasir Maqbool, etal 2018).

In other research some scholars such as Hall, Henriksen and Lohse (2011) Irena, Patel, Thompson, Gesese, Schleis and Battiola (2017) despite raising the issue of diabetes patients' inability to deal with socio-economic factors outside the clinic that include; lack of resource to improve lifestyle and dietary habits; lack of ability to provide financial support for medications; inability to influence social/cultural norms surrounding diabetic care literature has remained statistical and rarely gone into detailed explanations in relation to treatment seeking behaviours and how specific age groups deal with day to day challenges posed by diabetes.

In another study that points to the adoption of quantitative methods in diabetes studies, Sarfo-Kantanka, Kyei, Mbanya and Owusu-Ansah (2018) conducted a study on the Ghanaian context in which they used a Poisson Regression Model to examine for trends in the incidence rate of diabetic foot with categorical year variables. We used multivariable Cox proportional hazard models to estimate hazard ratios (HRs; and their 95% confidence interval (CI)) for predictors of diabetic foot during the study period.

It can also be argued that there a gap in research with specific focus on men, especially young men, who are at the stage where they are active participants in the society. Therefore, this study focused on young men and their day to day experiences on living with diabetes as well as its effects on their lives, and considered young women's experiences.

CHAPTER 2

LITERATURE REVIEW

According to Diabetes Care (2011), diabetes mellitus (referred here as 'diabetes') consists of a group of metabolic diseases characterized by hyperglycaemia. It results from defects in insulin secretion, insulin action, or both. Diabetes is characterised as a group of diseases marked by high levels of blood glucose resulting from insufficient insulin production, dysfunctional insulin action, or both (Wardian & Sun, 2015). Wardian and Sun (2015) argue that the chronic hyperglycaemia of diabetes is associated with long-term damage, dysfunction, and failure of different organs, especially the eyes, kidneys, nerves, heart, and blood vessels. National Institutes of Health (NIH) (2014) adds that being diabetic means that one's blood glucose (often called blood sugar) is too high. Blood always has some glucose in it because our body needs glucose for energy to keep us going. Too much glucose in the blood is not good for our health. Diabetes seems to be high in South Africa, and little is known about barriers to care.

2.1 Types of diabetes

There are two types of diabetes, namely: Type 1 and Type 2, but the result of these is the same: glucose builds up in the blood, while the cells are starved of energy (NIH, 2014).

2.1.1 Type 1

Type 1 diabetes is insulin-dependent, and usually affects young people. However, type 1 diabetes can also develop in adults. With this form of diabetes, your body no longer makes insulin or does not make enough insulin because your immune system has attacked and destroyed the insulin-producing cells. Statistics show that about 5 to 10 percent of people with diabetes have type 1 diabetes (NIH, 2014).

2.1.2 Type 2

Type 2 diabetes is the most common form of diabetes, and it used to be called adult-onset diabetes or non-insulin-dependent diabetes. Although people can develop type 2 diabetes at any age (even during childhood) type 2 diabetes develops most often in middle-aged and older people. Type 2 diabetes usually begins with insulin resistance—a condition that occurs when fat, muscle, and liver cells do not use insulin to carry glucose into the body cells to use for energy. As a result, the body needs more insulin to help glucose enter cells. At first, the pancreas keeps up with the added demand by making more insulin. Over time, the pancreas doesn't make enough insulin when blood sugar levels increase, such as after meals. If your pancreas can no longer make enough insulin, then treatment for type 2 diabetes will be needed (NIH, 2014). According to Manyema, Veerman, Chola, Tugendhaft, Labadarios, and Hofman (2015), Type 2 diabetes poses an increasing public health burden in South Africa, with obesity as the main driver of the epidemic. They estimated that over 20 years, a 20% sugar sweetened beverage (SSB) tax could reduce diabetes incident cases by 106 000 in women and by 54 000 in men; and prevalence in all adults by 4.0% (Manyema et al, 2015).

2.1.3 Signs of diabetes

Many people with diabetes experience one or more symptoms, including extreme thirst or hunger, a frequent need to urinate and/or fatigue. Some lose weight without them engaging in such attempts. Additional signs include sores that heal slowly, dry, itchy skin, loss of feeling or tingling in the feet and blurry eyesight. Some people with diabetes, however, have no symptoms at all (NIH, 2014).

2.2 Gender and health

It is of interest to look into gender differences in health seeking behaviour, in order to try and engage this topic. As an observation from the researcher in her environment, as well as talking to people around her, it is perceived that the majority of men pay inadequate attention to their health given their lifestyles, which includes lack of exercise, unhealthy diet, and alcohol drinking behaviour. This poor attention to his or her health may be associated with a masculine feeling of toughness or invulnerability. The lack of concern for their health by men can be seen in their reluctance for regular visits to health services for medical check-ups (Letsela & Ratele, 2009 and Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009). There are other reasons offered for not going for health check-ups, for example the fear of finding out that one is unwell as well as the idea that health check-ups are for people who are weaker,

therefore visiting health care services is viewed as not a masculine activity (Letsela & Ratele, 2009 and Oliver, 2005).

Some studies show that women access health care services in general more than men. According to the World Health Organisation (in Moodley, 2013), 68 percent of those accessing Anti Retro-viral Treatment (ART) are female; knowing that almost equal the number of male and female require treatment. A study conducted in Khayelitsha, Cape Town, on the uptake of ART showed that 70 per cent of those accessing treatment were women. Another study in Johannesburg General Hospital, found that the ratio of women: men accessing ART were 2:1 (Moodley, 2013). According to Smith, Braunack-Mayer, and Wittert (2006), general health for men is found to be poor than that of women and mortality rates are higher for men, compared to that of women. This can be because of men not accessing health care services until it is late, and the same habit could be applied in health issues in general not only HIV.

There are also some barriers, identified by men in my community, to the use of public and private clinics for sexual health services including HIV testing, and some men resort to seeking health care from traditional healers. Men often view public clinics as a place for women and they perceive some health care workers to be rude or judgmental towards them (Leichliter Paz-Bailey, Friedman, Habel, Vezi, Sello, Farirai & Lewis, 2011). In addition, norms of masculinity often discourage men from accessing health services, since these are viewed as showing weakness (Pettifor, Lippman, Selin, Peacock, Gottert, Maman, Rebombo, Suchindran, Twine, Lancaster, Daniel, Gómez-Olivé, Kahn & MacPhail, 2015). It is common in most South African communities for people to be affected by traditional beliefs and stigma associated with illness. This therefore forces them to prefer seeking alternative treatment paths (Penn, Watermeyer & Evans, 2011). These alternative paths affect their adherence to treatment and may lead to men ignoring symptoms and if not, delay seeking health related help, and therefore are more likely to go for health consultation in the case of a severe illness (Pettifor et al, 2015 and Letsela & Ratele, 2009).

Some studies though have found no significant gender differences in health seeking behaviours (Otwombe, Dietrich, Laher, Hornschuh, Nkala, Chimoyi, Kaida, Gray & Miller, 2015). This is an interesting factor to consider and also serves as a motivation for this study, it is an interesting finding and was taken into consideration while doing this research.

2.3 Gender and diabetes

Looking into gender differences in living with diabetes is of interest in this study since it is focusing on understanding young people's experiences living with the illness. Research shows that there seem to be some gender difference in people living with diabetes, and it seems that women are the ones that suffer mostly because of the illness, which might serve as one explanation, to some extent, of the above findings on why men do not access health services often, even though the above evidence is not specific to diabetes. Gebel (2011) found that death rates for women are higher than that of men, and this could be explained using physiological gender differences between men and women, and also the fact that health professionals treat patients differently, according to their gender (Gebel, 2011).

Gender differences in diabetes vary with different contexts, for example, Hilawe, Yatsuya, Kawaguchi, & Aoyama (2013) found that in many countries of sub-Saharan Africa, women are more likely to be obese or overweight than men and might therefore be expected to have higher prevalence of diabetes, compared to women in countries like Ghana, Nigeria, Sierra Leone and rural areas of the United Republic of Tanzania, where the prevalence of diabetes mellitus for women was found to be lower than the men in the same study areas. However, some studies show no significant differences between men and women in the prevalence of diabetes (Hilawe et al, 2013 & Perreault, Ma, Dagogo-Jack, Horton, Marrero, Crandall, & Barrett-Connor, 2008).

Poverty is another challenge facing most South African communities, and this can have an effect in the health care system. Furthermore, access to appropriate health care, including diabetes, in most South African communities is often limited because of inadequate health care systems, shortage of doctors and nurses with adequate training in diabetes diagnosis and treatment, shortage or unaffordability of medication and shortage of diagnostic tools and other equipment (Motala & Ramaiya, 2010; Majumdar & Mazaleni, 2010; and Bradshaw & Steyn, 2001). According to Hofman, Cook, and Levitt (2014), diabetes is the third leading cause of blindness in SA, and this creates a poverty cycle that disables breadwinners and burdens caregivers. Therefore, when a breadwinner becomes blind and cannot work that means there will be no income coming into that family. On the other hand, if one family member gets blind and needs to be taken care of, the caregiver then needs to dedicate most

time caring for that family member, and that might mean that the caregiver might have to miss work, and therefore also affecting income flow into the household.

2.4 Gender in South Africa (SA)

Looking into gender in South Africa is also important. A qualitative study conducted by Jewkes, Dunkle, Nduna and Shai (2010) revealed that the links between HIV/AIDS, gender inequity, and gender-based violence lie in the patriarchal nature of the society. Ideals of masculinity that are based on control of women and that celebrate male strength and toughness are also associated with the aforementioned issues. Women were found to be subordinate to men and expected not to be controlling, while men have power over women and are the ones that set rules or determine how the relationship will go. It is also interesting to note that even South African law, put in 1994, regards women as minors, under the guardianship of their husbands and fathers (Robinson, 1995 cited in Albertyn, 2011). Women have been subordinated to men in public and private life. While research conducted by Van der Gaag (2011) found that more men still hold power in government and earn the most money, but given the changes in gender roles, they (men) have a challenge with not knowing how to respond to the changes, for example their wives having to work or their children making their own decisions. This is still a challenge with most South African men, trying to adjust to the gender equalities.

2.5 Knowledge about diabetes

According to Sengbusch, Müller-Godeffroy, Häger, Reintjes, Hiort, and Wagner (2005), diabetes education based on structured and evaluated concepts is a cornerstone of diabetes management. Diabetes education is therefore a continuous process that should be repeated to ensure effectiveness. In addition, health care professionals need to have access to continuing training in diabetes education in order for them to be aware of any new developments in diabetes treatment, to share with their patients. This strategy could be efficient in changing behaviour and improving metabolic control than only teaching diabetes knowledge. They also argue that in rural areas diabetes education programmes are not provided sufficiently. The local hospitals in rural areas also lack sufficient expertise in treating patients with diabetes.

