# SWEET TALK: COMMUNICATION PRACTICES AND PERCEPTIONS AT AN URBAN CLINIC FOR GESTATIONAL DIABETES MELLITUS

A report on a study project presented to

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In fulfilment of the requirements

For the degree M.A. Speech Pathology

by

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**GDM COMMUNICATION PRACTICES** 

**Declaration** 

ı

I, Bianca Burkett, hereby declare that this study and dissertation are my own work and that

all due credit has been given to authors whose work was consulted. This work is being

submitted in fulfilment of the degree: Master of Arts (Speech Pathology) at the University of

the Witwatersrand. It has not been previously submitted at this university or any other

institution.

Signed:

Date: 1 June 2015

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# **List of Abbreviations**

| • | Acquired immune deficiency syndrome | AIDS  |
|---|-------------------------------------|-------|
| • | Focus group                         | FG    |
| • | Gestational diabetes mellitus       | GDM   |
| • | Haemoglobin A1c                     | HbA1c |
| • | Hemo Glucose Test                   | HGT   |
| • | Human immunodeficiency virus        | HIV   |
| • | Thematic Analysis                   | TA    |
| • | Tuberculosis                        | ТВ    |

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### **CHAPTER 1: INTRODUCTION**

This study explored the practice and perceptions of nurses and patients regarding communication at an urban GDM clinic in South Africa. South Africa forms an interesting research context, given its cultural and linguistic diversity. Constructs critical to this research study include empowerment and its history within South Africa and its effect on patients' experiences in the healthcare system, as well as the role of lifeworld in mediating healthcare experiences. The role of the nurse in the South African healthcare context is also considered extensively. It is thought that this study might provide insight into the facilitators and barriers to successful communication in the context of GDM in South Africa. These facilitators and barriers are explored using a variety of qualitative methods, with the hope of informing recommendations for the future care of and communication with patients who have GDM.

#### **Diabetes: A global burden**

The WHO (2014a) has named diabetes as the fifteenth leading cause of years of life lost globally. In 2011 336 million people were living with diabetes worldwide. This is expected to increase to 552 million people by the year 2030 (Whiting, Guariguata, Weil, & Shaw, 2011). A further fact to accompany these statistics is that the majority of people who have diabetes live in countries of low and middle income, which will experience the greatest rise in diabetes prevalence of the next 22 years (Guariguata, Whiting, Hambleton, Beagley, Linnekamp, & Shaw, 2014).

The prevalence of diabetes worldwide and particularly in Africa is hypothesised to be on the rise as a result of increases in obesity, the lack of physical activity and urbanisation. Sub-Saharan Africa is thus beginning to experience a triple and quadruple burden of disease, as a result of the increase in diabetes, along with that of conditions which have existed for longer in the area, including HIV/AIDS, TB and malaria. This has serious implications for the growth of developing countries in Africa, especially because resource availability in these countries is limited (Levitt, 2008).

Diabetes is a burden on the economy. Whilst South African data related to diabetes expenditure is lacking, it was estimated that 7% of total health expenditure was dedicated solely to diabetes in Sub-Saharan Africa in 2010, and 12% of health expenditure worldwide (Zhang, Zhang, Brown, Vistisen, Sicree, Shaw, & Nichols, 2010).

The data provided above suggest that diabetes is a growing challenge globally, with a specific marked increase in developing countries in Africa. This warrants research in the field of diabetes, so that work may be done to minimise negative effects of the condition on individuals, communities and global economies.

#### Gestational Diabetes Mellitus (GDM): Prevalence in South Africa

The prevalence of GDM in South Africa is not accurately documented due to a lack of data in this area (Levitt & Mollentze, 2006). An audit of diabetes during pregnancy was conducted

in Soweto between 1992 and 2002. This revealed that three hundred and forty eight out of seven hundred and thirty three of the mothers diagnosed with diabetes were in fact suffering from GDM (Huddle, 2005). A common risk factor for diabetes is obesity. In identifying and estimating its prevalence in South Africa the following statistic should also be considered. 31% of South African women have been found to be obese, as opposed to 20.7% in the United States of America (Levitt, 2008). This data thus suggests that GDM is, in fact, significantly prevalent in South Africa.

#### **GDM: What is it?**

GDM is a type of diabetes. It is defined as high blood sugar (hyperglycaemia) which begins during pregnancy (Levitt & Mollentze, 2006). Known causes of GDM include genetic and physiological abnormalities which cause the body to experience a severely reduced insulin response or an insulin resistance to glucose during pregnancy. The lack of sufficient insulin essentially results in the poor regulation of blood glucose, hence resulting in high blood glucose levels (Buchanan & Xiang, 2005). Naturally, all pregnant women experience a reduced response to insulin, in order to ensure an appropriate supply of glucose to the developing foetus. This process is mediated by the hormones which are secreted by the placenta. Women with GDM, however, experience an abnormally high resistance to insulin, resulting in various complications for the mother and foetus (Setji, Brown & Feinglos, 2005).

**GDM COMMUNICATION PRACTICES** 

**GDM: Risk factors** 

There are numerous risk factors which may render one more susceptible to developing

4

GDM. The most common risk factors are listed as a family history of diabetes, a history of

GDM during previous pregnancies, previous unexplained miscarriages, the birth of children

who weighed over 4kg at birth, a maternal age greater than thirty five years, maternal

obesity, lack of exercise, a diet high in glycaemic load and low in fibre, chronic hypertension,

pregnancy complications involving repeated urinary tract infections and ethnicity (with

Aboriginal, South East Asian, African American, Indian and Middle Eastern women

experiencing higher incidences of GDM) (Reedy & King, 2011).

**GDM: Symptoms** 

Symptoms of GDM are similar to those which result from type 2 diabetes mellitus and the

severity of symptoms is individually determined (Ali, 2011). Commonly documented

symptoms include fatigue, frequent urination, weakness, visual difficulties and infections

and irritation of the skin, bladder and vagina (Yu, Stjernholm & Munier, 2004; Mestman &

Umpierrez, 2007).

**GDM: Diagnosis** 

The American Diabetes Association (2010) states that GDM may be diagnosed if one or

more of the following thresholds are met or exceeded, regarding a patient's glucose level:

Table 1. Blood glucose levels used to diagnose GDM

| Parameter                    | Levels    |
|------------------------------|-----------|
| Fasting plasma glucose       | 5.3mmol/l |
| Plasma glucose 1 hour after  | 10mmol/l  |
| Glucose intake               |           |
| Plasma glucose 2 hours After | 8.6mmol/l |
| Glucose Intake               |           |

However, the GDM clinic involved in this research study makes use of its own evidencebased protocol to diagnose women with the condition.

#### **GDM: Treatment**

The treatment of GDM usually comprises dietary changes, nutritional counselling and an exercise plan, complemented by the appropriate medical treatment (Ali, 2011). Medical regimens for treating GDM may involve the administration of insulin via injection, and/or other oral agents to lower blood glucose levels, such as Metformin, which improve insulin sensitivity (American Diabetes Association, 2003; Ferrara & Kim, 2009). Insulin is usually prescribed only when nutrition-centred therapy is not found to maintain blood glucose levels effectively. Insulin increases the risk of low blood glucose (hypoglycaemia), which may result in the patient feeling shaky, confused, dizzy, weak, hungry and feverish or sweaty (Kettles, Cole & Wright, 2006).

Blood glucose monitoring also forms a vital aspect of the treatment for GDM, as it alerts patients and medical professionals to changed or unchanged blood glucose levels and in this way informs future treatment methods (American Diabetes Association, 2003). Treatment

for GDM is generally aimed at reducing the occurrence of maternal and foetal complications (Chasan-Taber, 2010).

#### **GDM: Effects on child**

GDM is linked to various complications. These complications include infant mortality, the need for a caesarean section delivery, stillbirths, hypoglycaemia (possibly resulting in seizures and cerebral damage), hyperglycaemia and hyperbilirubinaemia in the newborn infant (Levitt & Mollentze, 2006). Maternal risks include the development of type 2 diabetes mellitus (Hjelm, Berntorp, Frid, Aberg, & Apelqvist, 2008). Thomas and Gutierrez (2005) also identify maternal hypertension (during or after the pregnancy) and premature child delivery as further maternal complications that may result from GDM. Further foetal complications may include increased amniotic fluid resulting in congenital abnormalities of the central nervous system, a birth weight of greater than 4kg, delayed lung maturation often resulting in respiratory distress syndrome, decreased neonatal calcium levels resulting in feeding problems and seizures, increased red blood cell mass in the foetus and various congenital anomalies (Thomas & Gutierrez, 2005).

#### **GDM: Effects on mother**

Linné, Barkeling and Rössner (2002) note that whilst GDM generally resolves after pregnancy, women diagnosed with GDM have a significantly higher chance of developing type 2 diabetes mellitus later on in life. They suggest that this course may be prevented via

close monitoring of woman diagnosed with GDM, particularly with regards to lifestyle, exercise and dietary habits.

An acute condition may be defined as one with a sudden onset and/or a brief duration (WHO, 2004). A chronic condition, on the other hand, may be defined as one which meets at least one of the following criteria: is permanent in nature or results from an irreversible pathology or results in a permanent disability or requires that the patient be specifically trained regarding rehabilitation or needs care and management over a longer period of time (WHO, 2004). It should be noted that GDM is unique in that it does not fit neatly within the definitions of a chronic or acute condition. However, it may become chronic post pregnancy (resulting in type 2 diabetes) and appears to fit better within the definition related to a chronic or long-term condition, as it usually requires treatment over a period of months and requires that patients receive special training and education related to treatment. It is important that this distinction be made, as communication differs significantly in acute and chronic or long term conditions, in that the acute care model fails to adequately fulfil the needs of patients with chronic conditions. It does not accommodate the need to consider patients' backgrounds and everyday difficulties and foster active participation in treatment, which are vital aspects in caring for patients with chronic conditions (Shahady, 2006). Based on this discussion, it appears that the care required in treating GDM appears to reflect that of the chronic care model, more than the acute. Some discussion related to communication and care in the context of chronic conditions will thus be provided.

From the above information, it is evident that GDM is an intricate, multidimensional condition. It appears that a patient's physical health is mediated by a complex interaction of factors, including a variety of methods which require a comprehensive understanding of illness and treatment by patients and substantial changes in the patient's lifestyle and everyday practice.

As suggested by Black (2002), diabetes places additional strain on patients and their families in terms of the finances required for medication and low calorie foods. Black (2002) 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 ideology perhaps informs the possibility of GDM as a condition which affects entire families and social groups, as opposed to the patient exclusively.

The information provided about GDM above brings to mind the Millennium Development Goals (MDGs). The United Nations MDGs consist of eight global goals that have been agreed upon by countries around the world, with the particular objective of fulfilling the requirements of the poorest populations in the world. The goals were set to be achieved by 2015 (WHO, 2014b). This study is of particular relevance to the following MDGs:

- MDG 4- Reducing child mortality
- MDG 5 –Improving maternal health
- MDG 6- Combating HIV and AIDS, malaria and other disease

Some progress regarding the MDGs in developing countries has been made. However, a lack of progress in the area of maternal health has been noted and an increase in maternal death has been linked to childbirth and pregnancy. Increased efforts thus need to be made to prevent maternal mortality as a result of pregnancy and childbirth (United Nations, 2014). It is thus vital that more research related to the MDGs be done in order to foster greater progress on the African continent post 2015. It has been made clear that GDM forms a major threat to infant health and maternal health, and is a type of diabetes, which is a devastating condition on the rise globally, and particularly in Africa. Research studies, such as this one are thus of great importance and relevance to the global community.

#### Rationale for the study

The language specialist has a role to play to facilitate effective communication practices between healthcare professionals and patients, and should thus be an active team member within the field of health communication and ethics (Watermeyer & Penn, 2008). Ratzan, Payne and Bishop (1996) further suggest that health communication falls within the scope of speech and language specialists. Language therapists are thus obliged to explore and, where necessary, improve communication practices between healthcare professionals and patients in the context of medical conditions, such as GDM.

GDM is a condition that has been poorly documented in the South African context. Literature based on diabetes in South Africa, has however highlighted the need for increased insight into the communication occurring between patients and healthcare

providers and methods of altering communication methods and ways of patient teaching to improve patients' attitudes towards living with diabetes and taking treatment for the condition. This would be expected, given the unique healthcare context that South Africa poses, especially when there is often linguistic and cultural incongruence between the patient and the healthcare provider in this respect.

Health research done in the South African context has also suggested high levels of patient dissatisfaction and feelings of fear, mistrust, confusion and disempowerment regarding medical conditions and their treatment, as evidenced by previous studies in this area (Burkett, 2012; Penn, Watermeyer, & Evans, 2011; Watermeyer, 2008). There is a large corpus of literature which has proposed that patients' attitudes towards their medical condition and treatment are influenced by the way in which healthcare professionals communicate or deliver health-related information to them. For example, Haskard-Zolnierek and DiMatteo (2009) documented a 19% higher risk of non-adherence to treatment amongst patients who received poor communication from healthcare workers. This theoretical stance holds significant implications for the communication training and practices of healthcare professional.

A previous study by Burkett (2012) suggests the truthfulness of this theoretical stance. It suggested that poor communication practices in the context of GDM are leading to patient dissatisfaction and negative attitudes towards their condition and its treatment. These findings form the rationale for the proposed study, in that more information regarding the

communication practices in the context of GDM is required, so that the exact barriers and contributors to successful communication may be identified. The proposed study will thus build on the previous one. It is predicted that clear delineation of barriers and contributors to successful communication practices at the clinic may inform communication training guidelines and workshops for nurses which will allow for improved nurse-patient communication.

This study forms the initial step in working towards improving communication and overall practice at the GDM clinic, and exploring the possible link between communication practices and patients' attitudes towards their condition. This link has not yet been considered in health communication studies related to GDM, particularly in the South African context. It will thus give rise to new ideas and add to theory and clinical practice in a new sector of the South African healthcare system, which is in need of increased consideration, given its rising prevalence and serious health consequences.

This dissertation is presented in chapters, as follows:

**Chapter 2** presents a detailed review of the literature which relates to the critical constructs of this research study. This chapter provides the reader with important background information which is of relevance to the research findings and discussion presented later on.

**Chapter 3** describes and discusses the methods used to collect and analyse data during this project. Theoretical background, procedures and justification for the methods selected are provided. A detailed consideration of rigour and the ethical aspects of the project are also provided.

**Chapter 4** offers a presentation of the results of this study. The results are presented in conjunction with illustrative data extracts. Results are briefly discussed and compared to existing literature to introduce the reader to the most salient aspects of the study.

**Chapter 5** presents a comprehensive discussion of the most salient issues which emerged from the results of the study. These issues are discussed in detail in conjunction with a variety of existing literature. This discussion leads on to a description of implications of the study overall. These implications relates to practice, future research, policy and theory.

**Chapter 6** forms the conclusion of this dissertation. The author's methodological reflection is offered together with concluding comments and an emphasis on the way forward in this area of research.

## **CHAPTER 2: LITERATURE REVIEW**

This chapter provides a detailed consideration of aspects that are central to this study and understanding its results which are presented and discussed in chapters three and four. It begins by exploring the effects of communication on patients' health. It then goes on to discuss issues pertinent to comprehending the South African healthcare context, including the public health sector, diversity, socio-political factors, the burden of disease, stigma, information-giving and the role of the nurse. A consideration of empowerment and lifeworld are also provided. The chapter goes on to introduce the field of health communication and the communication challenges in the field of GDM in South Africa.

#### **Communication: An important determinant of health**

It has been suggested that patients' treatment-seeking behaviour, adherence and uptake of treatment recommendations and follow-up care are directly linked to information delivery and the social interaction of patients and healthcare workers within the health-care system (Hjelm et al., 2008). There have been a number of studies conducted related to the determinants of health. A number of these have suggested that the interactive aspects of the healthcare interaction have a significant effect on patients' treatment adherence, satisfaction levels and health outcomes. Some of these studies are highlighted below.

There is a plethora of literature that links increased treatment adherence and good health outcomes with improved patient communication and counselling (Falvo, 2011; Haskard

Zolnierek, & DiMatteo, 2009; Loh, Leonhart, Wills, Simon & Härter, 2007). Patients' perceptions and attitudes towards their condition are directly associated with the manner in which information is delivered to them in the medical setting (Hjelm et al., 2008). Various studies have demonstrated this link (Thompson & McCabe, 2012; Bultman & Svarstad, 2000; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Penn, Watermeyer, & Evans, 2011; Watermeyer & Penn, 2009a). Treatment adherence has been directly linked with factors specific to communication, such as patient involvement in decision-making, verbal and nonverbal encouragement (Haskard Zolnierek & DiMatteo, 2009), the development of trust, empathy, self-efficacy and mutual understanding (Street, Makoul, Arora, & Epstein, 2009). Even in the field of type 2 diabetes, medical professionals have perceived effective communication to be a predictor of treatment adherence (Wens, Vermiere, Van Royen, Sabbe, & Denekens, 2005).

A further determinant of patient health specifically in patients who have diabetes has been found to be clinician sensitivity to patient readiness when communicating the effects of diabetes (Davis, Pope, Mason, Magwood, & Jenkins, 2011). In this study, patients' levels of readiness to hear about various effects of diabetes on their health were predicted by the researcher via the analysis of their communicative utterances. Diabetes healthcare workers thus not only need to demonstrate greater cultural sensitivity, but need to be more aware of patient feelings and verbal cues so as to better identify barriers to treatment and encourage greater patient involvement in the treatment process (Davis et al., 2011).

Whilst most research advocates for a need for communication strategies which empower and involve the patient actively in their treatment, Koenig, Sabee, Wingard, Vandergriff and Olsher (2011), reveal the challenge of finding a balance between medical prescription and patients' desires in providing treatment for diabetes. The authors suggested that medical professionals need to interact in a way such that they medically substantiate the need for treatment and discuss obstacles to management, while simultaneously showing consideration of the patient's reluctance to adhere to treatment recommendations in order to achieve this balance. They suggest that healthcare workers consider patients' lifeworlds and delay the overt discussion of medical treatment methods of diabetes, until patients are less resistant, in order to achieve improved health outcomes. Whilst this relates to the importance of considering patients' lifeworlds, this may form a challenge for many healthcare workers, especially those working under strict time constraints. It is thus important that research be conducted to devise strategies to allow healthcare workers to provide balanced and effective management that is sensitive to patient needs.

Ethically-based clinical practice is entrenched in the examination and constant revision of health communication practices (Watermeyer & Penn, 2008). It is thus imperative that research continue to be done on the link between communication and patient health. Research findings should be used to improve health practices by changing patterns of communication and social behaviour within the healthcare context.

#### The South African healthcare context

#### The public healthcare sector

South Africa's healthcare services are split into two separate sectors, namely the private and the public sectors. The private sector consists of small facilities and businesses, which aim to profit and make healthcare services available to individuals who possess medical aid. The public sector, alternatively, includes government-run healthcare facilities which aim to serve individuals of a lower socioeconomic status who do not have medical aid (Mateus, Allen-Ile, & Iwu, 2014).

It is interesting to note that the population of South Africa served by the public or government health sector amounts to 82%. However, the government sector only accounts for 40% of the country's health expenditure. Furthermore, government healthcare services in South Africa are commonly found to be inefficient, inaccessible and unaffordable due to their use and allocation of appropriate resources. The private sector, on the other hand, is commonly noted to offer outstanding healthcare services and facilities by international standards (Pillay, 2009). Coovadia, Jewkes, Barron, Sanders, and McIntryre (2009) further highlight that despite comprehensive policies the public health sector in South Africa has been ruined by ineffective leadership, poor management and a lack of implementation.

In addition to the lack of resources, the public health sector in South Africa faces a decline in staffing. In 2006, over five thousand staff vacancies were noted within the public sector (Health Systems Trust, 2007). Between 2005 and 2007, approximately 40% of the jobs

advertised in weekly South African newspapers were for professionals in nursing and midwifery (Wildschut & Mqolozana, 2008). This poses a major challenge to government-run healthcare facilities nationwide.

The information provided above makes it clear that increased attention needs to be given to the public sector of the South African healthcare system. Such attention may begin in the form of research, so that further evidence can be generated to motivate for increased resource allocation and funding within the public healthcare sector, in order to improve patient care.

#### **Diversity and intercultural communication**

Differences in culture, language and education are amongst the most significant barriers to achieving healthcare that is of a high standard, as patients are often rendered vulnerable in such situations (Schyve, 2007; Saha & Fernandez, 2007). South Africa forms a unique healthcare context, where interactions take place between individuals of various cultural and linguistic backgrounds (Penn, 2007).

The effect of dual consultation is also of relevance in discussing the cultural and linguistic diversity of South Africa. Dual consultation may be defined as the co-existence of two approaches to medical treatment, commonly the biomedical approach and an additional medical approach, such as traditional medicine (Shih, Su, Liao & Lin, 2010). Dual consultation has been found to be prominent in the South African health care context

(Cocks & Dold, 2000; Gilbert, 2004). This augments the likelihood of cross-cultural communication barriers between patients and clinicians in the South African context, and thus justifies the need for further research in contexts where such diversity exists.

Diversity makes communication breakdowns more likely (Van Wieringen, Harmsen, & Bruijnzeels, 2002). Hence, whilst South Africa offers a rich and diverse background in terms of language, culture and tradition, such diversity presents a challenge to successful and effective communicative interactions. This occurs particularly often in the healthcare setting, where interactions frequently occur between patients and clinicians that are of differing cultural and linguistic backgrounds. This may lead to gaps in patients' understanding regarding their health condition, low levels of satisfaction and an overall negative experience of living with the health condition (Penn, 2007).

Cross-linguistic and cross-cultural differences are commonly overcome in South Africa, via the use of an ad hoc interpreter or mediator. Data indicates that as many as 80% of interactions between clinicians and patients are facilitated by an additional party (Penn, 2007). However, communication may still form a challenge as a result of terminology and cultural issues related to interpreting meaning across languages.

Cultural difference further complicates the health communication process; in that patients usually construct perceptions of their medical condition and its treatment through their cultural beliefs (Falvo, 2011). South Africa's linguistic and cultural diversity may thus give

rise to varying thoughts and ideas regarding illness which diverge from traditional biomedical theory (Penn, Watermeyer, MacDonald & Moabelo, 2010). The existence of various cultures and languages in South Africa highlights a caveat, that even in healthcare settings where clinicians are able to speak multiple languages; meaning may still be lost in cultural and linguistic mismatch.

Previous literature has been published on the elements that form effective intercultural existence or intercultural competence. Resourcefulness, intellectual inquisitiveness, extraordinary stability, inner security and appreciation for all cultures are among some of the earlier characteristics that were hypothesised to be associated with intercultural efficacy (Cleveland, Mangone & Adams, 1960; Gardner, 1962; Kleinjans, 1972). Hammer, Gudykunst and Wiseman (1978) later began to derive the elements that facilitate intercultural effectiveness. Similar elements were delineated in the study by Abe and Wiseman (1983) that took place in a different cultural context. Trubisky, Ting-Toomey and Lin (1991) further supported the correlation between communication style and intercultural efficacy by showing that participants of different cultures used differing styles of conflict-communication.

The link between communication and intercultural competence has since been studied more recently. Ulrey and Amason (2001) studied the link between cultural sensitivity, anxiety levels and intercultural communication efficacy. Van Wierengen, Harmsen, and Bruijnzeels (2002), also conducted research on the communication barriers that exist

between doctors and patients of an ethnic-minority and found that good rapport formed the basis of shared understanding between doctors and non-native patients. Gibson and Zhong (2005) found that both patients and medical providers associate good intercultural communication with empathy. Empathy was found to be a quality that was associated with putting oneself in patients' shoes, and being a skilled listener who is knowledgeable, motivated and an effective communicator. A specific style of communication was thus associated with intercultural communication competence. This highlights the potential of communication practices in contexts where cultural diversity exists, such as South Africa.

There has been a widely acknowledged need for further research and understanding of patients' cultural beliefs both nationally and internationally (Bradley & Puoane, 2007; Carolan, Steele, & Margetts, 2010; Haque, Hayden Emerson, Dennison, Navsa, & Levitt, 2005; Hjelm & Mufunda, 2010; Hughes, Puoane, & Bradley, 2006). An American study noted that racial and ethnic differences between doctors and patients yielded lower levels of patient centred communication and increased dominance by doctors in patient-doctor interactions (Johnson, Roter, Powe, & Cooper, 2004). However, no literature, other than that documented by Burkett (2012) has explored the cross-cultural and cross-linguistic aspects of GDM in South Africa and the effect of such aspects on the communication processes specifically.

#### Socio-political history of South Africa and its effect on healthcare

An additional factor to consider in understanding the South African healthcare context is the socio-political history of the country. Apartheid is a system of separation according to race, which was enforced legislatively in South Africa between 1948 and 1994, under which the rights and freedom of the South African black majority was controlled by the Afrikaner minority, who were the government during this time (MacDonald, 2006).

The implementation of apartheid resulted in a number of inequities within the healthcare context, which included the allocation of inferior health services and facilities to black people, delays in providing treatment, resource shortages, the removal of public healthcare to prevent healthcare access of black citizens and inhumane treatment of black patients in healthcare facilities (Dhai, 2012; Kautzky & Tollman, 2008; Price, 1986). In addition to this, the apartheid government began to eliminate missionary hospitals who had been delivering health services to the black majority (Coovadia et al., 2009). These inequities and the absence of an effective healthcare system for black South African citizens resulted in a rise of the burden of disease in South Africa (Kautzky, & Tollman, 2008).

The end of apartheid came in 1994 and was followed shortly by the 1996 constitution which promoted a democracy with equal rights and services for all South African citizens in the areas of food, water, social security and healthcare, despite race or ethnic background. However, the healthcare system of democratic South Africa has still been found to face various challenges related to access, poor service delivery, corruption, unethical practice,

inadequate management and inappropriate resource allocation (Dhai, 2012; Harris et al., 2011). Furthermore, it has been found that black South Africans from low socioeconomic backgrounds still face unequal access to healthcare services (Coovadia et al., 2009; Gilson & McIntyre, 2007; Goudge, Russell, Gilson, Gumede, Tollman, & Mills, 2009; Schneider et al., 2010).

This inequity is suggested to be an outcome of the lack of power and the vulnerability of these groups in claiming and making use of new opportunities, which has been entrenched since the apartheid regime. The majority of black South African patients remain disempowered (Frenz & Vega, 2010; Xu et al., 2003). This constitutes a major barrier to healthcare, in that empowerment is strongly linked with patients' self-efficacy, quality of life and physical health (Moattari, Ebrahimi, Sharifi, & Rouzbeh, 2012; Royani, Rayyani, Behnampour, Arab, & Goleij, 2013; Tol et al., 2013). This literature highlights the need to consider the possible effects of South Africa's past and current socio-political situation on patient care and patient characteristics, such as agency, empowerment and participation in the management of their health.

#### The burden of disease and stigma in South Africa

South Africa has a quadruple burden of disease which consists of HIV/AIDS (which accounts for the primary cause of mortality), pre-transitional diseases (including maternal conditions, perinatal conditions, communicable diseases such as TB and nutritional deficiencies), chronic diseases (such as diabetes) and injuries (Bradshaw et al., 2003). Fernandes et al.

(2007) highlight that varying degrees of stigma commonly accompany all health conditions. It is thus likely that high levels of stigma related to health conditions occur within the South African context.

A great deal of attention has been given to HIV/AIDS with regard to South African health research, given its high prevalence of 10.2% of the total population (Statistics South Africa, 2014). High levels of stigma have been documented in relation to the HIV/AIDS epidemic, and have been found to facilitate increased prevalence of the condition and inhibit treatment and prevention strategies (Mahajan, Sayles, Patel, Remien, Ortiz, Szekeres, & Coates, 2008). Diabetes accounts for 1.2% of South Africa's disease burden, as opposed to 39% which is attributed to HIV/AIDS. It is thus not surprising that the majority of research has given the most attention to HIV/AIDS in South Africa, and given less to other prevalent chronic conditions in the South African context.

There has been little documentation of the stigma related to a diagnosis of GDM. Fernandes et al. (2007) found that the stigma associated with diabetes was significantly lower than that associated with HIV/AIDS and epilepsy amongst people living in Brazil. Aikins (2006), however, identified diabetes-related stigma to be similar to that associated with HIV/AIDS in rural and urban Ghanaians living with uncontrolled diabetes, as a result of community responses to chronic conditions. This data suggests that the degree of stigma may be associated with the individual cultural and social beliefs of a community. It also suggests

that other long-term conditions, such as GDM, are no less devastating than HIV/AIDS for some patients, and thus should receive more attention in the forms of research and policy.

The fact that GDM only affects the female gender highlights the issue of gender inequality and the vulnerability of women in the healthcare context. Women have been identified as more vulnerable to chronic conditions in South Africa, particularly to HIV/AIDS (Jewkes, Levin and Penn-Kekana, 2003). This highlights the importance of researching the experiences of women within the South African healthcare context, so that evidence-based strategies to empower women and reduce stigma and a sense of vulnerability may be devised.

In addition to stigma and the quadruple burden of disease in South Africa are issues which include scarce health resources, time and staff shortages, lack of training and continuing staff education and a lack of continuity of care (Magobe, Beukes, & Müller, 2010). Time constraints have also been noted in other healthcare contexts, such as the United Kingdom. Brown and Crawford (2011) have highlighted the importance of conserving the caring nature of brief, healthcare interactions in what they term "fast healthcare". These negative working conditions complicate the South African healthcare context further and thus highlight the need for exploring and tailoring communication strategies specifically to this environment.

#### Giving information to patients in South Africa

An important part of communication within the healthcare setting is the way that information is given to patients. The practice of giving the patient information has in fact been documented as one of the most important communicative duties of the healthcare worker (Street, 1991). Effective information-giving has been linked with improved patient outcomes, including satisfaction and health (Maly, Bourque & Engerhardt, 1999). Street (1991) noted that the communicative styles of patients and healthcare workers had a direct effect on how informative healthcare interactions were for patients. Specific links have also been noted between how information is given to patients and patients' race, ethnicity, level of education and age (Simonoff, Graham, & Gordon, 2006). This may cause disparities in how much information different patients receive about their condition and how they understand it. Hence, various methods of educating patients or giving information have been explored in research. Some of these are described below in relation to diabetes.

Individual patient education is commonly adopted as a method of teaching patients about diabetes. It involves one-on-one, face-to-face interaction between a healthcare worker and patient, in which the patient is given information about his or her condition. Duke, Colaguiri, and Colagiuri (2009) noted individual education to be more effective than what the authors termed 'usual diabetes care' (which might have consisted of regular medical check-ups and education via pamphlets and visual aids), as it appeared to have a more positive effect on glycaemic control and on patients' knowledge, and self-care in certain cases.

However, a number of recent studies have suggested the success of group and peer education programmes (Deakin, McShane, Cade, & Williams, 2005; Franz, Reader, & Monk, 2002). In fact, certain authors have found group based education to be more effective than individual education and usual patient care (Plante, Lobato, & Engel, 2001; Rickheim, Weaver, Flader, & Kendall, 2002). Having noted the effectiveness of group education a number of researchers have attempted this method of patient education in South Africa. Serfontein and Mash (2013) found that group education for diabetes in South Africa had a positive effect on patients' reported health outcomes, recall and understanding of information. However, a number of studies which have looked at group education in the South African context have noted a number of limitations of the application of group education in this context. These include space and resource shortages, difficulties with patient attendance and the training of healthcare workers to run the groups (Botes, Majikela- Dlangamandla, & Mash, 2013; Mash et al., 2014).

Peer education has also been given attention as a method of educating patients with chronic conditions in South Africa. During peer education, patients receive information from an individual who has experienced the same diagnosis as him or her. Peer education has been documented as an effective and cost-efficient method of educating patients, and has in fact been noted as an effective and ideal model in diabetes care (Liu et al., 2014; Philis-Tsimikas, Fortmann, Lleva-Ocana, Walker & Gallo, 2011; Thom et al., 2013). These studies suggested that peer education positively affected glycaemic control and appeared to form a cost-effective method of educating patients. Fisher et al. (2012) found peer education to be effective in the context of diabetes education in South Africa. However, other authors have

documented that peer education is only discreetly effective at influencing patient behaviour and is in need of further study in developing countries like South Africa (Medley, Kennedy, O'Reilly, & Sweat, 2009; Sloan & Myers, 2005). Stokken (2009) outlined that a "patient-educated patient" may be successful or detrimental (in the event that the patient provides incorrect information or communicates poorly) to the treatment process. This summarises the above argument and suggests that education programmes need to be applied according to the setting and its individual characteristics and patient requirements.

Information-giving is a vital aspect of patient communication. It is suggested that certain methods of information giving may be better suited to one environment than another and the literature provided above emphasises the need for research to consider the efficacy of current information giving practices and generate more effective approaches to maximise patient outcomes and the use of available resources.

#### The nurse in the South African healthcare context

Nurses have been documented as playing a vital role in the South African healthcare system, constituting the largest component of the health service (van der Colff & Rothmann, 2009). In recent years the demand for nurses has grown extensively as a result of the increasing prevalence of health conditions such as HIV/AIDS and the increase in the emigration of nurses overseas (Hall, 2004). Simultaneously, the shortage of nurses has been documented to be on the rise in developing and developed countries (Alonso-Garbayo & Maben, 2009; Kuehn, 2007). In South Africa, studies have shown that there are 437 nurses for every

100000 people and that in 2008, the nurse to population ratio was 212806:48787300 (Mateus, Allen-Ile, & Iwu, 2014). Furthermore, Breier (2008) noted that the largest portion of job vacancies among health professionals in South Africa between 2004 and 2007 was accounted for by midwifery and nursing professionals.

The roles of the nurse in the South African healthcare context are numerous. Seboni et al. (2013) documented the perceived multiple roles which are taken on by the nurse within the Sub-Saharan African health framework. Consensus was reached on the following roles:

- Caring for patients
- Respecting patients
- Evaluating and observing patients' conditions
- Counselling of the patient and family
- Educating patients on health issues
- Overseeing and maintaining the place of medical care
- Advocating for patients, policies and resources
- Providing care in emergency situations
- Collaborating with other individuals in the medical team
- Taking on the role as a midwife for mothers and infants

In addition to this list, nurses in the South African context are expected to work under a variety of difficult conditions, including work overload, emotional exhaustion, lack of incentives, lack of opportunity for professional growth and promotion, inadequately equipped facilities and staff and resource shortages. These are likely to result in low levels of

job satisfaction (Hall, 2004; Pietersen, 2005). Based on these findings, it is no wonder that nurses in South Africa have been found to experience high levels of job dissatisfaction, stress, anxiety and burnout associated with job demands and a lack of support from the organisations that they work for (Khamisa, Peltzer, & Oldenburg, 2013; van der Colff & Rothmann, 2009).

The duties which nurses are perceived to fill within Sub-Saharan Africa are both extensive and pertinent to effective health care. Nurses in South Africa also deal with difficult circumstances related to the lack of support and copious workplace demands and inadequacies. This suggests that nurses may form a valuable source of information related to difficulties encountered in the healthcare setting recommendations for the future, especially where the nurses are the primary communicators with patients, as at the GDM clinic. Furthermore, this literature justifies the inclusion of nurses in healthcare research, as occupational stress in nurses has been noted to have a negative impact on their service delivery, performance, efficacy and behaviour in the work environment, amongst other things (Khamisa, Peltzer, & Oldenburg, 2013; Rothmann, 2003; van der Colff & Rothmann, 2009).

In addition to the difficulties experienced by nurses within the healthcare context, is the issue of skill shortages amongst nurses, particularly with regards to diabetes. Suboptimal knowledge and skills have been documented among nurses (El-Deirawi & Zurraikat, 2001). This is of great importance to consider as healthcare workers' knowledge, attitudes, beliefs

and skills related to diabetes will affect how it is managed, as well as patients' understanding of the condition and its treatment (Nam, Chesla, Stotts, Kroon, & Janson, 2011).

Hence, it is evident that nurses face challenging circumstances in their everyday work environment. It is, however, interesting to note that Seedat (2013) found that nurses are receptive and motivated to receive communication training despite poor working conditions. This suggests the importance of including nurses in healthcare research and ensuring the continuity of training amongst nurses, as they appear to form resilient figures in the complex and difficult South African healthcare context.