The prevalence of Diabetes in South Africa is not accurately documented due to a lack of data in this area (Burkett, 2015 and Levitt & Mollentze, 2006). Diabetes seems to contribute

significantly in the growing burden of non-communicable diseases in South Africa (Levitt & Mollentze, 2006). According to Bertram, Jaswal, Van Wyk, Levitt, and Hofman (2013), the prevalence of diabetes is estimated to be 9% in the age group 30years and above. Shaw, Sicree, and Zimmet, (2010) in their study estimated that the prevalence of diabetes among adults will increase to 7.7% by 2030, and that between 2010 and 2030 there will be a 69% increase in numbers of adults with diabetes in developing countries. This therefore indicates a growing burden of diabetes.

To further contribute to this growing burden is the fact that there is limited knowledge and understanding of the qualitative influences that relate to patient experiences with barriers inherent in dealing with the illness, thus making it a challenge to treat. Mendenhall & Norris (2015) investigated diabetes care among urban women in Soweto and found that most women have limited understanding of what diabetes is and what they should do in order to control the illness. Other studies also found that patients do not get adequate knowledge on their condition from their health care providers (Burkett, 2015; Murphy, Chuma, Mathews, Steyn, & Levitt, 2015; Steyn, Levitt, Patel, Gwebushe, Lombard, & Everett, 2014 and Motala & Ramaiya, 2010). According to Watermeyer and Penn (2008)'s study on ARV adherence, it was found that patients did not understand some concepts as well as the importance of adherence to ARVs. This could be evident with other illnesses as well, and could discourage patients from collecting or adhering to their treatment. Burkett (2015) in her study found that patients were "dumped" with a lot of information on diabetes and not given a chance to reflect and show understanding of the information provided to them. This could therefore be a barrier in terms of understanding the content of the information, and can pose a challenge in patients' treatment adherence.

2.6 Diabetes management

Therefore, management of the disease as well as educating the patients is crucial. Primary health care services mainly have a responsibility for management of the disease. Steyn et.al (2014) and Murphy et.al (2015) argue that the early diagnosis, management and outcomes of care for patients attending primary health care services are sub-optimal and few patients are achieving adequate levels of control, despite attending facilities on a monthly basis. It is important to also consider the fact that much emphasis when it comes to diabetes education is placed on diet and nutrition, and not much on exercise (Mendenhall & Norris, 2015). This is

a challenge since fewer patients are able to control their condition, through proper diet, treatment, and exercise. The National Department of Health has acknowledged that there is a pressing need to improve the quality of non-communicable diseases (NCD) care through appropriate training, the provision of resources and the reorganization of primary care so as to accommodate a more concerted focus on health promotion and disease prevention (Department of Health, 2013). In line with WHO recommendations, the National Department of Health proposed a shift to a more patient-centered model of chronic care, which emphasizes the importance of empowering patients to play an active role in self-management by enhancing their knowledge, motivation and skills for behaviour change, as well as their self-efficacy to carry out the behaviours necessary for long term self-care in their life context (Department of Health, 2013).

Even though there is a need for patient-centred interventions, there are challenges, like any other intervention. According to Dube, Van den Broucke, Dhoore, Kalweit, and Housiaux, (2015), despite the great variety of diabetes self-management education (DSME) programs that are currently available internationally, there is lack of information regarding educational interventions for the prevention of diabetes complications in developing countries. They also add that DSME in South Africa is limited in scope, content and consistency, especially in the public services (Dube et. al, 2015). There are other impediments to effective self-management and behaviour change, including poor health literacy, a lack of self-efficacy and perceived social support (Murphy et. al, 2015). Therefore, patients need greater assistance and support from their health care providers in order to help manage their condition effectively.

People with diabetes often experience distress related to the tasks of managing diabetes, therefore providing the support patients need to decrease negative thinking and enable them to effectively manage diabetes. This is an important task for health care providers and loved ones. Increased self-efficacy is significantly associated with a decrease in negative thinking from people living with diabetes. Because self-efficacy is a significant mediator in thinking about diabetes, people with diabetes are more likely to engage in self-care if they have the ability to carry out the health care plan and engage in effectively managing their blood glucose (Wardian & Sun, 2015).

Even though diabetes is a medical problem, there are psychological problems associated with living with diabetes. Diabetes-related worries are common among most diabetic patients, with also poor psychological wellbeing. This ends up affecting diabetes self-care because these patients are not motivated enough to care for themselves and adhere to their treatment. Addressing these problems may improve diabetes outcomes, but the most challenge with this is that health care providers are aware of this but lack skills, time and resources to manage this problem (Peyrot, Rubin, Lauritzen, Snoek, Mathews & Skovlund, 2005).

In a study conducted by Haque, Maryam, Emerson, Dennison and Levitt (2014) in Cape Town, they identified doctor, patient and system barriers to initiating insulin therapy in patients with type 2 diabetes. In this study, it was found that some doctors lack experience and use of guidelines related to insulin therapy, as well as language barriers between doctor and patients, which is common in most public sector health facilities. Barriers associated with patients included not complying with their treatment requirements, lack of understanding of what diabetes is, use of traditional medicine, and poor socioeconomic conditions. On the other hand, system barriers included lack of continuity of care and financial constraints. They then concluded that patient-centered approach which encourages better communication between doctors and patients. This may be achieved by reorganising aspects of the health system, and may improve patient knowledge, improve compliance, and help overcome barriers.

There are other challenges to the South African health system. According to Coovadia Jewkes, Barron, Sanders, and McIntyre (2009), there is a shortage of training, support, and supervision in the health care system of South Africa. They also argue that some of the challenges of health care in South Africa are resulting from the apartheid system, whereby there were inequalities between different races, in terms of access to health care and other services as well as training for provision of those services. These challenges include human resource challenges, whereby management lacks necessary skill and proper training for management of the health care system (Coovadia et al. 2009). This can also be a challenge in terms of providing proper service to patients in health care centres.

2.7 Diabetes treatment

There are also some hindrances when it comes to adherence to medication, including poor access to health care and overcrowding in clinics. There is also perceived stress related to patients' relationships with their loved ones in terms of relatives not supporting their diet, as

well as social stigma attached to being diabetic (Burkett, 2015; Mendenhall & Norris, 2015; and Penn, Watermeyer & Evans, 2011). Therefore, there is an urgent need to improve health care for patients with this condition in public sector clinics (Steyn et al, 2014). This requires acknowledging the fact that effective diabetes education and management in the clinical setting will require systematic changes to the overall healthcare system, supported by policy and organisational change (Mendenhall & Norris, 2015 and Murphy et. al, 2015). The healthcare providers will also need training, resources as well as tools in order to be able to serve and support the patients better, and patients can be motivated to care for their own health.

As suggested by Black, 2002 (in Burkett, 2015), diabetes places additional strain on patients and their families in terms of the finances required for medication and low-calorie foods, which can sometimes mean changing their diet completely. Burkett (2015) further describes the negative effects that diabetes has on maintaining culture within entire family groups, especially when women are affected by the condition, as they are generally the primary “keepers” of culture within families. This then informs the possibility of diabetes as a condition that affects patients’ families and their social relationships, as opposed to it affecting the patient as an individual.

However, diet plans and eating habits are very important factors in living with diabetes, therefore there is a diet plan called DAFNE that tries to address this. The Dose Adjustment For Normal Eating (DAFNE) is a way of managing Type 1 diabetes for adults and provides the skills necessary to estimate the carbohydrate in each meal and to inject the right dose of insulin. DAFNE is a high quality skills-based structured education patient programme in intensive insulin therapy and self-management where people with Type 1 diabetes are taught to match their insulin dose to their chosen food intake on a meal by meal basis. Its vision is to improve outcomes for people with Type 1 diabetes through high quality structured education which is embedded in the Health Service. The DAFNE programme was developed in the UK over 25 years of rigorous research. A DAFNE course follows the same principles and is of the same standard across different centres. To maintain course standards all DAFNE centres subscribe to a quality assurance programme whereby their patient courses are peer reviewed and their anonymised DAFNE patient data is audited (Oliver and Thompson, 2009).

2.8 Importance of a support system

There are also some challenges with perceived support that are associated with living with diabetes. For example, Hempler, Joenson and Willaing (2016) in their study found that people with type 2 diabetes had less contact with their social network, less certainty about support in case of severe illness and less healthy behaviour than people with type 1 diabetes. However, this might be because most people with type 1 diabetes are younger, therefore might have stronger social networks and have more information on what to do in case of need, than those with type 2 diabetes.

2.9 Education and employment when living with diabetes

Type 1 diabetes has some effects on school-going children's cognitive functions. Emre, Ozcan, Akici, Seyham, Sesli, Soyler and Kucukkavruk (2016) argue that time of diagnosis and ensuring metabolic control in diabetes might have consequences associated with the hazardous effects of diabetes on the development and function of the nervous system. Children typically spend one-third of the day in school and they should achieve the same level of diabetes management there as they do outside the school environment. This means that children should incorporate frequent glucose monitoring, meal planning, and possibly insulin injections at school, but also they should be allowed to participate fully and safely in all school activities. Therefore, school going children face challenges in terms of monitoring their diabetes, especially the younger ones who rely on their parents for example for insulin injection. Not testing blood glucose at school increases the risk of undetected hypoglycaemia. The study shows that few participants reported diabetes training for school personnel. Diabetes is treated as a private affair involving only the families. So, it is likely that the degree of knowledge about the different aspects of diabetes still appears to be superficial for everyone other than those who are directly involved, which is usually patients or relatives (Ješić, Milenković, Mitrović, Todorović, Zdravković, Ješić, Bošnjović-Tucaković, Marković, Vorgučin, Stanković & Sajić, 2016).

Childhood onset type 1 diabetes mellitus is also associated with lower education, lower rates of employment, and lower employment earnings in both men and women. Although the effect of T1DM on socioeconomic status is not well understood, lifestyle changes and complications related to childhood onset T1DM may result in greater rates of absenteeism and can decrease work capacity (Hitt, 2013). Lost productivity at work is an important

concern for employees, employers, and society. Lost productivity due to absenteeism, disability, and early retirement is an important economic issue for employers. According to Krstović-Spremo, Račić, Joksimović and Joksimović (2014), diabetes mellitus is a common cause of absenteeism, and their study showed that patients with diabetes mellitus were more likely to face problems with work productivity and being constrained in terms of work and other activities. Diabetes mellitus patients in this study reported a significant decline in all daily activities due to emotional and physical health problems. They also argue that diabetes appears to reduce an individual's ability to work in comparison to patients with hypertension (Krstović-Spremo, Račić, Joksimović & Joksimović, 2014).

2.10 Diabetes and sexuality

Other studies show that there are some challenges faced by men with regards to their sexuality, which are associated with being diabetic. For example, Andersson, Ekstrom and Lehtihet (2015) in their study found some differences in erectile dysfunction in men with diabetes between type 1 and type 2 diabetes patients. While Biswas, Hampton, Newcombe and Rees (2012) found that “testosterone levels are strongly affected by age and central obesity in men with type 1 and type 2 diabetes.” Another study conducted by Kemp and Rheeder (2015) at Steve Biko Academic Hospital diabetes clinic, found that a high prevalence of low testosterone levels in diabetic male patients. This shows that there are some sexual challenges that men face that are associated with living with diabetes.