## **Empowerment**

Empowerment in the healthcare context has been described as a paradigm shift from the healthcare worker being in charge to a collaborative relationship in which the patient takes responsibility for the self-management of their condition and treatment is patient-centred (Anderson & Funnell, 2005). The importance of empowerment has long been emphasised, particularly in the management of diabetes (Anderson & Funnell, 2010; Anderson & Funnell, 2005; Funnell et al., 1991).

Empowerment has been found to facilitate a number of positive effects in diabetes care, including improved self-care related to glycaemic control, diet, exercise (Corbett, 1999;

Johnston-Brooks, Lewis, & Garg, 2002). It has been stated that in order for patients to take responsibility for their management, they require a clear understanding of their own needs, goals and values, and also require adequate knowledge about the condition and its treatment (Sigurdardottir & Jonsdottir, 2008). The emphasis on the importance of adequate knowledge brings to mind the importance of how information is communicated to patients, as this is bound to affect their understanding of their health condition.

In South Africa, patients have been found to lack empowerment in healthcare interactions and in decision-making related to treatment (Patel & Dowse, 2013). A number of causes of this exist. As mentioned previously, the socio-political history of South Africa is a likely contributor towards the disempowered demeanour of many patients in the public healthcare sector today. The harsh laws of apartheid which imposed inequity on patients still contribute to the lack of access and empowerment amongst patients in the public health sector (Gilson & McIntyre, 2007; Harris et al., 2011). The cultural and linguistic differences which exist between patients and healthcare workers are further possible contributors to the lack of empowerment amongst patients (Burnette & Kickett, 2009). Given the diverse range of languages and cultures in South Africa, it is thus not surprising that many patients are passive and disempowered.

In discussing barriers to patient power and empowerment in South Africa, the issue of power relations in healthcare interactions is also raised. The power relationship appears to be affected by the role that has been adopted by the nurse. Henderson (2003) found a

significant power imbalance within nurse-patient relationships resulting in feelings of fear among patients. Nurses felt a sense of power over patients as a result of being more knowledgeable than patients and as a result of their desire to maintain power within the health care setting. It has been suggested that nurses contribute messages of power in that they provide the information and select the topics of discussion in patient interactions (Kettunen, Poskiparta, & Gerlander, 2002). This highlights the importance of studying nurse communication and behaviour patterns, as Shattell (2004) states that interactions and rapport between patients and nurses may have a significant effect on how patients experience healthcare and on patients' health outcomes.

In a US study, 98.2% of certified diabetes educators selected empowerment as the most useful approach in caring for patients with diabetes, suggesting that it is well-understood and applied in practice (Funnell et al., 2006). However, Anderson and Funnell (2010) state that this is not the case and the phenomenon of empowerment is still misunderstood by many healthcare professionals worldwide. Some of the reasons for limited understanding of empowerment among healthcare workers have been documented. It has been suggested that healthcare workers have taken the empowerment paradigm and have simply converted it into a method of fostering patients' adherence, highlighting that the route of misunderstanding or inaccurate application lies within the healthcare provider's personal beliefs about patient care (Anderson & Funnell, 2005). Other reasons include the lengthy amount of time that it takes for a shift in practice to be adopted, perceptions that an empowerment approach is not time-efficient, the difficulty of changing the paradigm in

which a professional was trained and the perceptions of the empowerment approach as being the latest "politically correct" term to use in diabetes care (Anderson & Funnell, 2005)

In addition to fostering patient empowerment, the importance of empowered healthcare workers has also been documented, as empowerment has been noted as a prerequisite to working effectively with other professionals in the healthcare setting as well as their ability to manage their work, cope effectively and use resources to render high quality patient care (Laschinger, Finegan, Shamian, & Wilk, 2001). This further justifies the generation of research in the areas of health communication and its effect on patient and staff empowerment and efficacy within the healthcare setting.

## <u>Lifeworld</u>

In 1984, Mishler studied medical interactions between doctors and patients. From his findings he generated the theory that doctors and patients in fact function within two separate types of communication and thought. The first was named the "technical rational", and involved the voice of medicine. This was hypothesised to be the voice of the doctor, and hence be scientific in nature. The other was called the "lifeworld". This was described as the voice of the patient, which allowed the patient to tell their story and share their personal experiences and emotions. It was further theorised that when the doctor and patient communicate in each of their separate ways, this may lead to patients feeling uncertain, isolated and even disregarded during their interactions with doctors. It is suggested that Mishler's work helped lead to the inclusion of humanities into the medical field.

Stewart et al. (2003) demonstrates that the voice of medicine may involves scientific questions such as 'Where does it hurt?' and 'what makes it better or worse?'. This voice does not facilitate emotional connection. The voice of the lifeworld, alternatively, may involve questions such as 'What do you think it is?' or 'How do you think I can help you?'. It is less scientific and focuses on establishing an understanding of the patient's concerns and experiences related to the condition within his or her everyday life.

Barry, Stevenson, Britten, Barber and Bradley (2001) noted four different patterns of communication. "Strictly medicine" was the first, in which both patient and doctor used the voice of medicine. This was found to be effective for acute physical problems. "Mutual lifeworld" was identified as the second, in which doctors and patients communicated in the voice of the lifeworld allowing patients to feel acknowledged as individuals, hence being effective for both physical and psychological difficulties. The third and fourth patterns, namely "Lifeworld ignored" and "Lifeworld blocked", occurred when patients made use of the voice of the lifeworld but doctors ignored or blocked this by using the voice of medicine, hence resulting in poor outcomes especially in the event of chronic physical illnesses or problems.

The importance of the patients' lifeworld has since been suggested to be a pivotal aspect in the application of true patient-centred care and the prevention of communication breakdowns which result from cultural mismatch (Dahlberg, Todres, & Galvin, 2009; Lo, 2010). There has been work done which looks at the lifeworld transition of patients with

diabetes and GDM specifically, such as that by Kneck (2011). The lifeworld perspective has also been used to study patients' and healthcare workers experiences of diabetes (Berg & Hotikasalo, 2000; Hornsten, 2004; Rasmussen et al., 2013). The concept of the "healthworld" has also been documented. It is described as an area of the lifeworld which encompasses complete well-being as its primary objective, and hence has a desire to recover anything that was lost (Germond & Cochrane, 2010). However, there appears to be no published work available on lifeworld or healthworld issues amongst women with GDM in South Africa specifically. This highlights the need for research in this area, as South Africa constitutes a unique environment in terms of social, cultural and linguistic factors.

#### **Health communication**

Health communication has been defined holistically by Schiavo (2007) as a multidisciplinary field in which information related to health is shared in order to impact on, involve and support individuals, groups or communities so as to promote, maintain or implement a specific practice or policy that will advance health outcomes. Health communication has emerged as a valuable application of social and behavioural sciences within the healthcare context, where social and communicative practices are examined to enhance service delivery within the healthcare setting (Kreps, Bonaguro, & Query, 1998).

Earlier models of healthcare focused on the scientific practice of medicine and lacked acknowledgement of the patient as a person and the importance of the social, humanistic aspects of the patient-provider interaction and relationship. A number of changes, however,

lead to a shift from the medical model of medicine to the social model, which considered the importance of communication and information delivery within the healthcare context (du Pré, 2006). One influential aspect was research which emerged within the fields of sociology and psychology, which linked patients' physical and psychological health with the communication that they received and the relationships that they had with healthcare workers (Kreps, Bonaguro, & Query, 1998). In the 1970s and 1980s, various associations implemented divisions dedicated to health communication, which became outlets for health communication research. This led to the development of health communication journals and hence the expansion of the field to what it is today (Thompson, 2014).

Investigating and improving the way in which health information is delivered between individuals or groups is of value, as it has been found that patients are often more preoccupied with how much healthcare workers care, as opposed to how much knowledge they have (Stein, Nagy, & Jacobs, 1998). This finding justifies the need for research related to the communication methods of health information, and not just the knowledge and academic skill of healthcare workers when communicating with patients (McDonald, Tiley, & Havstad, 1999).

The concept of the healthcare worker-patient relationship as being therapeutic has been highlighted in previous literature (DiMatteo, 1994; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004; Street, Makoul, Arora, & Epstein, 2009) and demonstrates the significance of communication practices in influencing patients' attitudes towards and experiences of living

with a medical condition. The patient-provider relationship or rapport and continuity of care have also been highlighted as predictors of patient outcomes in healthcare (Green et al., 2008). According to Leach (2005) healthcare worker behaviours associated with relationship building have been found to include trust, confidentiality, active listening, eye contact and being friendly and caring. It was noted that such behaviours are suggested to be linked with patient satisfaction, treatment adherence and positive patient outcomes. The importance of considering the nonverbal behaviours of healthcare workers in studying relationship building has been highlighted by a number of authors (Duggan & Parrott, 2001; Tickle-Degnen & Rosenthal, 1990).

In an interview with Moore (2007), Ken Moritsugu states that communication is at the centre of health services within the public sector, as the way in which medical information is communicated to patients can advance or essentially hamper their health outcomes. It is felt that this statement holds particular relevance to the South African health context, where cross-linguistic and cross-cultural interactions make communication breakdown between clinicians and patients a frequent occurrence.

Health communication has been applied in the study of various medical conditions, to better understand patient-clinician interactions, identify barriers to successful health outcomes and achieve improved treatment adherence (Auer, Sarol Jr, Tanner, & Weiss, 2000; Epstein & Street, 2007; Forrest et al., 2003; Lerman et al., 1993; Moore, Wilkinson, & Rivera Mercado, 2004; Myhre & Flora, 2000; Peltzer & Seoka, 2004; Penn, Watermeyer, &

Evans, 2011; Penn, Watermeyer, MacDonald, & Moabelo, 2010; Pieterse, van Dulmen, Ausems, Beemer, & Bensing, 2005; Steyn, van der Merwe, Dick, Borcherds, & Wilding, 1997; Watermeyer & Penn, 2008; Watermeyer & Penn, 2009a).

A number of qualitative South African studies have specifically highlighted the positive outcomes surrounding care and communication in the context of chronic health conditions, particularly HIV/AIDS. For example, the value of appropriate communication strategies has been noted in the informed consent procedure related to HIV/AIDS (Watermeyer & Penn, 2008), as well as in achieving patient understanding (Watermeyer & Penn, 2009a). Penn, Watermeyer and Evans (2011) also linked communication practices amongst pharmacists to treatment efficacy in HIV/AIDS.

Chronic conditions pose a number of challenges to patient care and treatment. It is necessary that some of these challenges be briefly discussed to provide insight into the experience of living with a chronic condition.

Wagner et al. (2001) highlight the following challenges in caring for patients who have chronic conditions: lifestyle changes and the necessary adjustments surrounding complex treatment regimens, reduced quality of life, disabling symptoms and health effects, emotional difficulties related to lifestyle changes, treatment and acceptance of the condition and the social constraints imposed by the chronic condition. These authors further emphasise that effective care for patients with chronic conditions is facilitated by

appropriate communicative interactions and continuity of care between these patients and healthcare workers. This suggests, again, that communication is at the core of achieving high quality medical care.

The discussion above highlights the benefits of applying health communication within the medical setting, in order to achieve care that is patient centred and that promotes positive health outcomes. This is of particular relevance, given the numerous challenges associated with chronic conditions.

# **Communication challenges in GDM care in South Africa**

It is predicted that the prevalence of non-communicable conditions, such as GDM, will rise rapidly in Sub-Saharan Africa (Gill, Mbanya, Ramaiya, & Tesfaye, 2009). It is thus important that research be done on ways of improving the health outcomes of individuals with non-communicable conditions.

There have been minimal South African data published on the topic of GDM. As evidenced by the literature above, all of the available South African research has focused primarily on the quantitative aspects of GDM. Little attention has been given to the qualitative aspects of the condition. Studies, such as that by Buchanan and Xiang (2005), Linné, Barkeling and Rössner (2002) and Ranheim, et al. (2004), all centre on the physiological aspects of GDM and do not consider the humanistic reality of the condition.

Whilst there is a paucity of research on the qualitative aspects of GDM, there is a larger body of qualitative research that has been done related to type 2 diabetes. Haque, Hayden Emerson, Dennison, Navsa & Levitt (2005) investigated the barriers to initiating insulin therapy and the reasons for poor glycaemic control in South Africans with type 2 diabetes. Whilst the study showed consideration of the qualitative aspects of diabetes care (such as clinician-patient communication, patient perceptions and cultural mismatch), it is felt that it was too rigid in its correlations. For example, the study simply attributed patients' consultation with traditional healers to poor treatment adherence and suggested that consultation with traditional healers was a breach of trust in the clinician-patient relationship. It also relied on a restricted sample population, in that data were only gathered from medical officers or doctors, perhaps rendering certain findings (particularly those related to patient barriers) questionable, as they are not validated patient reports. The study recommends improved patient-centred care by involving healthcare professionals in the development of guidelines and workshops, however disregards the valuable input that patients may have to offer in formulating the guidelines and workshops. This contradicts the term 'patient-centred'.

In another South African study related to type 2 diabetes, Hughes, Puoane and Bradley (2006) evaluated the knowledge, attitudes and beliefs of community healthcare workers regarding diabetes care. Whilst this study posited the valuable role that the community healthcare workers have to play in assisting with diabetes care in large populations of lower socioeconomic background, it also relied heavily on community healthcare workers' reports of patients' beliefs and understanding. No patients were actually involved in the study. The

study also only included participants of the Xhosa culture, suggesting that results are not necessarily generalisable to other cultures.

Subsequent to the study discussed above was that of Bradley and Puoane (2007). This study examined community healthcare workers' and community members' beliefs about hypertension and diabetes and implemented a training programme on living with diabetes. This sample of this study was broader in scope, however, it is felt that the training programme did not focus sufficiently on communication practices.

One of the only qualitative studies done on GDM in South Africa (Burkett, 2012) demonstrated the perceptions and beliefs of patients with GDM regarding their condition. Results of the study yielded high levels of patient distress and frustration and negative views towards the communication and education processes carried out at the site. Central to the issue of communication inadequacy were patients' reports of discomfort, fear and mistrust when discussing their condition with healthcare workers at the site, as well as perceptions that healthcare workers are "too busy" to spend time on education and counselling. Patients also reported confusion with regards to the roles of healthcare workers in the medical setting, insufficient informative counselling, as well as inadequate provisions for English Second Language (ESL) patients. The scope of the sample was, however, restricted in that only patients were included in the study.

This study thus aims to build on that by Burkett (2012) by including both patients and nurses in the sample population, to get a more holistic view of communication in the context of GDM. It will also make use of various data sources and methods of data collection and analysis to allow for increased credibility and rigor. It also shifts focus directly to the communication practices of patients and nurses, to achieve a more accurate indication of how these may be influencing patient care.

#### **Chapter summary**

This chapter has discussed issues relevant to this research study, in order to provide the reader with the necessary background information to understand results and issues discussed later in this dissertation. The multidimensional nature and the uniqueness of the South African healthcare context have been emphasised. The area of health communication has also been introduced. In discussing health communication research that has been conducted in South Africa, this chapter provides evidence that little qualitative work has been done related to GDM specifically, highlighting the need for projects such as this one.

# **CHAPTER 3: METHODOLOGY**

This chapter presents a discussion of the research design and methods used to gather and analyse data during this study. The chapter begins by providing background information about the site, as well as the aims and objectives of the study. It then presents a detailed description of the methods used to collect and analyse the data, including sampling methods and descriptions of the participant population. The chapter concludes with a consideration of rigour and ethical issues which arose during the study.

## <u>Site</u>

#### **Background**

The study was conducted at a GDM clinic located in a large tertiary academic hospital in Gauteng, which serves as a primary referral hospital for vast areas inside and outside of South Africa. The hospital plays an important role in training various medical professionals within the field of medicine and healthcare. The majority of patients served by the hospital 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 as suggested by statistics which note the unemployment rate to be 25% overall and households without income to be at 16.8% (Statistics South Africa, 2011).

#### **GDM** clinic

The GDM clinic is one of the few clinics of its kind in Gauteng. The GDM clinic is an in-patient and out-patient clinic that is run from one of the general wards within the maternity/obstetrics department. The in-patient clinic serves women who are pregnant and have diabetes (either GDM, type 1 or type 2 diabetes). The in-patient ward consists of 5 cubicles, one of which (cubicle A) is allocated to patients who are pregnant and have diabetes and on the rare occasion other endocrine-related conditions during pregnancy. The other cubicles house patients who present with other maternal conditions, such maternal hypertension. When cubicle A is filled to capacity, patients who are pregnant and have diabetes are placed in other cubicles in the ward (usually cubicle B).

The out-patient clinic is open to women who have diabetes specifically, but also women who are pregnant and present with other endocrine conditions, such as thyroid conditions. Patients generally attend the clinic as in-patients when they are newly diagnosed with diabetes or GDM during pregnancy or when they are delivering their babies. Out-patients attend the clinic on a weekly or fortnightly basis. The out-patients are seen by an obstetrician, physician, paediatrician and diabetes nurse educators. Blood pressure monitoring, weight monitoring, blood glucose checks and urine checks are all done at each of these visits. Whilst statistics related to adherence (to medication and lifestyle changes) are not available, a 15.4% reduction of the perinatal mortality was documented after the introduction of specialised care for GDM at the clinic (Huddle, 2005). The figure below (Figure 1) shows the process that each patient goes through, from diagnosis to delivery.

Figure 1. Patients' journey through the GDM clinic: From diagnosis to delivery

Diagnosis

 Patients are referred to the GDM clinic for testing. Patients are admitted into the GDM ward and tested for GDM. If diagnosed with GDM, patients are educated about the condition and taught to take treatment and monitor glucose levels

Outpatient  Once patients' glucose levels are found to be controlled, patients are discharged and attend the GDM clinic fortnighly up to 31 weeks of gestation and weekly between 32 and 38 weeks of gestation

Delivery

 At 38 weeks of gestation, patients are re-admitted for delivery which could take place naturally or via Caesarean section depending of maternal and foetal health

Post delivery • After delivery, patients are required to attend the GDM clinic for a diagnositic test 6 weeks post delivery to determine whether the GDM has cleared or become type 2 diabetes

Future

• If patients are found to have developed type 2 diabetes, they are referred to the separate diabetes school at the site for further counselling and monitoring. If patients do not present with diabetes 6 weeks poost delivery they are discharged from the clinic

A detailed ethnographic description of the clinic together and its layout, as well as further detail related to the clinic's diagnostic and treatment protocols are provided in the appendices (Appendices 1 and 2).

#### <u>Aims</u>

The primary aim of this research was to explore the perceptions and practices of nurses and patients with regards to communication at an urban clinic for GDM. Other objectives of the study included:

- To describe the communication practices and interactions occurring between nurses and patients at the GDM clinic.
- To identify inhibitors to and facilitators of effective communication between nurses and patients.
- To describe patients' understanding and attitudes towards GDM and its treatment.
- To gain insight into the training needs of nurses with regards to patient communication and counselling.
- To describe the way that information is given by the nurses.

## Research design

A qualitative framework was adopted, as qualitative data may yield comprehensive information about the practices and experiences of individuals within the healthcare setting and is thus becoming popular in health-related studies (Mays & Pope, 2000).

## Why a qualitative framework?

Qualitative research was initially used as a structured form of scientific investigation in the early nineteen hundreds by social anthropologists and sociologists (Al-Busaidi, 2008). It was only in the 1930s that more attention was given to the role of qualitative research in healthcare in developing counties when the Polela Health Unit was formed in South Africa, to study the health of the South African population using social sciences and statistical methods. This reflected a deeper interest in cultural, socioeconomic and community-

related factors that influence health and showed a greater consideration of individual patients in terms of their individual lives within their communities (Yach, 1992).

Through its application to achieve the benefits stated above, qualitative research has recently become increasingly popular and recognised in the field of health research, particularly with topics that are of a socio-cultural nature. One of the purposes and primary uses of qualitative research is to explore social aspects with a focus on participants' experience (Al-Busaidi, 2008). According to Britten (2011), qualitative research has benefitted health communication research greatly as it has the potential to develop new thoughts and theories by analysing communication as it occurs in realistic situations. Qualitative research has proven its efficacy in health-related topics by its use in numerous projects conducted by the Health Communication Research Unit at the University of the Witwatersrand, including studies in HIV/AIDS and TB. Such studies include those by Penn, Watermeyer, MacDonald and Moabelo (2010); Penn, Watermeyer and Evans (2011); Penn and Watermeyer (2012) and Burkett (2012). It is thus felt that qualitative research best fits the purpose of the proposed study and that with application of various methods to ensure rigour, accurate results will be obtained.

Qualitative research has been criticised for lacking in rigour, in that it is based on subjective opinions that are influenced by researcher bias, and is thus not reproducible. It has also been criticised for a lack of generalisability in that it uses a small sample to generate copious amounts of data (Mays & Pope, 1995). However, Jacelon and O'Dell (2005) state that

qualitative research can be rigorous if the researcher takes various methods to ensure accuracy in the way that the study is reported, consistency of methods used, reliability of the research via an audit trail, a clearly defined theoretical framework that is related to the data and the relevance of the research to the reader and existing knowledge on the topic. Qualitative research has also been described as a means of generalising data from the research setting to other similar natural settings, establishing empathy among readers, and as a unique way of understanding medical conditions, patient perceptions and patient teaching (Jacelon & O'Dell, 2005).

In the study of chronic conditions, similar qualitative methods to those used in this study have been used. For example, Watermeyer (2008) and Evans (2010) have made use of interviews, focus groups and interactional analyses to explore issues related to communication in the area of a chronic condition (HIV/AIDS). These studies both provided pertinent findings and implications for the way that healthcare workers communicate with patients and hence justify the use of similar qualitative methods to explore communication in the area of GDM. Qualitative methods have also been successfully applied in studying patients' perceptions and communication practices in the context of diabetes (Freeman & Loewe, 2000; MacDonald et al., 2013; Parry, Peel, Douglas, & Lawton, 2004)

The data collection and analysis methods used in this study are summarised in the diagram below and briefly discussed thereafter:

Data collection Nurse-patient Patient focus Ethnographic Nurse education observations interviews groups sessions 1. Audio 1. Audio data Written data Raw data notes 2. Written Audio-visual 2. Written notes notes Identification 1. Verbatim 1. Verbatim 1. Verbatim of patterns transcription/transl transcription/transl transcription of salient and trends ation of data ation of data Data analysis segments 2. Thematic 2. Thematic 2. Analysis into analysis analysis facilitators and inhibitors

Figure 2. Methods of data collection and analysis used

Comparison and triangulation of the data

# **Ethnographic observations**

Ethnographic observations were selected for the purpose of this study as they have been documented as a useful way of obtaining data on individuals' beliefs, thoughts and practices and of understanding a particular environment (Reeves, Kuper, & Hodges, 2008). Ethnography is also entrenched in culture and how culture may affect issues surrounding medical conditions (Goodson & Vasar, 2011). The benefit of ethnography in studying healthcare settings has been documented by various authors (Pope, 2005; van der Geest & Finkler, 2004).

# **Focus groups**

Kitzinger (2006) defines a focus group as a semi-structured group interview that places emphasis on discussion and group communication dynamics to yield specific data. Focus

groups were selected as a method of data collection, as focus groups carried out in the healthcare setting form a successful manner of promoting participants' input into care practices and identifying the needs of individuals in a particular environment. Focus groups achieve this through exploring participants' perceptions, ideas, cultural beliefs and practices (Rabiee, 2004).

Focus groups have been criticised for not yielding data that is as deep and rich as that obtained from individual interviews, as participants are generally not as willing to discuss personal thoughts or feelings in a group setting (Hopkins, 2007). However, it was felt that this did not apply to the proposed study, as all of the focus group participants appeared to feel comfortable discussing their personal thoughts and feeling about communication at the GDM clinic. The focus groups thus seemed empowering for participants. Another critique has been that focus group data may be skewed if it is influenced by the personality traits of certain participants in the group, and other participants may feel intimidated and thus not voice their opinions (Hollander, 2004; Krueger & Casey, 2009). The researcher avoided this effect, by maintaining control over the focus group discussion and facilitating fair turntaking in discussions between patients.

## Video recorded education sessions

Video recording was necessary for the purposes of the proposed study, as it allowed for detailed analysis of both audible and visual aspects of the communication or interaction process between nurses and patients during counselling sessions at the GDM clinic. It should

be noted further that video recordings allow for research to identify and analyse a larger variety of phenomena and concepts in analysing interactions (Heath, Hindmarsh, & Luff, 2010). Perhaps one of the reasons for this is the ability of audio-visual recordings to capture non-verbal communication and contextual cues. Non-verbal cues such as gestures, eye gaze and posture provide salient information regarding communicative exchanges. Such cues may indicate speakers' content, turn-taking patterns and emotions (Chen, 2008). Furthermore, Mast (2007) found that nonverbal cues play a crucial role in physician-patient interactions, in that they affect the quality of the communication perceived by the patient translating to patient satisfaction levels. Nonverbal communication thus needs to be considered in studying and analysing the interactions.

Whilst video recordings of interactions are thus effective and of great use in analysing interactions in their entirety, they do, however pose potential harmful effects for participants. These harmful effects are related to the sensitivity of the research topic e.g. videos of patients or other individuals who are vulnerable, participants' anonymity and confidentiality, participants' concerns related to stigmatisation and obtaining informed consent from participants for video recording (Heath, Hindmarsh and Luff, 2010). This is highly relevant to the South African context, where research has documented high levels of stigmatisation associated with health conditions, such as HIV/AIDS, as suggested by Visser, Makin, Vandormael, Sikkema, & Forsyth, (2009). For example, Watermeyer (2008) noted a degree of suspicion in participants as a result of the use of video recordings. The researcher thus ensured that the potential harmful effects of using video recordings were minimised by reassuring the nurses and patients who participated that all recorded data would be kept

completely anonymous and confidential and no one besides the research team (researcher, supervisors and translator) would have access to the videos.

#### **Nurse interviews**

Interviews in qualitative research are aimed at gathering data regarding the interviewees' life experiences and the meanings that they draw from these experiences. Interviews as a method of qualitative inquiry have gained much popularity as they allow researchers to understand social phenomena by drawing on the views and words of individuals based on their life experience (Runswick-Cole, 2011). The semi-structured interview is advantageous as it allows the researcher to gain a comprehensive and detailed idea regarding the topic of study and generally consists of the main research question followed by five to ten questions to gain a deeper insight into the main area of study (DiCicco-Bloom & Crabtree, 2006). Semi-structured interviews are generally based on open-ended questions related to the topic of study. They are useful in that, unlike structured interviews, they allow the researcher to probe specific areas of interest by diverging from the interview questions (Britten, 1995). They also produce large amounts of rich data (Runswick-Cole, 2011).

Interviewing as a method of qualitative research has faced various critiques. The interview has been viewed as highly susceptible to interview bias. Critics have also raised concern regarding the fact that interview data is based on what people say and not on what they actually do. Interviews have also been criticised for being personally invasive, if poorly conducted, and the recording of interviews has been said to have an inhibitory effect on participants' responses (Denscombe, 2010). However, these challenges were overcome in

this study by supplementing interviews with direct observations, by building rapport with participants prior to interviews (during the ethnography) and by ensuring that interviews were conducted in a sensitive manner which upheld participants' confidentiality at all times.

## **Participants**

## Sampling

Participants for the patient focus groups, nurse interviews, video recorded education/counselling sessions and ethnographic observations were gathered via purposive sampling. Guest and Macqueen (2008) describe purposive sampling as the method which allows for the most valuable and relevant data to be collected in qualitative research. Purposive sampling allows the researcher to select participants who possess valuable information and experiences that relate specifically to the topic of study, as participants are selected based on specific characteristics (Polkinghorne, 2005). In this study, the purposive sample was based on the characteristics of having GDM, being at a specific stage of learning about the condition or working as a stationed nurse in the GDM ward or out –patient clinic.

In qualitative research, the sample size is determined by the amount of data obtained. Sampling should be terminated when no new information emerges from the sample (Patton, 2002). The amount of data gathered was thus determined by the level at which redundancy was reached. All participants were invited to participate in the study by the researcher. The diagram below provides a summary of the participants in the study (Figure 3).

Figure 3. Summary of participants who took part in the study

| Ethnographic observations             |      |
|---------------------------------------|------|
| •All clinic staff and patients        |      |
| Patient focus groups                  |      |
| Out-patients diagnosed with GDM       | N=19 |
| Video recorded education sessions     |      |
| •In-patients newly diagnosed with GDM | N=6  |
| Nurse interviews                      |      |
| Nurses working at the GDM clinic      | N=11 |

# **Patient focus groups**

Purposive sampling was used to gather participants for the patient focus groups. Patients were invited to participate in focus groups. The focus groups were open to all patients who attend the GDM clinic as out-patients who were willing to discuss their thoughts and opinions of communication practices at the clinic.

Inclusion criteria for patient focus groups included:

- The potential participant was a female older than eighteen years of age.
- The potential participant had been diagnosed with GDM and was currently pregnant.
- The potential participant was previously admitted as an in-patient at the GDM clinic and currently attended the clinic as an out-patient (It was thus more likely that the patient had been counselled on GDM, its causes, consequences and treatment).
- The potential participant spoke English, Sesotho, isiXhosa, isiZulu or Setswana.

Exclusion criteria for patient focus groups included:

- The potential participant had any impairment (for example, a communication difficulty)
   that would limit their ability to participate in the focus groups.
- The potential participant was fatigued or in an unfit condition to participate in a one to two hour focus group.

The researcher ran four focus groups of approximately six to eight patients each, as suggested by Krueger and Casey (2000). Some of the groups consisted of less than six patients, due to logistical reasons. The patients varied in terms of their ages, gestation, treatment regimens and linguistic backgrounds. All patients were of Black African ethnicity and were able to read. All of the focus groups were conducted in English, except the third focus group which was conducted in isiZulu, Sesotho and isiXhosa. The demographic aspects of the patients who participated in the focus groups are presented below:

Table 2. Participant characteristics for focus group 1

| Participant | Age (years) | Gestation at time of focus group (weeks) | Gestation at diagnosis with GDM (weeks) | Treatment  | Languages<br>(fluent)   |
|-------------|-------------|--|---|------------|---|
| 1           | 39          | 36                                       | 26                                      | Oral       | isiZulu,<br>English   |
| 2           | 31          | 33                                       | 31                                      | Injectable | isiZulu,<br>Sesotho,<br>isiXhosa,<br>English                              |
| 3           | 27          | 24                                       | 12                                      | Injectable | isiXhosa,<br>English  |
| 4           | 24          | 36                                       | 32                                      | Oral       | isiZulu,<br>English   |
| 5           | 35          | 36                                       | 32                                      | Oral       | Sesotho,<br>English   |
| 6           | 33          | 35                                       | Previous<br>pregnancy                   | Injectable | Sesotho,<br>Tshitsonga,<br>Tshivenda,<br>isiXhosa,<br>isiZulu,<br>English |

Table 3. Participant characteristics for focus group 2

| Participant | Age (years) | Gestation at time of focus group (weeks) | Gestation at diagnosis with GDM (weeks) | Treatment  | Languages<br>(Fluent) |
|-------------|-------------|--|---|------------|-----------------------|
| 1           | 35          | 29                                       | 25                                      | Oral       | Sepedi,<br>English    |
| 2           | 40          | 35                                       | 26                                      | Injectable | Sepedi,<br>English    |
| 3           | 29          | 34                                       | 8                                       | Injectable | isiZulu,<br>English   |

Table 4. Participant characteristics for focus group 3

| Participant | Age (years) | Gestation at<br>time of focus<br>group<br>(weeks) | Gestation at diagnosis with GDM (weeks) | Treatment  | Languages<br>(fluent) |
|-------------|-------------|---|---|------------|-----------------------|
| 1           | 41          | 28  | 16                                      | Injectable | isiXhosa              |
| 2           | 37          | 37  | 22                                      | Injectable | Tshivenda,<br>English |
| 3           | 46          | 37  | 20                                      | Oral       | Sesotho               |
| 4           | 38          | 24  | 22                                      | Oral       | Sesotho               |
| 5           | 28          | 24  | 23                                      | Oral       | isiXhosa,<br>English  |
| 6           | 34          | 16  | 12                                      | Injectable | isiZulu               |

Table 5. Participant characteristics for focus group 4

| Participant | Age (years) | Gestation at<br>time of focus<br>group<br>(weeks) | Gestation at diagnosis with GDM (weeks) | Treatment  | Languages<br>(Fluent)   |
|-------------|-------------|---|---|------------|---|
| 1           | 34          | 18  | 8                                       | Oral       | Tshitsonga, Afrikaans, English, isiXhosa, isiZulu, Setswana, Sepedi |
| 2           | 27          | 33  | 26                                      | Oral       | isiXhosa,<br>Setswana,<br>English,<br>Afrikaans                     |
| 3           | 37          | 26  | 16                                      | Injectable | isiXhosa,<br>isiZulu,<br>Sesotho,<br>English                        |
| 4           | 33          | 37  | 20                                      | Oral       | Sesotho,<br>isiZulu,<br>English                                     |

#### Video recorded education sessions

Patients who were receiving education about their condition at the clinic for the first time were invited to participate in the study by allowing the researcher to video record their interaction with the diabetes educator nurse/s.

Inclusion criteria for the video recordings included:

- The patient had been diagnosed with GDM and was currently admitted to the GDM inpatient ward
- The patient had not received education or counselling about GDM previously

Exclusion criteria for video recordings included:

- The potential participant had any impairment (for example, a communication difficulty)
   that would limit their ability to participate in the education session.
- The potential participant was fatigued or in an unfit condition to participate in an education session with the diabetes nurse educator.

A sample of approximately five to ten interactions was targeted. It was felt that the interactional analytic method of choice for the education sessions would yield large amounts of rich data which would not necessarily rely on a large sample size (Heath, Hindmarsh & Luff, 2010). Six education sessions were recorded and data saturation was found to be reached at this level. Hence no further sessions were recorded. The patients who participated in the video recorded education sessions differed regarding age, gestation, treatment regimens and linguistic backgrounds. They were all of Black African ethnicity. All of these patients were able to read. The first education session comprised a variety of

patients, only one of whom had GDM (the rest had type 1 or type 2 diabetes). Hence only the demographic traits of the patient who had GDM were included. The demographic features of the patients who participated in the video recorded education sessions are presented in the table below (Table 6). The language used to conduct each education session has also been included.

Table 6. Patient characteristics in video recorded education sessions

| Participant            | Age | Home<br>language | Gestation | Treatment | Individual/Group | Language used in session         |
|------------------------|-----|------------------|-----------|-----------|------------------|----------------------------------|
| 1 (group session)      | 28  | isiXhosa         | 23 weeks  | Metformin | Group            | isiXhosa,<br>isiZulu,<br>Sesotho |
| 2 (individual session) | 26  | Sepedi           | 21 weeks  | Insulin   | Individual       | Sesotho                          |
| 3 (individual session) | 27  | Sepedi           | 10 weeks  | Metformin | Individual       | Sesotho                          |
| 4 (individual session) | 40  | Xhosa            | 33 weeks  | Insulin   | Individual       | isiZulu                          |
| 5 (individual session) | 38  | Setswana         | 32 weeks  | Insulin   | Individual       | isiZulu                          |
| 6 (individual session) | 34  | isiXhosa         | 35 weeks  | Metformin | Individual       | Sesotho                          |

## **Nurse interviews**

The semi-structured interviews were open to any nurse who worked with patients who have GDM, who was willing to discuss their thoughts and opinions about the communication practices that take place at the GDM clinic.

Inclusion criteria for semi-structured interviews were as follows:

- The potential participant was a nurse currently working in the GDM in-patient and/or out-patient clinic
- The potential participant had contact with patients who have been diagnosed with GDM

No exclusion criteria were implemented for nurses participating in the study.