According to the World Health Organization (WHO), the term ‘sexual dysfunction’ (SD) is defined as “various ways in which an individual is incapable to partake in a sexual relationship according to his/her wish” (Khan, Alam, Kumar, Adnan & Soomro, 2016). Yildiz and Boluktas (2015) argue that erectile dysfunction (ED) is seen in nearly half of all males who have had diabetes for more than 10 years. They also argue that research shows that sexual dysfunction is related to low self-esteem, a negative self-image, as well as depression, and sexual dysfunction negatively affects quality of life in general. SD's are more common in men with diabetes compared to non-diabetic males and SD is more common in people with type I diabetes compared to those with type II diabetes.

According to Khan et al. (2016), sexual problems are frequently diabetes-related complications in both male and female patients and they negatively affect their personal satisfaction.

They also argue that impaired sexual function in men is a common complication of diabetes. According to Corona, Giorda, Cucinotta, Guida and Nada (2016), sexual dysfunction is one of the major complication in men living with Type 2 diabetes. Talking about sexual matter in some communities is still a taboo, and most participants in their study did not readily discuss their problem unless they were specifically asked to do so (Khan et al, 2016). Men with diabetes are found to have an approximate threefold higher risk for ED than men without diabetes, and erectile dysfunction as a result of diabetes has an estimated prevalence of 20–85% (ranging from mild to complete ED), which occurs at an earlier age than in nondiabetic men (Stuckey, Jadzinsky, Murphy, Montorsi, Kadioglu, Fraige, Manzano & Deerochanawong, 2003).

There is also found to be diabetes-related challenges with regards to pregnancy. According to Dugan and Parthasarathy (2016), infants born to mothers with preconception diabetes have been shown to have higher rates of morbidity and mortality. Therefore, it is necessary to control diabetes especially during pregnancy in order to decrease the risk of complications during birth. Healthy dietary habits and regular exercise is also encouraged in all patients with diabetes, especially prior to pregnancy (Dugan & Parthasarathy, 2016).

2.11 Coping with diabetes

Men use various mechanisms in dealing with diabetes. As O'Hara, Gough, Seymour-Smith and Watts (2013) in their study in UK investigated how men experience life with a chronic illness like Type 1 diabetes, and found that men reduce the seriousness of diabetes by defining it in ways other than a serious illness. By viewing diabetes in this way, men are then able to prioritise the pursuit of their personal goals over adherence to the diabetes routine. Moreover, this could be a challenge as not adhering to the treatment can cause problems for them.

It is also important to look into people's attitudes and emotions related to living with diabetes. Siddiqui, Khan and Carline (2013) conducted a study in the UK and found men to be living more effectively with diabetes, they also have less depression and anxiety, but they

have more energy and better positive wellbeing. They are seen to be more satisfied with their management of the illness and experience lesser social worry (Siddiqui, Khan, & Carline, 2013). Men in South Africa can use such coping strategies in order to deal with diabetes. It is also an important consideration taken during this research.

The data provided above suggest that diabetes is a growing challenge, with a specific marked increase in developing countries in Africa. Looking into this data one will realise that there is a specific mention of the effects of the condition to women, as well as some mention of Type 2 diabetes. This then motivated the researcher to look into type 1 diabetes. It was also interesting to investigate how men in our society experience their living with diabetes, and how society and young men in particular perceive the diabetes condition.

2.12 Theoretical framework

This research is premised on a conceptual framework founded on mechanisms that link socio-economic position to the health of persons with Diabetes. A similar conceptual approach was adopted by Houle, Lauzier-Jobin, Beaulieu, Meunier, Coulombe, Côté, Lespérance, Chiasson, Bherer, and Lamber (2015:1); Agardh, Allebeck, Hallqvist, Moradi and Sidorchuk (2011: 805); Brown, Ettner, Piette, Weinberger, Gregg, Shapiro, Karter, Safford, Waitzfelder, Prata, and Beckles (2004:63). They argued that the socio-economic position (SEP) included two crucial views that is; the influence of the structural location of the individuals and groups in a society and the cumulative effects of time. As they rightly point out, although some compelling evidence exists to justify an association between a low SEP and adverse health outcomes for persons with diabetes and other chronic ailments, the pathways through which SEP and health are connected in persons suffering from chronic illness remain poorly understood. This can be said to be the case in the current study particularly with respect to young men. Whilst the SEP has been embraced by the aforementioned scholars and therefore it becomes key in this study it is important to note that its usage has not gone into the extent of capturing the voices of the patients in the level of depth reached in the current that focuses on young men and to a lesser extent young women leaving with diabetes.

CHAPTER 3

METHODOLOGY

3.1 Research aim

The aim of this research study was to explore the lived experiences of young people aged 18-35 years, living with type 1 diabetes, attending Chris Hani Baragwanath diabetes clinic.

3.2 Research questions

- What are the experiences of young men and women, aged 18-35years, living with Type 1 Diabetes?
- How are these young people living with Type 1 Diabetes coping with the illness?

3.3 Research Design

This study uses Qualitative research, which is a type of research that focuses on meaning, experience and understanding of phenomena. It also gives the researcher an opportunity to interact with the participants (Collins, du Plooy, Grobbelaar, Puttergill, Terre Blanche, van Eeden, van Rensburg, & Wigston; 2006, p.134). This study took a Phenomenological approach because it is relevant in trying to understand the lived experiences of people being studied. According to Creswell, Hanson, Clark Plano and Morales (2007) phenomenologists work much more from the participants' specific statements and experiences as they express them. This design was relevant in this study as it allows the researcher to obtain information about young people's descriptions of their experiences of living with diabetes. It was also well suited in order to understand the different dynamics involved in the study environment as well as how the young people experience and cope with them.

3.4 Participants

3.4.1 Sampling

The study used purposive sampling, which used the judgment of a researcher in selecting participants who were attending the diabetes clinic in Chris Hani Baragwanath hospital (Collins et.al, 2006). The sample included young men and women from the ages of 18-35, who are living with type 1 diabetes and are attending the Baragwanath diabetes clinic. Participants were recruited from the diabetes camp ran by the Baragwanath clinic. The

sample comprised of one focus group interview (this involved getting detailed explanations from each focus group participant in order to ensure deeper representation, consisting of 8 male participants as well as 3 in-depth interviews with female participants).

3.4.2 Inclusion and exclusion criteria:

Young people from ages 18-35 years old, living with Type 1 diabetes, attending Baragwanath hospital, were included in the study and those not falling into that category were excluded. Young people in this category stood a chance to be selected regardless of their race, class and ethnicity. The rationale behind this criterion was so that the study will fulfil its aim, which is to study the experiences of young people aged between 18-35, living with type 1 diabetes and attending the Chris Hani Baragwanath diabetic clinic.

3.4.3 Site

This study was conducted during a diabetes camp that is ran by the CHBAH diabetes clinic, which took place from 3-5 June 2016. The hospital trains various medical professionals within the field of medicine and healthcare. The majority of patients served by the hospital (including the diabetes clinic) are of Black African ethnicity. The area surrounding the hospital is densely populated, with the three most commonly spoken languages being IsiZulu, Sesotho and Setswana (Statistics South Africa, 2012). The population is also of a lower socioeconomic background, with a high poverty and unemployment rate (Statistics South Africa, 2012). The clinic is an out-patient clinic and is open to patients who have diabetes, both type 1 and type 2. Patients attend the clinic on a monthly basis to do check-ups and fetch their prescribed medication.

3.5 Data Collection

This study forms part of the Blood Sugars project run by the HCRU, mentioned above, and the relationships formed in the project was used in order to collect data for this study. This project is based at an urban hospital in Johannesburg, South Africa, called Chris Hani Baragwanath Academic hospital (CHBAH). Participants were drawn from the diabetes clinic in the hospital.

3.5.1 Focus group discussion

Data was collected using semi-structured focus group discussion as well as in-depth interviews. A focus group discussion consists of a small number of research participants that are drawn together for expressing their opinions and experiences on a particular issue or set of issues (Welman, Kruger & Mitchell, 2005). The reason for using focus group interviews is because sometimes people are free to express themselves in a group, realizing that other people may also be going through the same things as them. For example, it might be a challenge to discuss sexuality issues in an in-depth interview, but it can be easier in a group.

3.5.2 Triangulation

In addition, observations by the researcher and the assistant researcher, Sonia Mbowa, were done throughout the camp, taking note of participants' daily practises. Using these types of data help validate the data collected, and also help get more information which might not have come out if only one method had been used. This is what is referred to as triangulation, which means studying one phenomenon from different reference points and viewing it from different perspectives rather than converging on a single account (Smith, 2013).

3.5.3 In-depth interviews

On the other hand, an In-depth interview is “a qualitative research technique that involves conducting individual interviews with a small number of respondents to explore their perspectives on a particular subject” (Boyce & Neale, 2006).

3.5.4 Interview schedule

The semi-structured interview schedule that was used for the interviews entails 7 main questions and the researcher came up with probing questions from responses obtained from those main questions (see appendix 1). The interview questions explored the general experiences of living with diabetes as a young person as well as coping mechanisms they use in their daily lives, and the researchers probed more where need arose.

3.5.5 Collecting data during diabetes camp

These interviews were conducted during a diabetes camp, which happens every year on a weekend, and is organized by the Baragwanath diabetes clinic. The researcher attended this

camp, which made it easier to conduct the interviews. The researcher though was not part of the team conducting the camp; she was only there for the purposes of this research. Another important factor to keep in mind about this study is that there is a possibility that the group that will attend the diabetes camp is more empowered, or different from other patients. These could be expert patients, because of their exposure to the camp and participation at the initiatives by the clinic. Therefore, this was taken into consideration during the research as well as when analysing the data.

The researcher has done some fieldwork in the communities before; therefore, she is familiar with conducting interviews and understands the approach when working in communities. She is Zulu speaking, which is one of the dominant languages in the study site, but also knows the other languages used in the area, therefore this was of benefit as the participants were allowed to express themselves in their home languages. Since the interviews were conducted mostly in participants' home languages as well as English, this largely assisted in getting the participants to speak and express themselves freely and openly.

According to Watermeyer and Penn (2009), the way to communicate with patients is dependent on and influenced by contextual and environmental factors as well as interpersonal factors. The researcher's familiarity with the language and context of the participants therefore gave her a bit of an advantage in conducting this study. All the interviews were audio recorded, which aided in ensuring that all details were captured for saturation to be reached in each aspect discussed.