There were fourteen nurses who cared for patients with GDM at the time of the study, including two GDM educator nurses. The nurses worked in shifts of three nurses at a time. Although fourteen nurses were invited to participate, only eleven nurses were interviewed due to logistical and personal reasons. The nurses interviewed differed with regard to age, qualification, years of experience and linguistic background. The demographic features of the nurses who participated in the study are presented in the table below (Table 7):

Table 7. Participant characteristics for nurse interviews

| Participant | Age (years) | Qualification         | Time working in ward (years) | Languages   |
|-------------|-------------|-----------------------|------------------------------|---|
| 1           | 38          | Auxiliary             | 0.5                          | Setswana, isiZulu,  |
|             |             | Nurse                 |                              | isiXhosa, Tshitsonga,<br>English  |
| 2           | 31          | Auxiliary<br>Nurse    | 5-6                          | isiZulu, isiXhosa,<br>Afrikaans, English  |
| 3           | 53          | Professional<br>Nurse | 20                           | isiXhosa, isiZulu, Sesotho,<br>Setswana, Tshivenda,<br>Tshitsonga, Swazi,<br>Afrikaans, English |
| 4           | 42          | Professional<br>Nurse | 1                            | Sesotho, Setswana,<br>isiZulu, isiXhosa,<br>Tshitsonga, Tshivenda,<br>English                   |
| 5           | 24          | Professional<br>Nurse | 1.5                          | isiZulu, Sesotho, English,<br>Afrikaans, Tshitsonga   |
| 6           | 53          | Auxiliary<br>Nurse    | 13                           | Setswana, Tshitsonga,<br>isiXhosa, English  |
| 7           | 29          | Auxiliary<br>Nurse    | 4                            | isiZulu, English  |
| 8           | 53          | Professional<br>Nurse | 1                            | isiXhosa, isiZulu, English  |
| 9           | 30          | Professional<br>Nurse | 5                            | Tshitsonga, Sesotho, isiZulu, Tshivenda, English  |
| 10          | 35          | Professional<br>Nurse | 3-4                          | isiXhosa, English,<br>Afrikaans, Setswana,<br>Sesotho, Tshitsonga,<br>isiZulu                   |
| 11          | 52          | Professional<br>Nurse | 3.5                          | Sesotho, isiZulu,<br>Afrikaans, isiXhosa,<br>English  |

# Research assistant

As previously discussed, the majority of health interactions within South Africa require mediation by an interpreter (Penn, 2007). Given the ethnographic background of the research site, it was predicted that a research assistant would be required to assist with interpreting and translating during the study. A research assistant was hired by the

researcher to assist with interpreting of the patient focus groups, as well as transcription and translation of non-English data that were collected in the patient focus groups and video recorded nurse-patient education/counselling sessions.

The research assistant was trained by the researcher to interpret during the patient focus groups, so as to allow participants to communicate in the language with which they are most familiar and comfortable. This training took place prior to conducting the focus groups. The research assistant was also required to transcribe and translate (into English) the raw data from the patient focus groups (particularly group three which was not conducted in English) and all six of the nurse-patient education/counselling sessions verbatim.

A full language history of the interpreter was taken prior to employing her, in order to gain insight into her linguistic background and experience (Appendix 3). The interpreter is an experienced research assistant who has previously completed transcriptions for the National Health Laboratory Service at the University of the Witwatersrand. She has also conducted work in interpreting, transcription and translation during a previous study at the same research site, and was thus familiar with the GDM clinic and some of the nursing staff at the site, which promoted trust from the nurses who were familiar with both the researcher and the research assistant. The research assistant also holds an honours BA (Psychology) degree from the University of the Witwatersrand. Her home language is Setswana, however, she also understands and speaks English, Sesotho, isiZulu and isiXhosa.

# **Data collection**

Data collection took place over a period of two months. The data collection process is described in detail under the headings below.

## Pilot study of semi-structured nurse interview and patient focus group questions

Interviews and focus group guiding questions should be piloted before data were collected, in order to identify errors and refine questions before conducting the interviews or focus groups with participants (Silverman, 2009). The proposed interview or guide for focus group discussions should be piloted on individuals who are as similar as possible to the participants in the sample (Hennink, 2014).

The semi-structured interview for nurses was piloted on a diabetic educator nurse who works at the diabetic school at the same hospital. It should be noted that this diabetic school is run independently and separately from the GDM clinic, and staff at each of these clinics are not linked to one another.

The guiding questions for patient focus groups were piloted on a 45 year old black female who speaks Sepedi (home language) and is also proficient in English, Zulu and Tswana. She resides in urban Gauteng, and receives healthcare at a public healthcare facility. She was thus similar to the sample population demographically and hence suitable as a candidate to assist in the piloting process.

Results of the pilot study revealed that all of the questions derived by the researcher were appropriate and would allow for rich data to be obtained from participants. As a result of the pilot study some of the interview and focus group questions required linguistic simplification to facilitate improved participant understanding.

# **Ethnographic observations**

Ethnographic observations were conducted at the GDM clinic in one of the hospital wards in the maternity department, where both in-patient and out-patient clinics are housed, in order to gain an understanding of how the clinic functions and a broad idea of the communication practices occurring at the clinic. The compacted time mode of ethnography described by Jeffrey and Troman (2004) was used to ensure a feasible study. The compacted time mode generally refers to ethnography that takes place intensively (e.g. everyday) over a short period of time (e.g. a month) (Jeffrey & Troman, 2004). Ethnography for the purpose of this study took place for approximately two to three hours for the first week of data collection and continued less intensely for the rest of the duration of the data collection process. Ethnographic observations took place over a shorter time period than usual, as the researcher was familiar with the research site as she was previously employed at the hospital and had conducted previous research at the site.

The researcher's observations of the GDM clinic were recorded by means of field notes.

These field notes were triangulated with the other data that were collected. They were also used to provide the reader with insight into the research setting.

## **Patient focus groups**

The focus groups were conducted with GDM patients attending the out-patient clinic held on Tuesdays, over a three week period. Two focus groups were conducted on the first Tuesday and one group was conducted on each of the consecutive Tuesdays. Four focus groups were thus conducted in total. The four groups consisted of the following number of participants: six, three, six and four. Three of the focus groups were held in a private counselling room in the GDM ward whilst one of the groups was held in a private counselling room in the ante-natal clinic. The counselling rooms, although small, allowed for a quiet, private and comfortable environment in which patients could discuss their thoughts and feelings about GDM and communication practices at the GDM clinic. The groups were run by the researcher, with the help of an interpreter (research assistant) who was trained by the researcher prior to conducting the focus groups. The interpreter was encouraged to participate in side discussions with participants to explore their perceptions in more detail.

Guiding questions (which were piloted) were used in the focus groups in order to lead and focus discussions between patients, the interpreter and the researcher. The guide constructed by the researcher consisted of open-ended questions, as open-ended questions allow for a varied range of responses from participants when conducting qualitative research (Patton, 2002). The questions were derived from the aims of this study, as well as from previous qualitative studies on chronic conditions (Burkett, 2012, Watermeyer, 2008) and are attached as an appendix (Appendix 4).

As suggested by Krueger and Casey (2000), audiotaping was used to record the focus group discussions. Written notes about any important non-verbal aspects were also taken by the researcher and interpreter, when possible during the focus groups.

#### Video recorded education sessions

Nurse-patient interactions during the initial patient education sessions were video recorded. Six interactions were recorded in total over a period of two months. The diabetes nurse educator informed the researcher when there was a newly diagnosed patient with GDM who was going to be educated and counselled so that the researcher could video record the interaction. The video camera was set up on a tripod and positioned so that the nonverbal communication behaviours of the patients and diabetes nurse educators were clearly visible.

The first interaction was a group interaction which was held between patients (with various diagnoses including GDM, type 1 and type 2 diabetes, and at various stages of the condition) and a diabetes nurse educator around a table in the GDM ward. The rest of the interactions were one-on-one between a patient and a diabetes nurse educator and took place in a private counselling room in the GDM ward, with the patient and diabetes nurse educator seated opposite one another at a table.

Each interaction lasted between twenty and thirty five minutes. All of the patients and the two diabetes nurse educators consented to being video recorded and participating in the research. The researcher also observed the interactions herself and made written notes.

#### **Nurse interviews**

Semi-structured in-depth interviews were conducted with the nurses working with GDM patients at the time of the research study, in order to investigate their direct perceptions of communication at the GDM clinic. Focus groups would have been preferable, as they are time-efficient, generate large amounts of data, are socially oriented, give rise to spontaneous responses, and may foster a sense of togetherness which may increase participants' will to share information (Krueger & Casey, 2000; Onwuegbuzie, Dickinson, Leech, & Zoran, 2009). However, individual interviews were conducted as there were only three nurses on shift at a time, and logistical issues (such as workload and needing at least one nurse available to patients in the ward) did not allow for focus groups. The two diabetes educator nurses were, however, interviewed together as they both happened to have time available for the interview at the same time. The interview question guideline was derived based on previous studies (Burkett, 2012; Watermeyer, 2008) and the aims and objectives of this study. A copy of the interview question guideline used is available in the appendices (Appendix 5).

Each interview lasted between twenty and forty minutes. The interviews were conducted by the researcher. The open-ended interview questions were constructed in accordance with suggestions by Coolican (2014) and King and Horrocks (2010). The nurse interviews

were conducted over a seven week period, in which eleven nurses were interviewed. Three nurses were not interviewed as a result of personal and logistical issues. It took time to interview the nurses as a result of:

- Initial resistance from some of the nurses, which eventually resolved with increased familiarity with the researcher. It is realised that the nurses may have been coerced into participating in the research perhaps by managers or senior staff who had been made aware of the research being conducted.
- Workload and time restrictions
- Nurses being on separate shifts of three at different times

The interviews were audio-recorded, and written notes were also made by the researcher during each interview. King and Horrocks (2010) suggest that interviews be carried out in an environment which is quiet and offers privacy. The majority of the nurses' interviews were thus conducted in the private counselling room in the GDM ward. However, some interviews were conducted in the kitchen in the GDM ward, as some nurses only had time available to be interviewed during their lunch time. It was, however, ensured that no other nurses or individuals were in the kitchen during the interviews, so as to allow for confidentiality. Despite this, certain interviews were interrupted by other nurses or staff, both in the counselling room and in the kitchen.

# **Data analysis**

#### Treatment of data

All of the focus groups discussions were conducted in English, except the third focus group discussion which was conducted in Zulu, South Sotho and Xhosa. The focus group discussions were thus transcribed and where necessary, translated verbatim by the research assistant. All of the focus group discussions that were transcribed verbatim in English by the interpreter were checked by the researcher.

According to McLellan-Lemal (2008), verification of transcribed data by other professionals is essential. The researcher transcribed 10% of the English focus group discussions independently, as this was found to be a reasonable portion given the large amount of raw data that was collected. The researcher then checked this against the same data that was transcribed by the research assistant. Minor editorial differences were noted and hence the original transcriptions were found to be sufficiently accurate.

The reliability of the translations was established by employing an individual to verify the translations. The individual that was employed was the same individual who assisted with piloting the focus group questions. The employed individual independently translated and transcribed approximately 10% of the data from the focus group discussions and videos that were in Zulu. Her translations and transcriptions were then compared to the original ones done by the research assistant. Again, minor editorial differences were noted and original translations and transcriptions were thus judged to be sufficiently accurate and reliable.

The videos of the nurse-patient interactions were transcribed and translated verbatim by the research assistant according to the method of Clarke and Braun (2013). The reliability of transcription and translation of this data was verified by an independent rater who translated and transcribed 10% of the video recorded interactions. Her translations and transcriptions were compared to those of the research assistant and were found to be sufficiently accurate.

The nurse interviews were transcribed verbatim by the researcher. 10% of the researcher's transcriptions were verified by an independent rater and found to be accurate and reliable.

## Thematic analysis

Thematic analysis (TA) was used to analyse data from the patient focus groups and nurse interviews. TA is a method of analysing data into themes or consistent patterns that occur in the data, allowing the researcher to explore phenomena of interest. TA has been regarded as the basis of data analysis in qualitative research in that it may be applied within various methods and theoretical niches of qualitative analysis (Braun & Clarke, 2006). This method of making sense of data has been described as a flexible method of analysis of data in that it may be applied within multiple theoretical frameworks allowing for a comprehensive and rich data analysis (Braun & Clarke, 2006). TA has been shown to be particularly useful in analysing data in South African health communication studies, as evidenced by Bowen, Edwards, Simbayi, & Cattell (2013), Penn (2013) and Watermeyer (2013).

A critique of TA is that the importance of themes is judged based on recurrence within the data set. This neglects the possibility that themes which are equally crucial to data interpretation are ignored because they do not recur. O'Reilly and Parker (2013) have suggested that quantity is an inappropriate indicator of the quality of findings. A system of saliency analysis is thus suggested when applying TA, where themes are judged and identified based on their recurrence, their importance or both of these features (Buetow, 2010). Themes in the focus group data were thus identified via the recurrence of specific phenomena and the salience of specific phenomena in relation to the research questions.

TA has also been criticised for its poor conceptualisation, in that there is a lack of specified procedures or methods of identifying themes and conducting the actual thematic analysis (Floersch, Longhofer, Kranke, & Townsend, 2010). In response to this, Braun and Clarke (2006) describe a guideline for conducting TA, consisting of the following steps:

- 1. Transcribe the data and familiarise oneself with it
- 2. Code interesting or important aspects of the data
- Create themes from codes and gather data relevant to each them from the data set
- 4. Ensure that themes relate to all the coded extracts of data
- 5. Refining the names and definitions of each of the created themes
- Reporting on the themes in relation to literature, research questions and data gathered

The above steps were used to analyse data from the nurse-patient interactions.

Once data from the focus groups and nurse-interviews had been transcribed and, if necessary, translated, it was analysed according to the principles of TA suggested by Braun and Clarke (2006).

The patients' and nurses' perceptions of communication at the GDM clinic were analysed (from the transcriptions) into specific meaning units which describe the general perceptions of the communication that is occurring at the clinic. Meaning units may be defined as occurrences which are found to repeat themselves throughout the data i.e. content themes and categories). Meaning units may be grouped into larger units (Wilkinson, 2004). The data from the focus groups were thus analysed and a wide range of meaning units were obtained. These meaning units were grouped into sub-categories and into larger units (themes and categories), so that structured content could be obtained from the broad range of data surrounding the research question. The remaining steps (three to six) suggested by Braun and Clarke (2006) were then followed to derive themes that were of the highest degree of saliency. The credibility of the themes was ensured via consultation with research supervisors.

# **Interactional analysis**

Interactional analysis was used to analyse the video recorded nurse-patient education sessions. The researcher conducted an interactional analysis similar to that used by Evans (2010), in which the nurse-patient interactions were analysed according to perceived facilitators and barriers of effective communication. This approach was chosen as it

appeared to work effectively in identifying positive and negative communication behaviours in paediatric HIV counselling sessions. Facilitators and barriers were defined according to Evans (2010) as the following:

- Facilitator: A communication behaviour that allows for the message to be delivered to patients in a way that is easier to understand, accessible, clear, logically ordered and meets their informational and communicative needs. Communication behaviours that were observed to assist in establishing empathy and empowerment were thus also noted as facilitators. A justification of the communication facilitators was established via patients' demonstrations of understanding and the lack of communication breakdowns or uncertainty, as well as the researcher's or raters' subjective understanding of the messages being conveyed between the diabetes nurse educators and patients.
- Barrier: A barrier to communication was defined as exactly the opposite of a facilitator: a communication behaviour that hinders patient understanding of a message and/or prevents their informational and communicative needs from being met. Communication behaviours that were observed to hinder the establishment of empathy and empowerment were also noted as barriers. A communication barrier was noted to result in the message being inaccessible, unclear and poorly ordered. A justification of the communication barriers was established via patients' demonstrations of misunderstanding, the observation of communication breakdowns and uncertainty, as well as the researcher's or raters' subjective understanding of the messages being conveyed between the diabetes nurse educators and patients.

Barriers and facilitators were separated into nonverbal and verbal categories. Hence video recorded interactions were analysed to identify the following:

- Nonverbal facilitators
- Nonverbal barriers
- Verbal facilitators
- Verbal barriers

The researcher began the analysis process by watching the videos and reading through the transcripts repetitively and identifying nonverbal and verbal facilitators and barriers. A list of these was created. Two of the videos and transcripts were randomly selected and then shown to two independent raters (one of the researcher's supervisors and a fellow researcher at the Health Communication Research Unit), who compiled independent lists of nonverbal and verbal facilitators and barriers based on their observations of the videos and transcripts. A data session was held to discuss the common and conflicting nonverbal and verbal barriers and facilitators which had been identified. Through this discussion the researcher and raters derived a final list of commonly agreed upon nonverbal and verbal facilitators and barriers across the video recorded data. Further discussion and triangulation of these facilitators and barriers was conducted in order to derive the most salient nonverbal and verbal facilitators and barriers. This ensured credibility. These are presented in the results chapter.

# Triangulation of salient findings across data sets

According to Mays and Pope (2005) the triangulation of data collection and analysis methods facilitates the credibility and rigor of scientific work. Once all of the data were analysed according to the various methods discussed above, the findings which emerged from the various sources and methods of data analysis were triangulated. The triangulation process is described below:

- The selected salient findings across the data sets were written down
- The researcher compared each salient finding to all of the other relevant findings
   from the other data sets
- When findings were found to misalign or contradict each other, the researcher examined various possible reasons for the contradictions in order to make sense of all of the salient findings

The triangulation of the findings allowed for the research to gain an understanding of the data in its entirety and hence construct accurate and feasible implications from the data.

# <u>Rigour</u>

Rigour is a term that refers to methods implemented to ensure that qualitative research is applicable to the real world and is of a high-standard (Flick, 2007). A rigorous study was ensured through the application of the following strategies suggested by Long and Johnson (2000) and Finlay (2006):

## Reflexivity through journaling

Reflexivity is the researcher's reflection upon and examination of his or her reactions to participants or findings. Reflexivity is a prerequisite for a rigorous study (Rossman & Rallis, 2011). A field journal was kept by the researcher throughout the duration of the study. The researcher kept a record of her feelings and impressions regarding the data and consulted with other researchers to ensure reflexivity and prevent researcher bias from affecting the interpretation of data.

## Reflexivity through peer debriefing

Peer debriefing is when members of the research team (such as supervisors) reflect on the researcher's responses to the research process which assists with preventing researcher-bias and inaccurate analysis or interpretation of data (Hays & Singh, 2012). The researcher consulted regularly with her supervisors and other researchers regarding the analysis and interpretation of the data that were collected to ensure a credible study.

# Triangulation

Triangulation is the inclusion of more than one method in the research process to increase the validity of qualitative research (Malterud, 2001). Triangulation was achieved by the proposed study in various ways. The use of more than one method of data collection was implemented. The methods used allowed for both a subjective interpretation of observations made by the researcher, as well as direct participant reports provided in the interviews and focus groups. Triangulation of investigators was achieved by consulting members of the research team to analyse portions of the data. Methodological triangulation was also achieved through the application of more than one method of data analysis in the proposed study.

### Audit trail

An audit trail is the recording of the researcher's observations of the decision-making processes and chosen methods during the study to improve the reliability of the study. An audit trail is aimed at ensuring a credible study (Shenton, 2004). An audit trail was kept by the researcher in the field journal.

The possibility of the Hawthorne effect was anticipated during ethnographic observations and in the video recordings of the nurse-patient education sessions. The Hawthorne effect is defined as an instance in which the participants' responses change because they are aware that they are being studied (Hughes, 2007). It was anticipated that nurses might change the way in which they counsel and communicate with patients because they knew they were being recorded or watched by the researcher. Hughes (2007) suggests that the researcher familiarise himself/herself with participants before collecting data to overcome the Hawthorne effect, as once familiar with the researcher participants are more likely to openly discuss or demonstrate problematic phenomena. The researcher was familiar with the research site and most of the staff members, due to previous research having been conducted there. Multiple visits to the research site were conducted prior to commencing data collection to further familiarise the nurses with the researcher and obtain their trust, in order to overcome the Hawthorne effect. Whilst the Hawthorne effect was recognised as a possible disadvantage of ethnographic observations, the advantages of the approach outweighed this as it allowed for a detailed understanding of the site. No overt changes in behaviour were noted in observations and video recordings, however the researcher was mindful of the possibility of the Hawthorne effect when analysing the data.

# **Ethical considerations**

Participants in all studies, particularly vulnerable participants such as patients, should be protected through adherence to ethical principles and anticipation of ethical dilemmas (Ryen, 2010). The ethical aspects of this study have thus been considered in detail. Ethical clearance for this study was obtained from the HREC (Medical) of the University (Appendix 6) and the study proposal was presented at a departmental postgraduate seminar before being conducted. Written permission for this study was obtained from the head of the GDM clinic, head of obstetrics and gynaecology at the hospital, the nursing director and the chief executive officer of the hospital.

# Risks of participating in the study

Given the high levels of stigma associated with illness in the South African context, particularly in relation to conditions of a chronic nature (Brown, Macintyre, & Trujillo, 2003; Goudge, Gilson, Russell, Gumede, & Mills, 2009), as well as the perceived stigma associated with GDM (Burkett, 2012), it was imperative that potential risks to participants be considered.

The potential risks to participants were noted to be minimal. No physical risks to participants existed. However, thought was given as to other possible risks that might apply to participants. They were found to include the following:

- It was anticipated that patients may experience strong emotions during the focus group discussions when discussing their experiences of being diagnosed and living with GDM. The researcher thus planned to refer any emotionally distressed patients for counselling to the psychology department at the hospital in a sensitive manner, with patients' consent. Whilst some patients were noted to demonstrate and express a great deal of anger and frustration related to their condition, none of them expressed the need for professional counselling, and in fact frequently stated that sitting together in a focus group with other patients had helped to relieve their anger and stress.
- It was also recognised that patients might fear that the researcher may share their discussions with the nurses or staff at the GDM clinic. The researcher thus assured the patients that all information discussed and divulged during focus group discussions would be kept completely confidential and private by the researcher. The researcher explained to participants that confidentiality in focus groups could not be guaranteed, however, ground rules were set to prevent participants from sharing information from the focus group discussions outside of the focus groups.
- The researcher anticipated that the nurses might fear that they were going to be reported to managers or that their interview data would be shared with other staff at the site. This did occur, as some of the nurses expressed concerns about being recorded and about the researcher divulging the nurses' identities. One nurse even refused to participate as she did not want to be recorded in any way out of fear that her interview and identity would be shared publically. The researcher thus assured all nurses that their interviews would not be shared with anyone else besides members of the research team and that all data would be made anonymous and confidential.

#### **Informed consent**

The informed consent procedure is often challenging in the South African context, due to linguistic and cultural variability, as well as differing levels of education and literacy among the population (Watermeyer & Penn, 2008). All participants were provided with both written and verbal information about the study before being asked whether they would like to participate or not and being given a consent form to sign. All participants were given the written information to keep. Informed consent was obtained in writing from all participants who agreed to participate in the study.

Prior to conducting the focus group discussions, the interpreter was available to provide participants with verbal information about the study in Setswana, isiZulu, isiXhosa and Sesotho. The researcher explained the study in English to participants who expressed that they were able to understand English proficiently. After providing information about the study, participants were given time to decide whether they would like to participate or not and were encouraged to raise queries or concerns with the researcher or interpreter if they had any. Due to issues related to literacy patients were given the option of providing verbal informed consent. However, all participants were able to provide written consent, as all of the participants were able to read and write.

All of the patients who participated in the education/counselling sessions provided written informed consent to participating and to being video recorded. The researcher provided them with verbal information in English and the diabetes educator nurses assisted by

providing information in participants' home language, despite the fact that all of the patients were found to be proficient in English.

It was made clear to participants that participation in the study was voluntary and participants were informed that they had full right to withdraw from the study at any time without having to provide a reason and without having to face negative consequences.

Contact information of the researcher and the university HREC was made available to all participants on the written information sheets. Participants were also informed that all recorded information and that everything discussed with the researcher would be kept confidential. A copy of the information sheet as well as consent forms are attached (Appendix 7).

No patients expressed concerns about participating in the study and were all willing to participate. Some of the nurses did however demonstrate resistance initially and expressed concerns that the researcher would report them to management staff or the media, or share their interviews publically. However, after being assured that they would not be reported and that all information would be kept confidential they appeared less concerned and more comfortable and thus agreed to participate in the study.

One of the nurses did not consent to participate as she did not wish for her interview to be recorded in any way. Two other nurses also did not participate in the study. These nurses were not forced to participate and did not face any negative consequences, as they had been assured by the researcher.

# Confidentiality

All researchers are ethically bound to maintain the confidentiality and autonomy of research participants at all times (Wiles & Boddy, 2013).

It was made clear to all participants that they were under no obligation to provide any personal information and that pseudonyms would be used in the research report, if required. No personal information was divulged at any time.

It was recognised that confidentiality cannot be guaranteed in a focus group, however, ground rules were set prior to discussion within the focus groups, where participants were asked not to divulge the content of the focus group discussions when outside the focus group. It was made clear to participants that everything they said in the focus group would be kept completely anonymous by the researcher. Only the researcher, supervisors, and research assistant had access to the raw data which was stored in a locked cupboard, to which only the researcher had access.

It has been recognised that the small sample size and sharing the name of the hospital may pose a breach of confidentiality for the nurses and may allow for the nurses to be identified. Particular attention has thus been given to ensuring that all nurse data has been anonymised and that all identifying information has not been shared or divulged in any way. The hospital name has also been anonymised to uphold confidentiality.

# Data storage

Once data were transferred from the recording devices to a computer, the raw data were deleted from the external devices (audio recorder and video recorder) and transferred to a memory stick, which was stored in a locked cupboard, which could only be accessed by the researcher. The data will be stored in a locked cupboard for a minimum of two years after publication or six years in the absence of publication, as suggested by the HPCSA's ethical guidelines.

# **Ethical issues**

Whilst minimal ethical issues were found to arise from this study, the following issues or dilemmas were considered:

• It was anticipated that patients participating in focus group discussions might express uncertainty with regards to aspects of their condition and its treatment and possibly even request information about GDM and its treatment from the researcher. This occurred fairly often during the focus group discussions. The researcher felt ethically

bound to report this to a diabetes educator nurses, as patients' uncertainty about their treatment may have had adverse effects on their health or the health of their baby. The participants who demonstrated uncertainty were thus encouraged to seek information from one of the diabetes educator nurses and with their permission, were referred to one of the diabetes educator nurses for education.

• Although not anticipated, a further ethical issue arose during the study, in which a patient who had been admitted to the GDM ward when a newly diagnosed patient who had GDM requested information from the researcher. The patient reported that despite having been admitted for a week, she had not received any education or counselling about the condition or its treatment from the ward nurses or diabetes educator nurses. Again the researcher felt ethically bound to make the diabetes educator nurses aware of this, as the patient's lack of information about her condition or treatment could have had adverse effects on her health and the health of her baby. The patient's request was thus brought to the attention of one of the diabetes educator nurses in a sensitive manner.

# **Feedback**

Feedback to the research site will be given after the submission of this dissertation. Feedback will be provided to management at the GDM clinic as well as to the nurses who participated in this study.

# **Chapter summary**

This chapter described and justified the research design and methods used to collect data and derive results from it. The aims and objectives have been presented together with a detailed description of the research site. A summary of sampling procedures and participant characteristics has also been presented together with a detailed explanation of measures taken to ensure that the study was rigorous and ethically sound.

# CHAPTER 4: RESULTS: PATIENT FOCUS GROUPS, VIDEO- RECORDED EDUCATION SESSIONS AND NURSE INTERVIEWS

The findings which emerged from the analyses of the three data sets are provided in this chapter. Each of the findings is illustrated with excerpts of the data to provide the reader with a clear understanding of the findings. Whilst comparison to literature has been made in this chapter, the comprehensive discussion of the results is provided in the discussion chapter which follows.

# Patient focus groups

Patients were generally eager to participate in the focus groups and showed willingness to share information with the researcher about their experiences and perceptions related to their condition, its treatment and the communication practices at the GDM clinic. This generated large amounts of rich data. It was interesting to note that the focus group participants showed a desire to be active participants and agents in the management of their condition. Participants seemed generally eager to share their feeling and thoughts even if they were negative, suggesting a sense of comfort and security within the focus groups over and above patient empowerment. Minimal resistance and unwillingness to share thoughts and feeling was noted.

The focus group data yielded a large number of themes, categories and sub-categories which were tabulated in accordance with the method of Solomon, Greenberg, Futter, Vivian

and Penn (2012). The complete table of themes and subthemes which were extracted from the data is presented below.

Table 8. Patient focus group themes

| Theme                       | Category                    | Sub-category                     |
|-----------------------------|-----------------------------|----------------------------------|
| Counselling and education   | Quality of counselling and  | Lack of quality counselling and  |
|                             | education                   | information giving               |
|                             |                             | Partial counselling              |
|                             |                             | Referral to other persons for    |
|                             |                             | counselling                      |
|                             | Sources of counselling and  | Internet                         |
|                             | education                   | Doctors                          |
|                             |                             | Family                           |
|                             |                             | Other patients                   |
|                             |                             | Diabetes nurse educators         |
|                             | Suggestions to improve      | Peer support groups and          |
|                             | counselling and education   | counselling with other patients  |
|                             | _                           | Provision of more information    |
|                             |                             | 24 hour dedicated diabetes       |
|                             |                             | nurse                            |
| Communication at the clinic | Communication with ward     | Lack of knowledge                |
|                             | nurses                      | Dissatisfaction with             |
|                             |                             | communication with ward          |
|                             |                             | nurses at the GDM clinic         |
|                             |                             | Differing between nurses         |
|                             |                             | Mistrust                         |
|                             |                             | Isolation                        |
|                             |                             | New sisters as better            |
|                             |                             | communicators                    |
|                             | Communication with diabetes | High levels of satisfaction with |
|                             | nurse educators             | communication with diabetes      |
|                             |                             | nurse educators at the GDM       |
|                             |                             | clinic                           |
|                             |                             | Knowledgeable                    |
|                             |                             | Not present enough               |
|                             | Communication with doctors  | Adequate communication           |
|                             |                             | Not present enough               |
|                             | Communication with other    | Peer communication provides a    |
|                             | patients                    | sense of inclusion               |
|                             |                             | Preference for learning from     |
|                             |                             | individuals with GDM             |
|                             |                             | Peer communication as an         |
|                             |                             | effective method of learning     |
|                             |                             | Peer communication as a          |
|                             |                             | cathartic experience             |
|                             |                             | Peer education insufficient as   |
|                             |                             | only form of education           |

| Patients' understanding and thoughts about GDM | Understanding of what GDM is                     | Uncertainty regarding GDM       |
|--|--|---------------------------------|
|  |  | Incorrect blood sugar levels    |
|  | Understanding and thoughts about causes of GDM   | Anger and stress                |
|  |  | Pregnancy                       |
|  |  | Increased sugar intake          |
|  |  | Diet                            |
|  | Understanding and thoughts                       | Diet as most difficult aspect   |
|  | about treatment                                  | Uncertainty regarding           |
|  |  | treatment of GDM                |
|  |  | Differing thoughts on           |
|  |  | appropriate glucose levels      |
|  |  | Side-effects                    |
|  |  | Good understanding of how to    |
|  |  | take treatment and measure      |
|  |  | glucose levels                  |
|  |  | Fear of injecting               |
|  | GDM and HIV/AIDS                                 | HIV/AIDS as easier to live with |
|  |  | than GDM                        |
|  | Desires and requirements to                      | Agency                          |
|  | live positively with GDM                         | Respect                         |
| GDM as a difficult condition to live with      | Support in social networks                       | Lack of support                 |
|  |  | Adequate support                |
|  | GDM and HIV/AIDS                                 | Confusion of the two conditions |
|  | Feelings and thoughts about GDM in the community | Fear                            |
|  |  | Stigma                          |
|  |  | Lack of understanding of GDM    |

Four main themes are presented in the table above. These themes were derived via constant reviewing of the data and discussion with supervisors. The four themes are discussed below, with a focus on subcategories that were found to be the most salient under each theme. Salience was judged based not only on the frequency of the subcategories, but also on the importance of the subcategories as perceived by the researcher and supervisors. This is in line with suggestions by O'Reilly and Parker (2013). Quotes have been provided to illustrate these subcategories. FG followed by a number indicates the focus group that the quote was taken from.

# Theme 1: Counselling and education

The majority of participants reported information-giving that was poor in quality and, in some cases, absent entirely. Participants reported often having to consult sources outside of the clinic for information, such as the internet, dictionaries and family members who had diabetes. This theme is illustrated by the quotes provided below:

"Since I came to (hospital name), nothing, zero, no information at all" (FG1)

"Oh no I just looked it up in the dictionary" (FG2)

"They don't tell you what is happening or what happens or anything and that really irritates me" (FG4)

The importance of information provision and effective patient-healthcare worker communication for patients with diabetes has been emphasised in previous literature (Beeney, Bakry, & Dunn, 1996, Rubin, 2005; Visser & Snoek, 2004). Schoenberg, Amey and Coward (1998) have highlighted the link between limited diabetes knowledge and its effect on patients' glucose control, further emphasising the importance of information provision for patients who have diabetes. This finding in conjunction with the abovementioned literature suggests that patients attending the GDM clinic may be experiencing difficulty understanding GDM and its treatment as a result of limited education and information provision at the clinic.

The quality of information-giving and communication between patients with diabetes and their health care providers is of high importance as it has been documented as a predictor

of treatment adherence, physical wellbeing and emotional wellbeing (Jiang et al., 1999; Milenković, Gavrilović, Percan, & Petrovski, 2004; Ratanawongsa et al., 2013; Rubin, 2005).

As a method of learning about GDM, the participants frequently raised peer education as a successful method of communicating information, as well as an emotionally satisfying way of learning about their condition and living positively with it. This is suggested by the quotes below.

"I would suggest more of these classes [focus groups/support groups] (FG4)

"I feel better [having peer support] because at least you can see that it's not just me..." (FG1)

"I would rather be counselled by a diabetic person because they know what is happening and they are not there because of their jobs, because they want money" (FG2)

This finding coincides with a multitude of previous studies which have documented peer group education and management as a highly promising method of education and counselling for patients with diabetes (Brownson & Heisler, 2009; Heisler, Vijan, Makki, & Piette, 2010; Karlsen, Idsoe, Dirdal, Hanestad, & Bru, 2004; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). These studies have highlighted similar effects of peer group counselling and education, such as reduced anxiety and isolation, improved self-care and decision-making and increased coping and empowerment, in addition to improved health outcomes and physical wellbeing. It was interesting to note that the majority of participants requested more focus groups, suggesting that peer discussion in a relaxed environment created a positive, cathartic experience.

Whilst most participants demonstrated a desire for peer education and support, some participants highlighted that it should not be the only method of communicating information at the GDM clinic as participants wished to receive some information from trained professionals. For example a participant in FG1 said "It's just that the sugar level would be different mine would be eight and the other one is a four, so sometimes it's [peer education] not helpful". This coincides with the view of Heisler (2010) who suggests that the most effective method of facilitating education and support for patients with diabetes combines peer support together with a structured education programme led by the healthcare facility. This highlights the need for multimodal input and methods of communication and counselling for patients who have been diagnosed with GDM, throughout their experience of living with the condition. The possibility of implementing increased peer group education and support at the GDM clinic thus requires significant discussion and consideration.

#### Theme 2: Communication at the clinic

Furthermore, participants highlighted limited communicative interactions with the ward nurses at the GDM clinic. The majority of participants discussed communication with the ward nurses as being inadequate and depicted the attitudes of the ward nurses negatively as demonstrated by the quotes below:

"It [the communication] is not good...they [the ward nurses] end up shouting at me... as if it's my fault that every night I'm getting sick" (FG1)

"They [the nurses] are extremely rude, as if we are babies" (FG2)

"You are already scared to ask and you have a right to ask" (FG3)

"It's like they [the nurses] isolate us, they don't like us" (FG3)

Poor patient-nurse communication and negative behaviours have been documented in previous literature (McCabe, 2004; Rosenstein & O'Daniel, 2008). McCabe (2004) has highlighted that nurses are frequently described as poor communicators and also noted that patients reported nurses as unfriendly, lacking empathy and inattentive. It is likely that this gap in communication between patients and nurses at the GDM clinic may be resulting in patients' reduced understanding and negative emotions which were reported in the focus groups. One does, however, needs to consider factors that may be causing the nurses to isolate and communicate poorly with the patients, such as patient behaviours, nurses' prior negative experiences with patients who have GDM, cultural and linguistic differences and factors related to resource and staff shortages. For example, healthcare workers, particularly nurses have been noted to display negative attitudes towards diabetes specifically, as a result of its complexity and perceived lack of support within the healthcare system to help control the condition (Babelgaith, Alfadly, & Baidi, 2013; Larme & Pugh, 1998). Nurses' performance has also been documented negatively in South Africa (Meiring & van Wyk, 2013; Seedat, 2013).