3.6 Data Analysis

The data collected in interviews was recorded, transcribed, and translated before analyzing it. In analyzing data, information recorded from the tape recorder was transcribed and interpreted. In transcribing the data, the transcriptions were firstly written in the participants' languages and then translated into English. While listening to the recordings, themes were identified. Interpretation of the discussions was made using thematic analysis, which according to Braun and Clark (2006), is a qualitative method for identifying, analyzing, and reporting patterns or themes within data. Thematic analysis involves six phases of analysis, which do not necessarily need to be followed on a linear pattern, but one can move back and forth as required. The first phase is familiarization and immersion, which means that one immerses oneself in the data in order to be familiar with the content, and this includes

repeated reading of the data. This process begins during the interviews, whereby the researcher gets to understand and be familiar with the study subject, which helps make the analysis easier. The next phase is coding, which is breaking up the data in analytically relevant ways. With coding, one can select the relevant data for the study and organize it into meaningful groups. Then potential themes were identified from the codes developed in the previous phase. This is now when the researcher starts to analyse the codes. A bottom-up approach was used where the researcher looks at the material and tries to work out what the organising principles are. Since this study is explorative, the researcher worked from the data collected to form an understanding of the findings. The fourth phase is reviewing themes, which involves refinement of the themes. This phase requires the researcher to go back to the data and read again to confirm if the themes work in relation with the data set. After reviewing themes, one should have a clear idea of the different themes and of the story, they are telling. Review of themes is then followed by defining and naming of themes, which involves further refining and defining of the themes that will be included in the analysis. For each theme, the researcher needs to write a detailed analysis and identify what each theme tells us. Now the researcher elaborates, trying to make sense of the data collected and provides a discussion of the findings of the data collected. In the last phase the researcher produces a report, whereby has to provide sufficient evidence of the themes within the data. This phase includes interpreting and checking of the data by discussing the findings with other people, for example, a supervisor or someone who does not know anything about the topic. The usage of language was analyzed in terms of how the participants express themselves, also taking into account the fact that participants were allowed to use their home language, as discussed above. At the end the researcher evaluates if the study problem has been explored in full (Braun & Clarke, 2006 and Terre Blanche, Durrheim & Painter, 2006).

3.7 Validity and Reliability / Trustworthiness

In order to ensure that the study is trustworthy, the following need to be taken into consideration. Firstly, a researcher needs to ensure that the study can be dependable. According to Terre Blanche et al. (2006), dependability means how convincing the researcher can be to the reader that the findings are actually true. This can be done by providing the reader with the frank statement of the methods used to collect and analyse data. In ensuring dependability, Babbie and Mouton (2011) argue that the study must provide readers with evidence that if it were to be repeated with the same or similar respondents in the same

context, its findings would be similar. Therefore, in this report the researcher clearly states all the methods and procedures used and ensures that the data provided is the one obtained from the participants. It is also be ensured by providing clear information on the challenges and limitations faced during the research. Credibility on the other hand involves establishing that the results of the research are believable (Terre Blanche et al, 2006). This is ensured by confirming with the participants, during the interviews, that the information gathered is correct. Transferability refers to the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings (Terre Blanche et al, 2006, p.92). Due to the nature of this research, the small number of the sample implies that the sample will not be randomly selected; therefore, the results of this study cannot be generalized to other settings. According to Babbie and Mouton (2011, p.278), confirmability is the degree to which the findings are the product of the focus of the inquiry and not of the biases of the researcher. In the present study, confirmability is achieved by ensuring that only the information obtained from the respondents is used, as well as the researcher being aware of her own biases. It is also be achieved by constantly checking and rechecking data throughout the study, and also confirming with other researchers involved in the project (establishing multiple judges reliability).

3.8 Limitations-bias and reflection

The interviewer bias was taken into consideration during this study. Interviewer bias refers to a systematic difference between how information is solicited, recorded, or interpreted (Christopher, Pannucci, Edwin & Wilkins, 2010). It is important for the researcher to be aware of her own bias as she is a member of the society and might be affected directly by the subject. Therefore, in minimizing bias, the researcher was aware of her own beliefs and values, and avoided, as much as she can, assumptions by using the data obtained from the respondents only. The questions asked in the interviews did not offer opportunities for motivating the respondents to answer, meaning that leading questions were avoided by all means possible. Also to create transparency of the research the researcher kept a reflective journal that she will record her feelings, experiences, observations and reflections during the research. According to Lamb (2013) this helps in creating and clarifying the meaning of experience in terms of self in relation to oneself and self in relation to the outside world. This process also helps the researcher be aware of her own limitations.

However, like any other research, there are limitations to this study as well. Initially this research was aimed at understanding young men's life experiences living with diabetes,

through conducting three focus group discussions. But because of the challenges with getting young men in one place at the same, to allow for focus group discussion, the data had to be collected during the diabetes camp, which assisted with getting them in one place for a weekend. However, only a few young men attended this diabetes camp, which meant only one focus group discussion with young men would be conducted. However, the researcher saw an opportunity to also interview young women living with diabetes, which was not part of the initial plan, in order to try and see if the young women's experiences would be any different from that of young men, which proved to have slight differences. Regardless of interviewing young women as well, the number of participants in this study is still small. However, enough information came out of these participants, making it possible to report on the experience of the young people living with diabetes.

Qualitative research by nature is a limitation on its own as it uses a small sample of participants in order to understand a phenomenon, which means that results to this study cannot be generalised to the whole population of young people living with diabetes type 1.

Another limitation comes with using the participants attending a diabetes camp, because there is a possibility that this is a group of expert patients, who usually attend diabetes related events or receive necessary information, and therefore could be more informed than the general population, and therefore might not be a good representation of the population of young people living with diabetes type 1. However, the results to this study are specific to the participants interviewed, but can also be of benefit to other people living with diabetes.

3.9 Ethics

The participants were requested to sign a consent form before the interviews begin as an agreement to participate in the study (see appendix 2). The consent form entails the aim of the study. It was explained to the participants that participation is voluntary and they can leave the study anytime if they feel they do not feel comfortable. Their names and identity are not used in the report, for confidentiality purposes. Because of the nature of the focus group interview, full confidentiality cannot be promised, but the researcher also emphasized to the participants the importance of not sharing the information outside of the interview. Names were not used during contributions but participants were coded. Pseudonyms in the form of participants being named using codes was used to substitute participants' names in order to ensure anonymity. Direct quotations are used in reporting the findings, but

participants' identities are not revealed. Any information concerning the participants is also not revealed in order to ensure further anonymity. The information, including transcripts and recordings, is kept safe in the Health Communication Unit. The researcher made sure that the participants always felt comfortable and not deceived through briefing them fully about the research and what is required. The results will be shared with the relevant parties, if need be. This study is part of Phase 4 of the Blood Sugars project ran by the HCRU, and ethical clearance (M160335) for the whole study was obtained from the University of the Witwatersrand ethics committee (appendix 5 attached separately). Ethical clearance was obtained in order to protect the researcher as well as the participants in the research, to confirm that no one will be harmed by this research.

CHAPTER 4

RESULTS AND DISCUSSION

Initially, this study was supposed to focus mainly on young men, but due to the limited number of willing male participants that also impacted on data the researcher decided to extend the interviews to a few female patients in order to gain some insight on the experiences of female patients are any different or similar to those of male patients; 3 females were interviewed. The discussion of findings centres on how these young people describe their lived experiences living with diabetes.

4.1 Observation from the focus group discussion

The focus group had a variety of participants, with different ages, different languages, and people who come from different places, even though it was a small group of 8 male participants. The participants were a bit reserved at the beginning of the focus group discussion, but eventually they got to open up and talked freely, allowing others to share their experiences. There were some disagreements along the way, which also helped in terms of finding out the participants' thoughts about the illness and the knowledge they have. There was limited time due to the fact that there were other activities happening at the same time but all the questions in the interview guide were addressed. Having assistance of the research assistant, Sonia Mbowa (an intern working on the Blood Sugars project), was of benefit in terms of coordinating the group as well as listening and facilitating the discussion.

4.2 Experience of the camp

At the beginning I felt a bit out of touch because of being in a new environment and with people I do not know, who also don't know me. I was also not sure how to behave in a manner that is not going to offend anyone. That could also be a result of my own personality, I take time to adjust to new environment, I usually need time to observe and learn first before I can be comfortable. As time went on it was easy to relate to everyone around and they were very welcoming and understanding the "Type 3" around them. The participants referred to me and my colleague as 'Type 3' since we were neither type 1 nor type 2 diabetic. We explained why we are there and also the fact that we are learning from them, therefore they were willing to share. There seemed to be a sense of curiosity in other patients though, in terms of not understanding why we are there since we do not have diabetes, the first question they would ask usually was "how long have you been diagnosed" and responding and saying

“I don’t have diabetes” just seemed wrong even from me saying it because I knew that is followed by “why are you here then?”

We participated in a lot of activities that were happening during the camp, including testing our blood sugars, except for the 2am sugar testing. Even though I was not much knowledgeable on experiences of living with diabetes but I could relate to the participants on some issues, but I tried to be objective. I had engaged with some participants at a personal level, which has a possibility of affecting the way we relate during interviews.

Some participants were studying during the time of data collection, some already working and others were looking for jobs. What I found to stand out from this group was a sense of brotherhood among them, especially on Friday whereby they made sure that no one is left behind even though it meant arguing with the driver who wanted to leave people behind because they were late. I also found that they help each other in terms of sharing information on job opportunities as well as funding opportunities and motivating each other to live better. The patients also seemed to have a good relationship with the nurse educator that was at the camp, the doctor, as well as the team from Accu-check which was coordinating the camp. I also learned that food must always be available (called “a hypo pack”) and we were even given food packs for the road when we were leaving. Overall, the camp experience was very good and informative.

4.2.1 Life Changes resulting from diabetes

Most participants felt that their lives changed after they got diagnosed with diabetes. The changes include bodily changes, losing eyesight and sometimes getting hurt. Most of them felt that their behaviour is not the same as before; they are now not able to do some of the things they used to do before they were diagnosed. This mostly includes recreational activities like going out with friends freely, drinking alcohol, and smoking. They reported that they are not as social as they used to be. In essence the illness confirms notions that people are usually evasive of approaching health facilities due to the fear of confirming the diagnosis and what lifestyle changes it might bring upon their lives.

P1¹: “nomzimba wami wasileka waphansi ngoba ke ngoku sendisaba lesifo ... yeah ngoku nda affecteka kanjalo sandibulala amehlo sandibulala umzimba wami yabo”

¹P1 up to P8 represent the young men who participated in the focus group discussion which also embraced some in-depth focus on issues in which the participants were afforded the opportunity to detail their explanations. This enhanced the data and aided saturation.

Translation: “even my body went down because now I am scared of this illness ... yeah now I got affected like that it killed my eyes it killed my body you see”

P2: “ay go boa nnete nna ne ke rata ho tsoba motekwane nna he se kena le swikiri ne ke thola di black out tse ning always hypos and everything”

Translation: “ay to tell the truth I used to like smoking weed when I got diabetes I used to always have a lot of blackouts hypos and everything”

P5: “but before then I was I was the in thing because I was living ilife erough like I used to drink like nobody’s business”

Translation: “but before then I was I was the in thing because I was living a rough life like I used to drink like nobody’s business”

P3: “till last year uhm I wasn’t controlling it I was a fucken drunker I’m a fucken drunker I’m a drunken master anyway so”

Some participants mentioned that before being diagnosed with diabetes they were just doing things not caring about what is going to happen after, but now they have to adjust to this new lifestyle where they have to be cautious of everything they do.