It was also suggested from some quotes (e.g. "When you ask the nurses they tell you you must wait for the doctors" (FG4) and "If you don't know they [the nurses] will tell you to go to the others [patients], they [patients] will teach you" (FG1)), that the ward nurses' limited knowledge of GDM and GDM related skills may be further hindering effective

communicative interactions with the patients. General diabetes knowledge amongst nurses has been found to be questionable in various other studies (el-Deirawi & Zuraikat, 2001; Chan & Zang, 2007; Rubin, Moshang & Jabbour, 2007). This finding gives rise to important implications related to staff training with regards to medical content, attitudes and communication skills.

Despite participants' negative perceptions of the ward nurses, all of the participants expressed a deep respect for the diabetes nurse educators and described communication with them as highly satisfactory. The diabetes nurse educators were reported to possess effective communication skills, a thorough knowledge of GDM and positive attitudes towards communicating with the patients. The quotes below demonstrate this:

"They [the diabetes nurse educators] are the only two nurses that are better" (FG1)

"They [the diabetes nurse educators] listen" (FG2)

"You just have to keep quiet and wait for Tuesday to come so that you can tell sister X and sister Y [diabetes nurse educators] this is the problem I am experiencing" (FG2)

"We are happy with them [the diabetes nurse educators] because they always look at each and everybody with a smile, they never speak in a disrespectful manner" (FG3)

Diabetes nurse educators appear to have become key team members whose role includes educating and supporting patients who have been diagnosed with diabetes (Funnell et al., 2011; Thompson, Kozak, & Sheps, 1999). Patients at the GDM clinic appear to perceive the diabetes nurse educators as being effective communicators and seem satisfied with their knowledge of GDM and the interactions that they share with them. Based on participant

reports, the diabetes nurse educators were suggested (by the patient participants) to possess the following traits facilitating effective communication:

- Friendliness
- Helpfulness
- Respect
- Patience
- Listening
- Consistency

Patients in previous studies have identified similar desirable communication traits to those above (Bakić-Mirić & Bakić, 2008; McCarthy, 2014), It is, however, interesting to note that some of these traits were not evident in the video-recorded communicative interactions between the nurses and newly diagnosed GDM patients, perhaps suggesting a paradox or mismatch between the researcher's observations and patients' perceptions. This paradox, together with its possible causes and implications are discussed in detail in the following chapter.

# Theme 3: Patients' understanding and thoughts about GDM

Whilst participants highlighted communication with diabetes nurse educators as being effective communicators, their responses seemed to suggest a limited knowledge of GDM with regards to its nature, its causes and its treatment and how it works. This is suggestive

of gaps in the communication of information, patient education and possibly the counselling provided at the GDM clinic. This theme is illustrated by the quotes provided:

"I don't even know how to explain it, I just know that I have diabetes" (FG1)

"Ok now I am guessing [what diabetes is], but let me not guess, please tell us" (FG2)

"I don't know what to eat and what not to eat" (FG4)

"...I didn't even know what is the correct number that it [blood sugar level] should be" (FG4)

This theme suggests the complexity of GDM and just how difficult it is for patients of diverse linguistic and cultural backgrounds to understand a new condition that has multiple treatment methods, strict times that treatment needs to be taken, drastic lifestyle changes and numerous outcomes related to the foetus and mother. Delamater (2006) has similarly highlighted the complexity of diabetes as a condition and of its treatment regimen. The complexity of the diabetic diet and patients' difficulty with understanding and being able to adhere to the diet (due to cultural, socioeconomic and lifestyle reasons) has also been widely documented in previous diabetes research (Frandsen & Kristensen, 2002; Nthangeni et al., 2002). This theme also suggests gaps in the communication of information and the provision of support and counselling at the GDM clinic, which were highlighted by participants.

#### Theme 4: GDM as a difficult condition to live with

The complexity of living with GDM in South Africa was highlighted in all four patient focus groups. Participants often likened GDM to HIV/AIDS, suggesting the dominance of HIV/AIDS in South Africa and perhaps the neglect of other conditions. Participants also highlighted the lack of understanding of GDM among family and community members and the difficulty of balancing family beliefs and desires with their own needs related to GDM. The quotes below illustrate this:

"With me diabetes is worse [than HIV]... because with HIV you can control it and you can see that now I'm dying, with diabetes you can't see" (FG2)

"HIV is better because you can eat everything" (FG4)

"And then you find that someone does not want food that is boiled, they [family and friends] want fried meat" (FG3)

"Some people when you tell them they think you are going to die" (FG1)

"The community talks bad about it" (FG3)

These findings are in line with those of Burkett (2012). Although HIV/AIDS may increase patients' risks of developing diabetes (Kalra, Kalra, Agrawal, & Unnikrishnan, 2011), the fact that participants spontaneously compared GDM to HIV/AIDS suggests that HIV/AIDS dominates health-related aspects of the participants' lives, perhaps because it is the most prevalent chronic condition in South Africa. Furthermore, the comparison of conditions, such as GDM, to HIV/AIDS appears to be causing a sense of stigmatisation amongst GDM patients, given the high levels of stigma associated with HIV/AIDS (Young et a., 2010; Visser

et al., 2009). A need for awareness-raising and outreach related to GDM is thus highlighted by this data.

The difficulty, yet importance of establishing family and community support was also highlighted by participants (e.g. "It [living with GDM] takes a while to get used to but it's better with support" (FG1) and "It [living with GDM] was hard for me but they [the family] would make sure you get well" (FG4)). Wysocki et al. (2006) has previously linked increased family support with positive health outcomes in adolescents who have diabetes. This highlights the importance of facilitating an understanding and supportive attitude of family and community members regarding GDM and its treatment. GDM is a complex condition with multiple treatment methods that require patients' adherence to achieve positive physical and emotional outcomes. This theme suggests that mediation of the social aspects of patients' lives (including family and community perceptions and attitudes) is required to achieve these positive outcomes and that the nurses at the clinic perhaps need to focus more on communicating with patients and even the community about the social aspects of GDM and its treatment.

# Video recorded education sessions

The education sessions were observed to be fast-paced. The diabetes nurse educators were observed to always be in a hurry to get to a meeting or to another clinic after the counselling sessions with GDM patients. On one occasion, a newly diagnosed GDM patient requested counselling from the researcher as she reported that she had not received any

information regarding GDM despite having been admitted to the ward for over a week, whilst the diabetes nurse educator had reported that there were no newly diagnosed GDM patients in the ward that week. When this was brought to the attention of one of the diabetes nurse educator, a counselling session was arranged for the patient. The diabetes nurse educator had questioned the benefit of counselling the patient as she was to deliver within the following two weeks, however the patient showed a desire for information about her condition, hence she was counselled.

The sessions commenced with an explanation of GDM, its pathophysiology, causes and health consequences during and post pregnancy. Diabetes nurse educators then went on to explain its symptoms and treatment, including dietary and medical recommendations as well as blood glucose monitoring. Little or no time was allocated to answering patient questions. All of the communication facilitators and barriers which were identified are provided in the table below.

Table 9. Communication barriers and facilitators noted in video recorded education sessions

| Verbal  | Nonverbal   |
|---|---|
| <ul> <li>Nurses inconsistently checked patients' prior knowledge related to GDM during sessions.</li> <li>English and code-switching were used to emphasise important information, instructions and for jargon.</li> <li>Nurses made use of figures of speech, in order to simplify explanations and facilitate patients' understanding</li> <li>Nurses were observed to</li> </ul> | <ul> <li>Gestures were used to emphasise important information.</li> <li>Patients nodded sometimes to suggest that they were following the nurse.</li> <li>Patients' personal files were used during individual sessions to make the counselling more specific to the patient.</li> <li>Nurses were focused and engaged throughout their interactions with the patients, suggested by consistent eye</li> </ul> |
|   | <ul> <li>Nurses inconsistently checked patients' prior knowledge related to GDM during sessions.</li> <li>English and code-switching were used to emphasise important information, instructions and for jargon.</li> <li>Nurses made use of figures of speech, in order to simplify explanations and facilitate patients'</li> </ul>  |

# be friendly and use humour with patients

- Patients asked questions at times during the sessions, suggesting some level of participation.
- The nurses inconsistently gave patients opportunities to ask questions.

## contact with patients

- Nurses made use of demonstrations and pencil drawings to facilitate patients' understanding.
- Patients were generally engaged and attentive and minimally distracted.

#### **Barriers**

- The nurses were observed to dominate the interactions, with patients taking a passive role.
- The nurses were observed to provide large amounts of convoluted information in a short space of time, with minimal patient input.
- Minimal requests to check understanding were used by the nurses and when they were, patients were not given time to respond or were interrupted by the diabetes nurse educator.
- There were language barriers at times and language preferences were not always considered. At times patients were discriminated against based on their language.
- Information given to the patients by the nurses was not matched to patients' questions or utterances, when they had been given an opportunity to clarify information.
- At times nurses presupposed that patients had no questions to ask.
- Nurses were insensitive, didactic and condescending at times.
- Minimal topic markers and setting statements were used.
   Topics were changed abruptly.

- No hand-outs or visual aids were used to supplement the verbal information given to patients.
- Breaches of patient confidentiality were observed, as various individuals were observed to enter the room throughout the nurse-patient interactions.
- Sessions were extremely rushed and fast-paced due to time constraints.
- Patients were often staring blankly at the nurses perhaps suggesting a lack of understanding and even boredom.

- Information was given at inappropriate times during some of the sessions.
- The nurses asked minimal questions related to patients' lifeworld and personal experiences, even when patients demonstrated distress related to GDM or its treatment.

The communication facilitators and barriers found to be the most salient (via discussion with supervisors and raters and comparison with findings across data sets) are discussed further below (these are indicated in bold text in the table above). All of the video recorded interactions were translated into English. The excerpts used to illustrate the facilitators and barriers have only been provided in English due to space-related constraints. However, a transcript with original and translated data has been attached (Appendix 8). Abbreviations have been used to indicator speakers as follows:

- N =Nurse (in this case, the diabetes nurse educator), at times N is followed by a number indicating other ward nurses who have been involved in the interactions
- P=Patient
- D= Doctor

#### Verbal communication facilitators

 The nurses were observed to be friendly and use humour during all six interactions with patients:

## Extract 1: Session 2

N: We lend you the machine so that you can test at home, but don't test the grannies in the location because the machine will show sugar levels that don't reflect here, we will see 25 when 25 is not even here ((points to the paper)) and then the doctor will say where does this 25 come from and then they will say it's your sugar you see. (laughs))

P: ((laughs))

## Extract 2: Session 5

*N*: You should know how to test now.

*P:* I know how to test.

N: Ja ja...

Yes yes

P: And I know how to check how it is.

N: Ok so here here here I don't teach anything. She's going to teach me about diabetes. ((smiles))

P: Hehahahaha.

Humour has been shown to be an effective tool in the context of healthcare interactions as it assists with rapport building and ensuring the patient of social support (de la O Hernández López, 2009; Graham, 1995; Martin, 2001). Humour has also been identified as a prominent coping strategy employed by patients who have type I diabetes (Tuncay, Musabak, Gok, & Kutlu, 2008). Friendliness and smiling during healthcare interactions has similarly been associated with increased patient satisfaction (Deveugele et al., 2005; Hiscock, Legard, & Snape, 2001). This may form one of the reasons for patients' affinity for the diabetes nurse educators at the clinic.

 Nurses inconsistently checked patients' prior knowledge related to GDM during five out of the six sessions

## Extract 3: Session 2

N: Do you know the signs? Do you have any idea what are the signs that show that you have?

P: I heard that sometimes you feel dizzy and then you have headaches

N: Sometimes the headache is caused by high blood pressure. With sugar you are likely to urinate constantly, drink lots of water and you don't gain weight and when you pregnant we cannot easily diagnose it because when you are pregnant you have those signs as a result of pregnancy, such as urinating frequently, going to the toilet over and over again.

## Extract 4: Session 4

N: Do you have an idea of what is diabetes?

P: I have a bit because my father had it.

N: Oh your father had diabetes?

P: Yes he did.

Checking understanding or prior knowledge in healthcare interactions by starting off with a question to the patient has been suggested to identify an individual's level of understanding of the topic and hence determine the level of detail required in the explanation (Spencer, 2003; Vermiere, Hearnshaw, Van Royen, & Denekens, 2001). In the extract above, the diabetes nurse educator uses the patient's understanding of symptoms as a starting point for the counselling session and builds on what the patient already knows. However, the diabetes nurse educator does not sufficiently

build on what the patient has offered, and is almost dismissive of the patients' perceptions, in that she continues with what the actual symptoms of GDM. There is no validation of the patients' contribution to the session. This may provide an explanation for patients' passivity and uncertainty related to GDM.

 The nurses made use of figures of speech in five out of the six sessions, in order to simplify explanations and facilitate patients' understanding

# Extract 5: Session 2 (personification of GDM)

N: For some people the illness stays even after pregnancy and becomes their chronic illness, sometimes you will find that the sugar [GDM] was there all long and waiting for you to be pregnant and it is then revealed once you are pregnant.

#### Extract 6: Session 3

- N: It's [the pancreas is] in our body, it's one of the parts in our body, and one of the duties of this pancreas is to put in certain water, right. This water is called insulin, what you will find is that it takes out this water across the body. After eating the food turns to sugar in the body, it becomes sugar; this sugar enables us to be active, to walk. It flows with the blood vessels towards different parts of the body so that we can be able to live.
- P: Ok.
- N: The blood that flows in the body has nutrients, it has everything. The food is digested after eating; the digested food is then turned into sugar.
- P: Hmm.
- N: When this food is turned into sugar in our body, our sugar levels go up and then the pancreas releases water [insulin] and this water causes the sugar

level to decrease and go back to normal.

Previous research by Casarett et al. (2010) showed that healthcare workers who included analogies and metaphors in their communication and explanations to seriously ill patients obtained higher ratings of communicative effectiveness from patients. Whaley (2014) documented similar findings in the context of explaining type I diabetes. In South Africa, the use of metaphors in understanding and explaining HIV/AIDS has also been documented, for example patients have likened having HIV/AIDS to having dirty blood and a disease which kills the "soldiers" in their body. However, authors have cautioned that the use of metaphors in explaining diseases and treatment may relate ambiguously to cultural fears, for example witchcraft (Ashforth & Nattrass, 2006). Whilst the diabetes nurse educators make use of analogies and metaphors to facilitate patients' understanding of GDM, they should however heed caution not to confuse or cause potential negative attitudes towards the condition or treatment in doing so.

#### Nonverbal communication facilitators

 The nurses were focused and engaged throughout their interactions with the patients in all sessions, suggested by consistent eye contact with patients.

## Extract 7: Session 5

- N: Ha ha is it in the family? ((joint eye contact))
- *P:* My mom has it. ((joint eye contact))
- N: Your mom has it ((nurse looks down and patient looks at nurse)). What does she use? ((joint eye contact))
- P: She uses pills. I think she uses metformin. ((joint eye contact))
- N: Is she still alive? ((joint eye contact))

*P*: Yes she is alive. ((joint eye contact))

## Extract 8: Session 6

- N: Ok, all right what do they say sugar is? ((joint eye contact))
- P: It's an illness caused by eating a lot of sugar. ((joint eye contact))
- N: Haa, haa ((shakes her head)) ((laughs)) do you eat a lot of sugar? ((joint eye contact))
- P: Yes I drink cold drink. ((joint eye contact))
- N: Ok some it's not because... Hee you don't get sugar because you eat a lot of sugar. ((joint eye contact))
- P: Ok. ((joint eye contact))

Eye contact has been documented as a vital communicative aspect in showing interest in the patient's situation and prompting patients to express their concerns (Gask & Usherwood, 2002; Goldberg, Jenkins, Miller, & Farrier, 1993). From the extract above, it is evident that the diabetes nurse educator maintains eye contact with the patient for the majority of the time that she is talking to her. This appears to elicit reciprocal eye contact from the patient, hence it appears to encourage joint interest and engagement from the patient and possibly a sense of comfort, further contributing to patients' reported affinity for the diabetes nurse educators.

#### **Verbal communication barriers**

 The nurses were observed to dominate the interactions, with patients taking a passive role during all six sessions

## Extract 9: Session 1

N: I always say your meal is your snack so you must wait and not wait for the child to be affected, it's not right. We must drink lots of fluids lots and lots of fluids, water, we must drink juice and not just any juice it must be 100% juice but don't drink cold drink if you love cold drink you can drink a little and you have to eat a lot of vegetables, we eat carrots, we eat spinach. You know that when you are pregnant you have a problem of anaemia, anaemia means the blood in your body goes down because you are now sharing it with the baby and it's usually around eight and nine. That is why they give you vitamins so that you don't have anaemia so you need vegetables, you need to eat things like beetroots, and things like spinach for anaemia and so on and you also need water

P: Mmm.

N: Right now what I want from you is that when you have a problem you must not sit at home, even if you are vomiting, when you are vomiting you must report it because diabetes and diarrhoea is not right for you. It will take you where you don't want to go, so when you vomit you must not just sit. Don't wait for Tuesday, you see the SMS that says sister X, you must SMS sister X and ask for help. Just say I am coming with a certain problem and we will meet you half way but don't stay at home and tell us that you have diarrhoea. When you are here we will tell so the hospital staff that there is a diabetic coming and they will wait for you. And also if the child is not playing don't just stay at home, you must come so that we can see if the child is positioned well. Don't go to your local clinic, when you go there they will tell you to come here and you would have wasted your time.

## Extract 10: Session 2

N: Some have it before pregnancy while others get it during pregnancy. The reason you get it when pregnant it's because of some of the things that happen to every mother. These things are caused by hormones; I don't know what they call hormones in our language. These things happen so that the

baby can grow and when these things happen they cause you to have sugar, you know there are certain infections that pregnant women are prone to. Sugar is one of the illnesses and high blood, but sometimes you can find that the sugar will go away after the pregnancy. For some people the illness stays even after pregnancy and becomes their chronic illness, sometimes you will find that the sugar was there all along and waiting for you to be pregnant and it is then revealed once you are pregnant and for some after pregnancy it goes and then how do we see the signs that you have sugar.