P7: “yeah yeah ishintshile because when I was young ... yeah bengenza izinto nje benganandaba bengiziphilela nje ... yeah so ngithe after diabetes then then eziny’ izinto neskhati vele naso kwamele ngi adjuste vele to iskhathi sokudla iskhathi sokuhlaba ... yeah izinto ezinjalo”

Translation: “yeah yeah it changed because when I was young ... yeah I was just doing things not caring just living life ... yeah so I did after diabetes then then other things time as well I had to adjust the time to eat time to inject ... yeah stuff like that”

FP1: “there is a difference in my life because of diabetes coz now you have to keep tabs of what is going on in your life, in case you see any signs in your body”

There was also a feeling that if one didn’t have diabetes they wouldn’t have to attend the camps or any of the activities including having to constantly visit the clinic for one’s medication. They would be living their lives freely and would possibly be far in life.

P4: “ngabe angikho la”

Translation: “I wouldn’t be here”

P3: “mina ngabe if like I wasn’t having this sugar neh ne ke tlabale ke baile ntho tse baie in my life ke be ke spana grand wabona ... I think I missed that opportunity ke dropile skolo out wabona”

Translation: “if I wasn’t having this sugar neh I would have bought a lot of things in my life I would have a good job you see ... I think I missed that opportunity I dropped out of school you see”

P8: “but sometimes kmele uhlale ucabanga ukuthi uma ngphuza ...uyacabangisana kaningi ushukela”

Translation: “but sometimes you have to keep thinking that if you drink... diabetes makes you think all the time”

However, others think that living with diabetes is of benefit in some way otherwise if they didn’t have diabetes they would be living recklessly, but now since they have diabetes they have to always think about what they do. One participant even mentioned that if he didn’t have diabetes he would probably have many scars by now because of the life he used to live.

P5: “mina if benganashukela mina I believe maybe ngabe nginezcar or something ((others laugh)) maybe ngabe ngineycar I won’t lie to you”

Translation: “If I didn’t have diabetes I believe maybe I would have scars or something (others laugh) maybe I’d have scars I won’t lie to you”

There seemed to be an overall concern with getting hurt because of diabetes, especially losing teeth. Most participants reported falling on their face and breaking or losing teeth when they experience a hypo. A ‘hypo’ as referred to by the participants, refers to hypoglycaemia, which is when one’s sugar level would be low and may end up collapsing. Mostly when this happens one would not be aware of what is going on and will hear when they wake up, often with a scar or missing a tooth. They also mentioned that one can lose a tooth while he is chewing on something hard, like a bone, thinking it’s still a bone while it’s the tooth and can even swallow it. Others put on gold tooth, but it doesn’t always work as they fall again.

P2: “even ka losa le leno la cutteka like chomi ya ka so wa bona ... ke jele teaspoon so bake bang kenya teaspoon so... so ne ke e luma ya cutteka so”

Translation: “I even lost a tooth it got cut like my friend so you see ... I bit a teaspoon so they put a teaspoon... so I was biting it it got cut so”

P5: yeah then yeah I slept mangphaphama ekseni like ey amazinyo kwenzakalani ((others laugh)) ... uhm lent' lomuntu ungtshela ukuthi like bese ngilwa because my sugar was low besengilwa and I fell ... yabona then ok fine amazinyo wam aphuka ngahamba ngayolungisa I put a gold then ngabuya futhi you know yeah I went out ngaphuza ngaphuza ngaphuza same thing happened again and now but bengiyi la amazinyo ngiwapheshe khona same thing aphuka futhi”

Translation: “yeah then yeah I slept when I woke up in the morning like ey the teeth what's happening ... uhm this this person told me that like I was fighting because my sugar was low I was fighting and I fell... you see then ok fine my teeth broke I went to fix them I put a gold teeth then came back again you know yeah I went out and I drank drank drank same thing happened again and now but I was alone where I had patched my teeth same thing they broke again”

P1: “ay mina ngawa vele laphuma izinyo ngaphinde futhi ukuwa nda ndaright neh so kwenzakala futhi ngathi ngidla inyama yahlangana nethambo ngoba inyama ngiythanda ihamba nethambo mina ngiyakhukhuza lento ekthiwa ukukhukhuza uyakwazi ukukhukhuza ... ngaluma kanti kuphuka izinyo and ndiyalihlafuna ndiyaliklumuza ngeskhathi lisemlonyeni angizwa ukuthi liyaphuma ngizitshela ukuthi ngihlafuna ithambo kanti yilo izinyo seliphumile ngizobona ngesisini akuvakali ukuthi liyaphuma libhlungu livele laklamuzeka nje

R: so wacina uligwinyile vele izinyo lakho

P1: ye njengethambo yabo”

Translation: “P1: I fell and lost a tooth and fell again and I I was fine neh so it happened again when I was eating meat it got mixed with the bone because I like meat with a bone I was crushing the bone this thing called you know crushing the bone Crushing the bone ((lack of a better word)) ... I was biting while the tooth was coming out and I am chewing it the time It was in the mouth I was not aware that it's coming out I thought I was chewing the bone while it was the tooth it's out I only saw with the gap I didn't feel it coming out or painful it just went out

R: so you ended up swallowing your tooth

P1: yes like a bone you see”

It is evident in observations where some participants have some scars or missing a tooth, which they confirmed that it was a result of a diabetes related episode (often a hypo).

As mentioned above, not much is reported in the literature about the lived experiences of the people living with type 1 diabetes, and this includes the changes in their lifestyle after being diagnosed. Therefore, this study provides some insight into this matter, through the participants’ own voices.

4.2.2 Acceptance and Understanding

This study found that most people in the community, according to participants, do not have enough knowledge and understanding of what diabetes is, and all participants reported that when they were diagnosed they did not understand what diabetes is and what it means. They would often ask themselves ‘why me?’ and some are even the only ones in their family who have diabetes, so they did not understand. After attending the diabetes clinic they got to understand it, and it then became easier. They were then able to explain to the people around them, because they feel that it is important for them to understand in order to be able to help in case one gets sick they will know what to do.

P7: “yeah I didn’t understand ne ke ebotsa gore keng nthwe bare ke swikiri”

Translation: *“Yeah I didn’t understand I was asking myself what is this thing called diabetes”*

P8: after I met like some couple of guys like getting to know gore diabetes ke keng what’s happening around it that’s when I started gore ok le nna I can be normal like everyone I can still work do other things

Translation: *“after I met like some couple of guys like getting to know what diabetes is what’s happening around it that’s when I started saying ok I can also be normal like everyone I can still work so other things”*

P8: “uzobatshela loko ... so but mase ujwayele ukukhuluma ngayo it becomes much more easier coz the next person oxoxa naye at work it’s easy you can tell the next person ukuthi ey

mfethu mina ngi so so so so if anything you just highlight if anything was to happen to me ngcela ungenzele ungincede nga 1/2/3”

Translation: *“you will tell them that ... so but once you get used to talking about it it becomes much more easier coz the next person you talk to at work it’s easy you can tell the next person that ey brother I am like this this this this if anything you just highlight if anything was to happen to me please do this for me help me with 1/2/3”*

P8: ne ke ne ke sa I was not ne ke sa e accepti gore I’m a diabetic ne ke phela as a normal person like eating normal foods eating sugars eating lot of things you know”

Translation: *“I was I was not I could not accept that I’m a diabetic I used to live like a normal person like eating normal foods eating sugars eating lot of things you know”*

Another factor found to be beneficial in understanding is seeing other young people who are living and coping with the illness. According to the participants, seeing other people, even younger than oneself, as well as talking to other people living with diabetes helps them understand that the illness also affects young people the same way, there is nothing wrong with them; others felt that they were cursed at the beginning until they saw others.

P2: “up until I meet I went to my first camp ke bona batho kare ey hona le batho banang swikiri and balekana lenna ba bang baba nyane le bona then I became so comfortable ka yona then ebe ke amogela ntho tse joalo”

Translation: *“up until I meet I went to my first camp and saw people and said ey there are people my age who have diabetes others are younger as well then I became so comfortable with it then I accepted things like that”*

Accepting that one has diabetes is found to be important in this journey. Most participants found it hard to accept the illness in the beginning, and eventually got to accept because of the knowledge and support provided by the family and friends as well as the Baragwanath diabetes clinic through classes, camps and patience and support from the clinic staff. Acceptance also helps one be able to take care of oneself and know what to do, because if they have not accepted they might not take good care of themselves and not do what they are supposed to do, making their sugar level to be problematic all the time because it is not controlled.

P6: have to manage my my my diet hore ke ja joang hore what's happening with my body how must I inject how must I test myself

Translation: *“have to manage my my my diet how I'm eating, what's happening with my body how must I inject how must I test myself”*

R2: and then you learned this from mo, ba go rutille mo?

Translation: *and then you learned this from here, you were taught here?*

P8: yeah from this clinic

Acceptance is found to also help one to be able to talk freely about living with diabetes and explaining to other people what that means, because lack of knowledge about diabetes in our society is still a challenge. Them being able to tell people about living with diabetes is beneficial in a sense that those people can be able to help should anything happen they know what to do. This was also observed in the way they were sharing the knowledge during the interviews, one could see that they have accepted the illness and are knowledgeable about it.

Findings from literature prove that some patients have limited understanding of what diabetes is and what it entails, mainly because of the manner in which the information is given to them, which could be a lot of information at once or information given in complicated and not easy to understand language (Mendenhall & Norris, 2015; Burkett, 2015; Murphy, Chuma, Mathews, Steyn, & Levitt, 2015; Steyn, Levitt, Patel, Gwebushe, Lombard, & Everett, 2014 and Motala & Ramaiya, 2010). This has potential of posing a challenge to patients, whereby they can get overwhelmed with information they do not fully understand and end up not following the treatment correctly.

4.2.3 Perceived Support

Another context in which the socio-economic position has a bearing on diabetes patients relates to availability of a strong support system that might be found in communities or families. It does benefit patients in the journey with diabetes. Participants reported to have benefitted from the support provided by their loved ones and the assistance they give them in terms of knowing what to do and helping in case one gets sick. Some participants reported that their families were not supportive at the beginning and did not even talk about diabetes, which also affected their own acceptance of the illness. But they argue that once the family gets to understand the illness, often through attending diabetes classes, it becomes better and

they support and help where needed. Most participants were diagnosed when they were still young and could not understand what was going on, therefore having that support system seemed to make a difference.