## P: ((nods her head))

This finding suggests that patients are obliged to listen attentively to large amounts of information, and are not given any opportunities to show that they have understood it. The desire of patients with diabetes to maintain a passive role in the healthcare interaction and leave education and decision-making up to the healthcare worker has been noted previously (Charles, Redko, Whelan, Gafni, & Reyno, 1998; Cooper, Booth, & Gill, 2003). Reasons for and implications of this finding are discussed in detail in the following chapter.

 The nurses were observed to provide large amounts of convoluted information in a short space of time, with minimal patient input i.e. information dumping. This was observed during all six sessions. This is also indicated by the extracts provided above.

This finding links with the statement by Chan, Wong, So, Kung and Wong (2013) that copious amounts of additional information in medical consultations may lead to limited understanding and patient recall of information. Hence, it is likely that this

information dumping results in patients' limited memory and recall of facts about GDM and its treatment as suggested by the findings of the focus group discussions. Furthermore Parker, Davis and Williams (1999) and Parker (2000) state that copious amounts of information given to patients in education or counselling sessions may result in patients feeling overwhelmed and as a result unable to ask questions. This suggests that the "information dumping" observed in the interviews may be contributing to the minimal responses and passivity of the patients.

Minimal requests to check understanding were used by the diabetes nurse educators
during all six sessions, and when they were, patients were not given time to respond
or were interrupted by the diabetes nurse educators.

## Extract 11: Session 1

N: Some get it when they're pregnant while others had it before the pregnancy and when you are pregnant it is not easy to see the symptoms such as urinating a lot you see? ((patient not given a chance to answer)). And one of the ways in which we pick it up is that it is hereditary.

## Extract 12: Session 2

N: How long you will stay here will be dependent on the sugar you see because we have found out we are going to check with the doctor as to which treatment should be ordered so that you can be discharged by the weekend, so far so good you don't have another question ((this is assumed)), and don't worry about the machine because when we discharge you we are going to borrow you the machine and the machines are the same that other one is black.

Baker, Crockett, Uus, Bamford and Marteau (2007) have identified checking patient understanding as a vital part of the communicative interaction between patients and healthcare workers, but have also identified that it is often not used and thought to be ineffective by most healthcare workers. West and Baile (2010) highlight that although checking patients' understanding may be time-consuming, it may help to make information giving sessions more time efficient by ensuring that they focus on areas in which the patient is struggling and requires support and explanation. Graham and Brookey (2008) also highlight that healthcare workers need to ensure that when checks for understanding are used, they are used appropriately and not in a manner that is insensitive or humiliating for the patient.

The use of tag questions, such as "you see?" or "ok?" has been documented as a method of checking patients' understanding in South African healthcare interactions (Watermeyer & Penn, 2009b). Whilst this is evident in the extracts above, the nurses' tendency to rush through the checks for understanding and tag questions appeared to reduce the number of realistic opportunities offered for patients to ask questions and clarify information. The lack of chances provided for patients to respond to tag questions may be perceived as condescending and insensitive and may well cause patients to feel humiliated and disempowered.

 In four out of the six sessions, information given to patients by the nurses was not matched to patients' questions or utterances, when they had been given an opportunity to clarify information.

## Extract 13: Session 2

*P:* So once I have tested after lunch I must write?

N: Yes you write everywhere, we are going to give you a ball pen.

*P:* Ok but I don't write here?

## Extract 14: Session 5

P: So now as I have my sugar, the baby has their own sugar as well?

N: But because a system is a system.

P: Mmm.

This has been noted previously by authors such as Macdonald et al. (2013). Based on the findings of this study, diabetes nurse educators appear to have adopted the agenda of solely giving patients information about their condition, and not necessarily addressing patients' specific difficulties. Barry, Bradley, Britten, Stevenson and Barber (2000) found that poor health and patient outcomes are associated with patients having agendas which are not voiced directly during medical interactions and posit that it is important that healthcare providers facilitate the voicing of patients' needs and agendas in consultations. It appears that the patients who have GDM are not directly voicing all of their agendas and thus maintain a passive role in their interactions with the diabetes nurse educators, possibly resulting in unanswered questions, limited understanding and negative attitudes towards treatment recommendations and adherence.

During all six sessions, the diabetes nurse educators asked minimal questions that
were related to patients' lifeworld and personal experiences, even when patients
demonstrated distress related to experiences with GDM or its treatment.

## Extract 15: Session 3

*P:* Until I give birth I will be injecting my fingers?

N: Everyday.

P: Everyday?

N: Everyday six times a day.

P: Oh no.((patient hides face in hands))

N: This is the machine, you saw how it works.

## Extract 16: Session 6

N: Do you have a family history of people who have sugar at home?

P: Yes my father had sugar.

N: What did he use?

P: Pills.

N: Pills ok, is he still alive?

*P*: No he is no longer alive.

N: Ok all right what do they say sugar is?

The importance of considering a patient's lifeworld as part of his/her care and management has been previously highlighted (Dahlberg, Todres, & Galvin, 2008; Johansson, Ekebergh, & Dahlberg, 2009; Kurtz, Silverman, Benson, & Draper, 2003). A consideration of the patient's lifeworld and how it affects their understanding has been linked with increased patient satisfaction, recall of health information and improved health outcomes, in the context of various conditions, including diabetes (Hörnsten, Lundman, Stenlund, & Sandström, 2005; Stewart et al., 2003). It is thus likely that the apparent lack of exploration of the patients' lifeworld in relation to GDM and its treatment may be another contributing factor to the

stigma, negative attitudes and lack of understanding related to the condition and its treatment which patients' demonstrated in the focus groups.

#### Nonverbal communication barriers

 Breaches of patient confidentiality were observed in five of the six sessions, as various individuals were observed to enter the room throughout the nurse-patient interactions.

## Extract 17: Session 1

- N: You must come here. Don't go to casualty, they will turn you back and tell you to come to maternity because you are pregnant. When you are pregnant you come here, when you are pregnant we deal with everything here and when you are not pregnant you go to casualty. Please come here take your file and come here, don't leave your machine alright...
- D: ((walks past and shouts)) Can I see the patients here? ((interruption))
- N: We are coming Doctor. Don't leave your machine behind, because what if you get here and there is no machine, because a machine is your weapon that shows you level of sugar. If the baby is not playing come to the clinic. I don't want us to realise that the baby's heart is no longer beating when we are checking them. I am telling you because people have stories, some they will tell you that I went shopping and others will tell that I was visiting and I could not test.

#### Extract 18: Session 3

P: Yes they didn't have it, my grandmother is still alive and she doesn't have anything.

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N2: ((opens door into counselling room)) You are going to appear on TV N.

N: No heeheeheehee...

P: Ahahaha.

N2: N look this side are you going to appear on TV.

N: Heeheehee ...

N2: ((leaves room and closes door))

The frequency of interruptions, extraneous distractions and breaches of patient privacy within the South African healthcare context have been previously recognised by Penn (2007). It is, however, interesting to note that the patients, although perhaps uncomfortable, did not seem to become disengaged from the interactions with the diabetes nurse educators and continued to attend to the information being provided. The lack of patients' concern related to these interruptions is in line with previous research which has found that the majority of patients and healthcare workers do not feel negatively affected by interruptions in medical consultations (Dearden, Smithers, & Thapar, 1996; Jiwa et al., 2009).

# **Nurse interviews**

Interestingly all of the nurses (including the diabetes nurse educators) were allocated to the GDM ward, but only some of the nurses reported a willingness to be involved in GDM care. Allocations and the dismissal of individual's requests or preferences is perhaps a result of nursing staff shortages at the site, which is a common occurrence in the South African healthcare context.

As with the patient focus groups, the analysis of the nurse interview data yielded a large number of categories and sub-categories. These were derived from three main themes. The table of these themes and related categories and sub-categories is presented below (Table 10).

Table 10. Nurse interview themes

| Theme                       | Category                         | Sub-category                   |
|-----------------------------|----------------------------------|--------------------------------|
| Communication at the clinic | Communication with patients      | Difficulty communicating and   |
|                             | who have GDM                     | caring for patients who have   |
|                             |                                  | GDM                            |
|                             |                                  | Differing between various      |
|                             |                                  | patients and nurses            |
|                             | Communication with other         | Good communication             |
|                             | nurses                           | Hierarchy and conflict         |
|                             |                                  | Limited communication          |
|                             |                                  | between ward nurses and        |
|                             |                                  | diabetes nurse educators       |
|                             | Communication with doctors       | Poor communication between     |
|                             |                                  | doctors and nurses             |
| Perceptions of GDM patients | Preconceived ideas of GDM        | Difficult                      |
|                             | patients                         | Arrogant                       |
|                             |                                  | Resistant                      |
|                             |                                  | Manipulative                   |
|                             | Perceptions of GDM patients'     | Good                           |
|                             | understanding of their           | Poor understanding of diet     |
|                             | condition                        | Poor understanding of          |
|                             |                                  | treatment and glucose          |
|                             |                                  | monitoring                     |
|                             |                                  | Increased understanding and    |
|                             |                                  | acceptance with time           |
|                             | Perceptions of GDM patients'     | Good adherence to treatment    |
|                             | adherence to treatment           | generally whilst in the ward   |
|                             |                                  | Poor adherence to diet         |
|                             | Perceptions of patients feelings | Fear                           |
|                             | and concerns                     | Preference of diabetes nurse   |
|                             |                                  | educators                      |
|                             |                                  | Dissatisfaction with diet      |
|                             |                                  | Negative preconceived ideas of |
|                             |                                  | nurse                          |
|                             |                                  | Sense of neglect and isolation |
|                             |                                  | Satisfaction                   |
|                             |                                  | Anger and denial               |
|                             |                                  | Concerns about the future      |
|                             | Relationship with GDM patients   | Good                           |
|                             |                                  | 1                              |

|                               |                            | time                            |
|-------------------------------|----------------------------|---------------------------------|
| Nurses' perceptions of selves | Perceptions of good        | Listening                       |
| and the GDM clinic            | communication skills       | Friendliness                    |
|                               |                            | Trust and mutual                |
|                               |                            | understanding                   |
|                               |                            | Spending time                   |
|                               |                            | Respect                         |
|                               |                            | Acceptance of the patient as a  |
|                               |                            | person/ patient-centred         |
|                               |                            | communication                   |
|                               | Environmental difficulties | Staff shortages                 |
|                               |                            | Resource and space shortages    |
|                               |                            | Workload                        |
|                               |                            | Low interest levels             |
|                               |                            | Burnout                         |
|                               | Perceived needs to improve | In-service training to increase |
|                               | GDM patient care and       | GDM knowledge                   |
|                               | communication              | Communication and personal      |
|                               |                            | connection between nurses and   |
|                               |                            | GDM patients                    |
|                               |                            | Decentralised GDM services      |
|                               |                            | Peer education                  |
|                               |                            | Family involvement              |
|                               |                            | Change in patients' and nurses' |
|                               |                            | attitude                        |

The three main themes are discussed below, with a focus on sub-categories which were found to be of highest salience, based on their frequency and perceived relevance and importance, as with the patient focus group data. N followed by a number has been used to show which nurse provided each of the quotes.

# Theme 1: Communication at the clinic

"It's so challenging... especially when you don't have a lot of idea to tell them, a lot of information to tell them ne" (N1)

"It's difficult ...like maybe you understand Zulu but you don't speak it fluently and you're trying to explain the condition it would be difficult for them" (N5)

<sup>&</sup>quot;It's difficult to talk to them, they just become negative" (N11)

"We once in a while get a stubborn patient who wants to do things their own way...they'll refuse and decide to just do their own thing" (N2)

The above findings relate to previous literature in the area of diabetes, in which nurses have reported communication with and education of diabetes patients to be extremely difficult. Jansink, Braspenning, van der Weijden, Elwyn and Grol (2010), documented that nurses found lifestyle education and counselling of diabetes patients difficult due to resistance and lack of motivation amongst patients, as well as barriers such as time constraints and limited counselling skills. Lee, Lee, and Ng (2012) further highlighted language issues as an inhibitor to effective nurse-patient communication in diabetes. This highlights the need for strategies to improve the communication, skills and attitudes of nurses and patients at the GDM clinic This notion is supported by Siminerio, Funnell, Peyrot and Rubin (2007), who documented nurses as being better communicators than physicians in educating and counselling patients with diabetes, and hence healthcare workers who should take the main responsibility for counselling and educating. Whilst there are two diabetes nurse educators at the clinic, this finding may also highlight the need to train more ward nurses in GDM, as the ward nurses appeared to have the most difficulty (more so than the diabetes nurse educators) dealing with GDM and patients who have the condition.

Further salient sub-categories which emerged under theme 1 include hierarchy and conflict between nurses working at the GDM clinic, as well as limited communication between the ward nurses and the diabetes nurse educators. This is highlighted by the following quotes:

"Since we are the nurse without anything [lapels or badges] the work is mostly upon us... and then they [professional nurses] are oppressing us" (N1)

"It's difficult you know when you're young, you're a senior...I don't think we should do it that way...but you know we've been doing it like this for years, you can't come here and tell us" (N5)

"We [diabetes nurse educators] communicate well with them [ward nurses]...but some they don't have interest...because they know that there is somebody else who is responsible for this" (Diabetes nurse educators)

"There are some things that aren't possible to do here and you'll find that they [diabetes nurse educators] didn't do it, now the patients are left with us" (N8)

From the illustrative quotes provided above, it appears that the intra-professional difficulties among the nurses relate to level of qualification, the institution where the qualification was obtained and the amount of experience and time that an individual has spent working at the clinic. Similar intra-professional issues among nurses have been raised by Daiski (2004), Randle (2003) and Rouse and Al-Magbali (2014) who have highlighted bullying, a lack of intra-professional support and hierarchy as common obstacles to intra-professional and nurse-patient communication within the healthcare context. This finding highlights the need for methods to change and improve communication practices among nurses so that reported conflicts and disproportional power relations are prevented at all levels at the clinic.

#### Theme 2: Perceptions of GDM patients

"Patients have got this thing that the nurses are rude" (N2)

"If you tell the patient something...they want the information from a professional nurse or the doctor" (N7)

"I don't know if it's socialisation or what but the diabetic women are like a community on their own. Those women. They're full of drama...you will not find a diabetic woman who is different from the others...they will trick you" (N5) I think diabetic[s] they are proud.....they want to be special...they come [with] 'us diabetic we want this and this'" (N9)

"We know that they [the patients] are not honest...someone it's the first time, no family history, nothing and there is that negativity, or if you are not available you as a diabetic sister...and other patients are helping them to do their glucose test they feel like they don't want to be shown by another patient" (Diabetes nurse educators)

From the data provided above, it appears that the nurses have constructed a stereotypical view of patients with GDM, based on their prior experiences and perhaps from information gained within their community (e.g. that patients think that all nurses are rude). The nurses appear to be generalising this stereotype across all patients who have GDM. The existence of negative nurse and patient stereotypes has been documented in previous literature related to other chronic conditions (Brown, 2006; Lethoba, Netswera, & Rankhumise, 2006; Ross & Goldner, 2009). However, minimal work on stereotypes in diabetes care seems available. Whilst nurses and patients have been documented to stereotype one another negatively, in a comparison of stereotypes inter-professionally between doctors and nurses, nurses were stereotyped positively (Carpenter, 1995). This highlights the effect of context, socialisation and prior experience within the healthcare system. At the GDM clinic, nurses appear to view the patients with GDM as "stubborn", "full of drama" and "difficult", suggesting prior negative experiences with patients who have GDM. It is suggested that these negative stereotypes affect nurses' attitudes and communication with patients who have GDM, as a link between negative stereotypes and negative attitudes has been noted among nurses by Brown (2006). This highlights the need for increased collaboration between nurses and patients with GDM and the setting of common goals.

## Theme 3: Nurses' perceptions of selves and the GDM clinic

"The [GDM] clinic does not come with staff" (N11)

"Shortage of resources... 'cause when we have too many patients and we don't have resources they look at us" (N2)

"If you're short staffed and there's a lot of workload, you're not the same person, no matter how passionate you are" (N5)

"There's a workload. It's demanding, very demanding...if there's a fully dilated [patient] you can't be seated with a patient busy explaining this [GDM]" (N8)

The difficulties voiced by the nurses provide some indication as to what it is like to work within the government healthcare sector in South Africa. The difficulties reported above by the nurses working in the GDM ward have also been documented extensively by other South African authors such as Peltzer, Mashego and Mabeba (2003) and Oosthuizen (2012). These difficulties probably account for the many communication difficulties experienced at the GDM clinic and hence contributing to some of the negative attitudes and dissatisfaction demonstrated by nurse and patient participants. New solutions need to be devised and implemented to reduce the stress and anxiety imposed on nurses by shortcomings related to the environment and resources.

#### **Chapter summary**

This chapter has provided a systematic representation of all of the results that emerged from the data sets. A specific focus has been placed on the most salient and relevant of these findings, which have been presented in conjunction with existing literature, facilitating some brief discussion.

It is evident that there are gaps in communication practices at the GDM clinic and that these gaps are resulting in a multitude of difficulties for patients and nurses. The findings that emerged from the data of this study have been provided and briefly discussed in conjunction with earlier related literature. However, some of the findings and issues raised by participants require further exploration and discussion to be optimally understood and useful in terms of informing solutions. Hence, in the following chapter all of the salient issues raised in this chapter will be explored in greater depth and triangulated with all data sets to provide a clear understanding of the communication practices at the GDM clinic, their possible causes, their effects on nurses and patients, and possible implications that they inform.

# **CHAPTER 5: DISCUSSION**

This chapter provides a detailed consideration of the findings which were presented in the previous chapter. In this chapter, findings are triangulated across data sets and compared to previous literature. Causes and consequences of the findings are subsequently explored to provide an understanding of the communication practices at the clinic, barriers and facilitators and the consequences of these communication practices on patients' understanding of the condition and its treatment, and living with the condition in South Africa. All of these phenomena are then used to inform implications of this study for the areas of practice, research, policy and theory. These implications are discussed thereafter.

## **Communication at the GDM clinic**

Based on the findings of this study various facilitators of communication appear to exist at the GDM clinic. These facilitators include those