P2: *“ay ay and le nako engtswara swikiri eo ko ntlung the parents and everyone they didn’t talk about it they were like just quite so it should raise concerns to me hore kanti batho”*

Translation: *“ayay and even the time I got diabetes at home the parents and everyone they didn’t talk about it they were like just quite so it should raise concerns to me that but these people”*

P4: *“mina actually I grew up in a house where both of my parents were diabetic uhm back then I never understood ukuthi what are they doing because we never talked about it endlini”*

Translation: *“I actually grew up in a house where both of my parents were diabetic uhm back then I never understood what they are doing because we never talked about it at home”*

P3: *“uncle ya ka ke ena na ampusha wa bona mara ko hae like eh ba ko mme wa ka ne ba sae understandi dai ding hore etswa ko kae wa bona”*

Translation: *“my uncle was the one pushing me you see but at home like eh at my mother’s side they didn’t understand where this thing is coming from you see”*

P7: *“nna first time ke tlo ba na le bo lwetsi bo ba swikiri eish ne go le nzima because ne ke se na le support ko familing ne ke sa ne motho o understandang and then ne ba se na taba le nna ... yeah so I had to go ko ngkono wa ka ke ena motho ne anghlokomela”*

Translation: *“the first time I had this diabetes illness eish it was difficult because I didn’t have support in the family I didn’t have anyone who understood and then they didn’t care about me ... yeah so I had to go to my grandmother she’s the person who was taking care of me”*

FP1²: *“the family is very supportive”*

FP2: *“I was staying with my mom, dad and granny but the person who was more supportive was my granny and my older sister, she also has it now”*

²This is a code for female participant whilst FP2 represents female participant 2 etc.

Peer support is also found to be valuable. Most participants mentioned that meeting other young people who are living with diabetes, going to diabetes camps and receiving information and knowing that there are other people going through the same thing that can share their challenges with, is very helpful. The patients also have a WhatsApp group where they discuss issues, help each other and share experiences instantly. The peer support was also visible during the camp, whereby the patients were helping each other where need be and doing things together, the spirit of brotherhood was very visible. There is also support group meetings that take place once a month at the clinic, which also helps with peer support. This seems to be beneficial in the participants' journey with diabetes and makes it better to manage the illness.

“P5: yeah and along the way I managed to meet ... yeah these people I didn't know them ((all laugh)) but now I know them because of sugars

R: and they providing support as well I guess

P5: yeah but you know you cannot take support from everyone there are people you know those you know that yeah you know”

Support and understanding from friends is important because they spend most of their time with friends therefore they should know what to do in case one gets sick. However, some reported having being stigmatised, whereby their friends change towards them after knowing that they have diabetes, distancing themselves in fear of getting infected, which is also a result of lack of knowledge about the illness.

FP1: “friends know about it but not all of them, only the ones I know listen when I talk to them, unlike the others that don't even take it serious when you tell them. The friends that know and are close to me are very supportive”

FP2: “my friends are ok they are supportive, and they help make food for me when they see that I my sugar might be down. Even the person I'm staying with ((boyfriend)) understands and helps me”

FP4: “my friends understand because they knew since I was in primary school, but they only got to really understand when I was doing grade 10”

P3: *“because ngineshukela the the they have heard that I’m diabetic I’m gonna spread them ... you know like ey they started to go away like amajita now asisaringisani sharp wa bona asisaphuzisani amabeer like sort of those stuff wa bona”*

Translation: *“because I have diabetes the the they have heard that I’m diabetic I’m gonna spread them ... you know like ey they started to go away like guys now we don’t talk properly you see we don’t share beer like sort of those stuff you see”*

Participants were asked if it is easier to be friends with people who have diabetes or those who don’t have it. They said it is the same, but they prefer being friends with people who do not have diabetes because being friends with someone who has diabetes means that you’ll always be talking about diabetes, and you will both be acting and doing the same things.

“R2: is it easier then to become friends nabantu abane... like being friends with these guys than with people who don’t know about diabetes

P8&4: kyafana

P5: it’s easier to be friends with people who don’t know about diabetes

R: why?

P5: because being friends with people with diabetes is like ... ninento eyi1 nonke meaning nizoacta ngokfana akunamehluko”

Translation: *“R2: is it easier then to become friends with people who have... like being friends with these guys than with people who don’t know about diabetes*

P8&4: it’s the same

P5: it’s easier to be friends with people who don’t know about diabetes

R: why?

P5: because being friends with people with diabetes is like ... you all have the same thing meaning you will act the same way there’s no difference”

There was a strong feeling from the participants that they want people to treat them normally like other people and not give them any special treatment. They also mentioned that people who do not have diabetes treat them like children by always checking on them, whether they have injected, tested, or eaten. This might be because those people care and want to ensure that they take care of themselves, but the participants find this a bit too much.

P5: *“lomuntu loyo futhi uyamtshela ukuthi nginoshukela and don't treat me like a diamond because if uzongtreata kanjalo soxabana ngitreat njengenormal person uyaunderstanda ... and mawuzoba most uzoba umngane nomuntu onoshukela like unoshukela so so so nihlale nikhuluma ngoshukela”*

Translation: *“you also tell that person that you have diabetes and don't treat me like a diamond because if you treat me like that we'll have a problem treat me like a normal person you understand ... and if you will be mostly friends with someone with diabetes like you have diabetes so so so you always talking about diabetes”*

P2: *“that's the thing that I hate wa bona motho o non-diabetic o go treata like o ngoana man ((all agree)) 'o jile o tihabile we ntseng we ntseng' ay man (fokof)” ((group agrees))*

Translation: *“that's the thing that I hate you see someone who is non-diabetic treats you like a baby ((all agree)) 'have you eaten have you injected did you do this did you do that' no man (f**k off)” ((group agrees))*

R: *“so don't you think that they do that because they care”*

P5: *“they do care but it's annoying”*

The participants mentioned that there is also some back stabbing, whereby their friends use the fact that they have diabetes and sabotage them when it comes to women, telling women that they have poor sexual performance because of diabetes, especially if the friend also wants that woman. Some participants mentioned that they often discuss with the girlfriend beforehand so that they are aware of their state of health, especially the main girlfriends who are the ones they regard as serious girlfriends. Participants made mention of what they call “half past six”, which refers to not being able to have an erection, and this is derived from the way the clock shows time when it is 06:30.

P5: *“like maybe ngizbambela wena uyakbona uyakfuna naye uzoza kuwe aktshela ukuthi ey lomuntu lo since ey half past six yabona”*

Translation: *“like maybe I'm dating you he sees you and he also wants you he will come to you and tell you that hey this person since ey half past six you see”*

Other participants mentioned being left by their partners because of having diabetes. Others even though they haven't gone through that but they also fear that they might go through it someday. Partner support seems to be important for both gender participants. All female participants seem to not have much challenge when it comes to that as their partners are

supportive, even if they are scared of injecting them but still support in other ways. With male participants it is a challenge because of its perceived effect on sexual performance; hence they fear their partners will leave.

P3: "... wa bona so like amacheri ami bangyeka bathi ay leouti le ineshukela le"

Translation: "... you see so like my girlfriends left me saying ay this guy has diabetes"

FP2: "the one I'm staying with is scared of injecting me what he does is to give me sugar in case I have a hypo, and he is very supportive. Him, my sister and my brother they are very supportive"

FP3: "at home they are supportive, even my boyfriend is also supportive"

A support system is of importance to any human being, especially living with a chronic illness. Hempler et al. (2016) also show the importance of having a social network and support, which is found to be more prevalent with people living with type 1 diabetes. They also add that the support system helps with healthy behaviours as well (Hempler et al, 2016). The participants in this study reveals the importance of a support structure as well as the importance of having someone in their lives, whether a partner or family members.

4.3 Challenges posed by the diabetes condition

4.3.1 Work-related challenges

This study revealed some work-related challenges that young people living with diabetes face. Some participants mentioned that their work got affected either because of getting sick at work, fear of getting sick at work or the employer telling them they cannot work in that particular place in their health state. There is also a challenge of finding employment as some employers do not want to employ people living with diabetes given the nature of the work they do, especially in the mines. The fact that one has to take a day to go to the clinic every now and then, to fetch their treatment is a challenge to some employers as they think that their business will be affected if the people miss work on some days. One participant

mentioned that he had to quit his job for fear of getting sick or collapsing at work; he thought that he will not be able to work with the illness. But meeting other young people in the same position and getting to understand that others are able to survive work just fine that motivated him to look for employment and live positively. This also confirms the importance of a social space in which the patient is found as some contexts with less support coupled with myths exacerbate the challenges already brought by the diabetes condition.

P1: “sandiphelelisela nensebenzo ngoba bendisebenza emgodini emayini yabo kwaphetha ukuba maniresigne ndiphume emgodini ngenxa yaleswekile ngoba umntu oneswekile akakhoni ukhlala i30 minutes ebushushwini phansi komgodi”

Translation: *“it took my job because I was working in the mine you see I ended up having to resign get out of the mine because of this diabetes because someone with diabetes cannot stay 30 minutes in a hot place underground”*

P8: “nna one challenge that I had since ke na le diabetes is when I was having to quit my job because of lack of knowledge ke tsaba gore since I was working at the warehouse ne ke tshaba gore ke tla collapse”

Translation: *“one challenge that I had since I have diabetes is when I was having to quit my job because of lack of knowledge I was scared that since I was working at the warehouse I was scared that I will collapse”*

What is important in most employers' eyes is their business succeeding and production growing, which means that their employees should be fully functional and at work every day. However, for an employee living with diabetes, they have to sometimes miss work on the days they have to go to the clinic to get their treatment or if there is any complication they are facing. According to Krstović-Spremo et al. (2014), diabetes is a common cause of absenteeism and diabetes patients most likely face challenges with productivity and other challenges. This study supports Krstović-Spremo et al. (2014)'s findings, whereby we found participants who have had to lose jobs because of their health condition.

4.3.2 School-related challenges

Some participants revealed that they have faced challenges with school, whereby others even had to quit school because they felt that they were not coping because of they sometimes

collapse at school, having to inject, as well as the belief that diabetes affects older people not young ones. One participant mentioned having challenges when studying and therefore he uses insulin as a drug that he takes in order to be able to study and remember what he had read.

P3: “started to go away ... so like eh ka tlogela skolo ka grade 10 two years coz ne ke sa swikiri ne esa mphilisi sharp ne ke sa accepti ne ke sa e rate ka tlogela skolo 2 years eish then kabona kare eish ho bane ke ile koNorth West ka fitla da ka spana mara kuyafana lapha espanini like eish tsoanetse ke injecte ke tlogele spani wa bona”

Translation: *“started to go away ... so they eh I left school in grade 10 two years coz I was not diabetes was not treating me well I had not accepted I didn’t like it I left school 2 years eish then I saw and said eish because I went to North West I got there I worked but it was the same there at work like eish I had to stop working and inject you see”*

P4: “coz most of the time ngingafunda but nothing izongena ngzokhohlwa sametime so sometimes nginoku like manje njengoba kungamaexam kuzomele ngthathe extra insulin ukuze ngikwazi ukuconcentrata ngfunde kahle so sometimes ngifeela ngathi idrug yami uma ngjove yona ngiba right yonk into iyafunctiona kahle”

Translation: *“coz most of the time I would study but nothing will go in I’d forget same time so sometimes I would like now since it’s exam time I have to take extra insulin so that I can be able to concentrate and study well so sometimes I feel like it’s my drug when I have injected it I become alright everything functions well”*

Literature also supports that there are challenges with school-going children associated with living with diabetes (Emre et al, 2016). Even though this study focuses on young people, who are not children anymore, but some issues mentioned are also relevant for when they were younger, and some also face cognitive challenges even now as adults. As Emre et al (2016) add that there is limited training for school personnel on diabetes as well as what to do in case of a learner living with diabetes at school. Learners would end up quitting school because of this, therefore diabetes awareness as well as basic training for school personnel is recommended, as this would also help the teacher(s) know what to do in order to support or assist learners should they have any challenge while at school.

4.3.3 Treatment and diet related challenges

Other challenges that came out from the interviews were related to the treatment and service received by these patients. Some participants had a challenge with the prescribed diet, which requires them to eat boiled food and vegetables, they say it makes them lose weight, they rather prefer the diet plan they call DAFNE whereby they can eat anything but in calculated quantities. DAFNE teaches patients living with diabetes type 1 to match their insulin dose to their chosen food intake on a meal by meal basis (Oliver & Thompson, 2009). During the camp, food that was served was normal every day food that you would find in an ordinary house, only prepared in a healthy way, for example steamed or boiled viennas instead of fried. This shows that one can leave with what they ordinarily eat at home, without having to dig very deep into their pockets. This aspect highlights the influence of the socioeconomic position as patients from poorer families find it hard to afford to prescribe diet.

P5: "it was ok after it was ok ok and then ngayiyekela that diet for ...

R: idiet le abakunika yona

P5: yeah le yokuthi amaveg boiled what what and I was like ay this thing is not for me yabona because like bengiluzwa iweight suddenly ngizodla lezi zinto lezi like there's no difference"

Translation -> *P5: "It was ok after it was ok ok and then I stopped that diet for ...*

R: the diet they gave you

P5: yeah the one of veggies boiled what what and I was like ay this thing is not for me you see because like I was losing weight suddenly I'm eating these things like there's no difference"

FP1: "the diet is not easy to get used to because other people at home they'd be frying chicken but yours is steamed with no salt, steamed veges, no spices because our parents still have that theory that people with diabetes are not supposed to eat spices, salt, oil, sugar so if you are visiting them they'll be telling you all those things. You end up feeling as if you are being discriminated against"

P16: "yes because most most of me I am not working at the moment but can say that when I want to buy to purchase like diabetic food I'll say I do not have money so I'll eat that food that each and every person is eating"

Literature also supports the benefit of the DAFNE diet plan (Oliver and Thompson, 2009). This plan also helps to address the issue of the socio-economic status to some extent, whereby the patients would have a challenge with sourcing the necessities for the prescribed diet. Instead, using the DAFNE plan allows them to be able to use what they have and what is eaten by everyone in the house, but ensuring that one adheres to correct quantity adjustments. It is also confirmed in the literature that people living with diabetes face challenges with regards to their loved ones not supporting their prescribed diet (Burkett, 2015; Mendenhall & Norris, 2015; and Penn, Watermeyer & Evans, 2011), and using the DAFNE plan could be of benefit in such cases.

Another challenge reported by participants is with rural clinics, where the service is found to be poor and patients are not given proper information in terms of what to do and not to do, which can result in their diabetes not getting better.

P3: “like ko magaeng like ko magaeng neh uhm like ko di clinics or di hospital ba na le poor like aba medication ntho ya hao aba like I don’t know if abarotega ka dai ding or ka this diabetes or bjang but ay”

Translation: *“like in the rurals like in the rurals neh uhm at the clinics or hospitals they have poor they don’t medication your thing they are not like I don’t know if they are not well taught about this thing or about this diabetes or what but ay”*

P1: “kuyenzakala wena sisi uthole ukuthi xa ngaba ugula uqalwa ile swekile le uhambe uye esbhedlela bakbone ukuthi ay bazoktshela ukuthi ay uneswekile so nazi inazinga mina bangqalise ngeepilisi uya bona ... nazi iipilisi ufike nawe uthathe iipilisi awubuzi ukuthi kudliwani kwenziwa ntoni kanjani uyahamba ufika endlini uyaphuza iipilizi zakho udla ukudla loku okujwayele”

Translation: *“it happens sister you find that when you are sick when this diabetes is starting you go to the hospital they see that ay they will tell you that you have diabetes so here is this they started me with pills you see here are the pills you take the pills and don’t ask what you are supposed to eat what needs to be done you get home and take your pills and eat your usual food”*

Research confirms that there is a need to improve health care for diabetes patients especially in the public sector clinics (Steyn et al, 2014), where most of the population accesses the

service. This would also mean providing more training for health care personnel on diabetes care in order to be able to provide proper information to patients as well as proper service.

Participants mentioned that they wish the medication could cure the diabetes because just managing it is not good enough because their lives are not easy and they have to take that treatment till they die, they can't live freely like other people.

P1: “nayo lapho ndiyoyika khona ndizasuke ndife ndishiye abantabami ngoba lento yokuba ukube bekuthiwe ezi injection ziyayiphelisa nya ay bengingajabula sisi manje ke ziyayehlisa kuphela”

Translation: *“that’s where it scares me I could just die and leave my children because this thing of if the injections were curing it I would be happy sister now they only bring it down”*

4.3.4 Hypoglycaemia (Hypos)

One general challenge that all participants find problematic in their journey with diabetes is experiencing hypoglycaemic episodes, referred to by participants as ‘hypos’, as defined above. The hypos sometimes happen in the public areas whereby they collapse and people around them wouldn't know what is going on or what to do with them. This sometimes happen when they are out having fun with friends, and other friends would not know that they have diabetes, therefore don't know how to help. They often wake up in hospital and will be told what had happened. This is why they feel that it is better for people around them to know so that they can be able to help in case one has a hypo.

P2: “ketsamae ko traineng ka ka tswarwa ke hypo ko traineng but luckily be ke na le bangle ya ka mo so ba bona hore ke na le swikiri”

Translation: *“going with a train I I got a hypo in the train but luckily I had my bangle here so they saw that I have diabetes”*

Friends are often only told of the fact that one has diabetes after one had collapsed in front of them, then they explain that one has diabetes and what the friend needs to do in case it happens again. Some of the participants said that it was not easy to tell friends at the beginning, therefore they would make up stories.

P7: *“uhm no it’s not that easy because of you know abangani bam kade bangazi ukuthi nginoshukela until one day ngicollapsa in front of them ... so kade bangazi ukuthi kuyenzeka bangikuka bangisa ekhaya... ekhaya babatshela ukuthi lomuntu lo kmele nenze kanje nakanje”*

Translation: *“uhm no it’s not that easy because of you know my friends didn’t know that I have diabetes until one day I collapsed in front of them ... so they didn’t know that it happens they carried me home at home they told them that this person you have to do this and that”*

P8: *“but mayenzeka kuwe kuba iexperience enye kubo at the same time”*

Translation: *“but if it happens to you it becomes an experience to them at the same time”*

The participants were asked if they feel when they are going to have a hypo. Some of them said they do feel it, which allows them to quickly make something to eat, but that is not always a success because if something disturbs you then you won’t be able to finish. However others do not feel it they just collapse and get told what happened when they wake up. It also happens that one gets a hypo when they are sleeping, this could be dangerous in case one stays or sleeps alone because no one will see what has happened and will not be able to assist.

P5: *“ngoba something something something unokufeela ukuthi my sugar is low neh wenze wenz’ ukudla uprepare ukudla wadla kahle but kuba nesomething ekudistractayo you understand that’s that’s where most of my collapse ayenzakala ngoba ngiyaprepare ukudla uma kfanele ngidle eish maybe kube nesomething engidistractayo and once ingidistracta ngiyawa”*

Translation: *“because something something something you sometimes feel that my sugar is low neh make make food you prepare food and eat but there’ll be something distracting you understand that’s that’s where most of my collapse happen because I do prepare food when I have to eat eish maybe there’ll be something distracting me and once I get distracted I fall”*

FP14: *“especially if they drop in the middle of the night when you sleeping and then there’s nobody around to help you or you can’t get up and you know”*

A patient had a hypo episode during the camp, and it was interesting to see how much support and attention she was given by the other patients to make sure that they boost her sugar level and she gains back her strength. Even though this episode happened in the middle of the night, however almost everyone attended to the incident.

4.3.5 Sexual and Reproductive Challenges

The study found that there are some sexual and reproductive challenges facing young people living with diabetes. What male participants fear the most about living with diabetes is what they call “half past six”, which means not being able to get an erection. Even though they were not open about having experienced it, one of the participants mentioned that if they get a weak erection they eat a lot of sweets so that they can gain energy.

P2: “so now gona janoong my most fear now ke gore se ke na 19 years any complication ekana etsahala se ke na 19 years ke na le swikiri any complication e ka na etsahala anytime my most fear half past six mama batla ntshia mo ntlung phela nna if ayemi”

***Translation:** “so right now my most fear now is that I have 19 years any complication that can happen I have 19 years now having diabetes any complication that can happen anytime my most fear half past six mama they will kick me out at home if it doesn’t stand/get up”*

P2: “no wa tseba half past six a se hore ya etsahala vele motho ya etsahala a hore wena you don’t take care of yourself”

***Translation:** “no you know half past six it’s not that it happens it happens to a person if you don’t take care of yourself”*

They also fear not being able to have children because of diabetes. They say this is because they are told at the clinic that if they do not manage their diabetes well they will not have children, and this scares them because they are still young and hoping to have children. This results in others rushing to have children so that by the time it becomes a problem at least they would have children. This topic caused a big debate in the discussion whereby one participant was saying that is a myth and they must not hurry to have children without proper planning, and others asking how sure he is that it’s a myth. Another participant mentioned that he was told that after age 25 he will not be able to have children.

P5: “and the thing is imistake esiyenzayo thina laba especially iyouth once they tell you ukuthi udiabetic baktshela ukuthi this stupid this myth bathi eh angeke ube nabantwana”

Translation: “and the thing is the mistake we make especially the youth once they tell you that you are diabetic they tell you that this stupid this myth they say you won’t have kids”

P5: “it’s a myth amanga ... uzibuze ukuthi mangizophapha mawuzophapha wenza abantwana fast fast usuke ucabangani ngoba umntwana is nie pap n vleis”

Translation: “it’s a myth lies ... ask yourself that if I’m gonna hurry if you gonna hurry and make babies fast fast what would you be thinking because a baby is not easy”

P1: “inje lento sisi yabona udoctor akaktsheli ukuba awuzu awuzukuba Nomntwana ... udoctor uthi kuwe mangaba ungayicontrrolli iswikile yakho awuzukubathola abantwana namanursi bayasho pha mawulele pha ebhedini ‘yabona njengoba iswekile yakho iphezulu ngeke avuke umhlekezi uzawufa abantwana awuzu kuba nabo’ uyayibona into enjalo”

Translation: “this thing is like this sister you see the doctor doesn’t tell you that you won’t have a child ... the doctor says to you if you don’t control your sugar you won’t have children the nurses also say that where you are sleeping there on the bed ‘you see since your sugar level is high you won’t get an erection you will die without kids’ you see something like that”

Participants also seemed to have a fear of losing their sexual partners due to poor sexual performance and their non-diabetic friends sabotaging them to women telling the women that they have diabetes and hence they don’t get an erection. They also argued that it is not easy to tell a new partner that one has diabetes; they then come up with excuses in case it happens that the penis shrinks while they are still busy having sexual intercourse.

P1: “bayayenza asuke aysuka udlala ngexesha ngoba lanto ayizuvuka ngoba uwaste iskhathi sakho lomuntu unoshukela ncono uthathe mina”

Translation: “they do it he’d say hey you are wasting your time because that thing won’t get up because you are wasting your time this person has diabetes rather take me”

P5: *“you busy it’s not easy ukumtshela ukuthi hey motho ha o le so o tlo etsa so it’s not simple ungababuza bonke you know once nilibele ni have ifun then uJomo then uyancipha kancane ... uJomo and then uyancipha kancane babuze most yabo ungababuza beza nama excuse amanye alame ukuthi eish sengphethwe ikhanda yey abamtsheli ukuthi eh sisi ushukela sewuphansi kwenzakalani ... uthole ukuthi icall iyangena aye ngaphandle adle amaswidi amaningi ukuthi abuyise ienergy (all laugh) that’s what happens I’m telling you that’s what happens”*

Translation: *“You busy it’s not easy to tell her that hey if it’s like this you will do this it’s not simple you can ask them all you know once you are having fun then Jomo (penis) shrinks slowly ... Jomo and then shrinks slowly ask them you can ask most of them they come with some lame excuses that eish I have a headache they told tell her that eh sister the sugar level is low what’s happening Yeah you find that the phone rings then he goes outside and eats a lot of sweets to bring back the energy ((all laugh)) that’s what happens I’m telling you that’s what happens”*

Pregnancy-related challenge was found when it comes to female participants, whereby they often experience difficult pregnancies because of their health status. Participants reported that it is possible to fall pregnant and give birth to a healthy baby while one has diabetes, even though it can be challenging. One participant mentioned that she is thinking twice about falling pregnant because chances of passing diabetes to her child are high and she doesn’t want to pass it on.

FP1: *“I’m even rethinking about becoming a parent because I’m scared of passing this gene to my child”*

FP2: *“Even though I had a miscarriage it was because of negligence of the nurses in hospital not because of diabetes, diabetic people do have children. I got my other child before I was diagnosed with diabetes
It is possible to have a child while living with diabetes and through a normal birth”*

Quite a number of studies show that there are indeed sexual challenges faced by men living with diabetes, both type 1 and type 2, (Anderson et al, 2015; Biswas et al, 2012; Kemp &

Rheeder, 2015; Khan et al, 2016), and it is shown that this may result in low self-esteem. This is also supported by the findings of this study. Research also support the findings on pregnancy related challenges associated with living with diabetes (Dugan & Parthasarathy, 2016).

4.4 The question of gender

This study shows that the challenges faced by young people living with diabetes are no different from those revealed in previous studies. Young men are equally at risk and feel the impacts of the disease. This is further affected by cultural myths that prevent young men from seeking treatment earlier. This is therefore important to note when considering service delivery for diabetes patients and treatment seeking behaviours. However, as indicated in previous studies, there does not seem to be much difference in the way young men and women access diabetes care, which is supported by Ot wombe et al. (2015), who also found no significant gender differences in health seeking behaviour. Furthermore, this is a contradiction to quite a number of studies (Pettifor, 2015; Moodley, 2013; Letsela & Ratele, 2009; Coovadia et al., 2009; Smith, 2006; Oliver, 2005) who have found significant gender differences in health seeking behaviour, especially focusing on diabetes health care.

4.5 Discussion

The above results are findings that present and insight into the life of young persons living with diabetes. However, regardless of the small sample size used, saturation was reached, which enabled an in-depth discussion of issues relating to how young men handled diabetes and its associated challenges on a day to day basis. The diabetes challenges among young men are so much pronounced such that the conditions has led to a disruption of their lifestyles. It needs to be emphasised as well that the socio-economic position of patients does influence their treatment seeking behaviour and also how they respond to the challenges presented by the diabetes condition.

CHAPTER 5

CONCLUSION AND RECOMMENDATIONS

In understanding the young people living with diabetes type 1, it is important to note that these young people need to still balance being young as well as living with diabetes in their everyday lives. This implies that living with the illness means facing some challenges that usually disrupt their routine lifestyles. Regardless of the challenges these young people go through in their journey, they try and find ways to cope with the illness. This in some instances is done through carrying a hypo pack as well as sharing their experiences with persons who are close and may assist in case one is having a hypo.

This study gives some insight on understanding the young diabetes patients' life experiences, as well as their needs that are beyond medical. It has always been a limitation of previous studies which have not gone deeper in getting the voices of the diabetes patients expressed with the kind of depth attained in this study. For instance with the females the main challenges also come when one is planning to have a baby and they have to deal with the diabetes condition which presents them with extensive challenges. On the other hand young men get to deal with frustrations especially in relation to their sexual lifestyles. This study's in-depth discussions have therefore presented valuable information on the nature of challenges and how challenges related to diabetes care particularly among young people, are handled outside the medical remedies. This has in a way shown that there are other components that include the socio-economic position that have potential of affecting diabetes treatment seeking behaviour and consequently the management of the illness. Therefore it is also important to emphasise and implement a multidisciplinary approach, allowing for subject to be understood holistically.

In terms of recommendations for future research, it would be good to also consider interviewing health professionals that are working with the young people in health facilities. It would also be crucial to also embrace multiple geographic contexts, in order to see how young people living with diabetes type 1 in other areas experience and deal with the illness. Conducting a focus group discussion with more young women as well could have been of benefit, and their voices would have been more visible. These are a few considerations for future research in relation to exploring the lived experiences of young people living with type 1 diabetes.

Another recommendation that could assist those involved in treating young persons in health facilities, it is recommended that young people be allocated time and place dedicated to serving them in the health facilities, and also if possible, they be attended by young health care providers, which allows the health care provider to better understand what they are going through, as this could also allow the young patients to better relate and open up to persons they might perceive to be sharing common interests.

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APPENDIX 1

Semi-structured interview guide

1. Tell me about your life from the time you were diagnosed with diabetes.
2. How long have you known that you are diabetic?
3. Tell me about your lifestyle.
4. How is it living with diabetes as a young man?
5. Has your life been different from before you were diagnosed?
6. How are you coping with the illness?
7. Do you think your life would be different if you were not living with diabetes?

APPENDIX 2

Participant informed consent form

STUDY TITLE: *Exploring the lived experiences of young men (18-35 years old), living with type 1 diabetes, attending an urban diabetes clinic.*

AIM: *The aim of this research study is to explore the lived experiences of young men, aged 18-35 years, living with type 1 diabetes, attending Chris Hani Baragwanath Hospital diabetes clinic.*

This sheet will be explained verbally in the person's home language where necessary by the researcher.

Dear Sir / Madam

My name is Zamokuhle Thwala and I would like to invite you to help me find out your experience of living with type 1 diabetes. I am asking you because you have diabetes type 1 and attend the clinic at Chris Hani Baragwanath Hospital. If you agree to take part in this study, I would like to ask you a few questions, in a group discussion with other diabetes type 1 patients. You are requested not to share information about other patients discussed in this interview outside of this discussion. This discussion will take approximately an hour during the diabetes camp, and I will make sure that you do not miss out on other activities that you are supposed to take part on during the camp. In order to ensure that your name or identity is not revealed, a fake name will be used when reporting. Please note that information from this interview, and sometimes direct quotations, might be used in public places, at academic conferences, and on websites, without revealing your identity. Please also note that this research does not involve any treatment or medicines, and there is no payment for taking part. You do not have to take part – it is entirely up to you. If you don't want to take part, your medical care will not be affected at all. You can also decide to stop taking part at any time and I will not keep or use any information about you.

Thank you for taking the time to read this information sheet.

Please contact us at any time if you have any questions or are worried about anything.

My contact details:

Researcher's name: Zamokuhle Thwala

Telephone number: 083 7974 745

Email address: thwala.zamo@yahoo.com

Please also feel free to contact my supervisor if you have anything you would like to ask.

My supervisor's details:

Professor Claire Penn

Telephone number: 011 717 4579

Email address: Claire.penn@wits.ac.za

If you have any comments or complaints about the research you are also welcome to contact Zanele Ndlovu at the Wits Human Research Ethics committee (Medical).

Telephone number: 011 717 1252

Email address: Zanele.Ndlovu@wits.ac.za

APPENDIX 3

Consent form for focus group interviews

- I hereby give my consent to be part of a study about lived experiences of young men living with diabetes type 1 in the diabetes clinic at Chris Hani Baragwanath Hospital
- The project has been explained to me and I understand what the project is about
- I understand that I will be part of a focus group discussion with other young men living with diabetes
- I understand that information from this study might eventually be used in public places, at academic conferences, and on websites.
- I understand that my name will not appear in public
- I understand that this project does not involve treatment or medicines, and there is no payment for taking part.
- I am taking part in this study on my own free will, and I understand that I do not have to take part, and my medical care will not be affected at all if I do not
- I understand that I can withdraw consent at any point before the information is made public by contacting the researcher
- I understand that I do not have to answer any questions I would not want to answer.

Name _____

Signature _____

Date _____

APPENDIX 4

Consent form for audio recording

- I hereby give my consent to be part of a study about lived experiences of young men living with diabetes type 1 in the diabetes clinic at Chris Hani Baragwanath Hospital
- I hereby give consent to be recorded during the focus group discussion
- It has been explained to me that the recording is only for purposes of reporting, and my identity will not be revealed for
- I understand that the recording for this interview will be kept safe in the Health Communication and Research Unit files.
- I understand that I can refuse to be recorded if I do not feel comfortable.

Name _____

Signature _____

Date _____

APPENDIX 5

Ethical clearance certificate



R14/49 Prof Claire Penn et al

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M160335

NAME: Prof Claire Penn et al
(Principal Investigator)

DEPARTMENT: Health Communication Research Unit
Chris Hani Baragwanath Academic Hospital


PROJECT TITLE: Phase 4: What are the Barriers and Facilitators to Care Experienced by Types 1 and 2 Diabetes Patients and Healthcare Professionals in Soweto and Johannesburg?
Phase 1: M150522 / Phase 2: M150715 / Phase3: M151114

DATE CONSIDERED: 01/04/2016

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR:

APPROVED BY: 

Professor P. Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 04/05/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 10004, 10th floor, Senate House/2nd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand. I/We fully understand the the conditions under which I am/we are authorised to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit to the Committee. **I agree to submit a yearly progress report.** The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. in this case, the study was initially review in March and will therefore be due in the month of March each year.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES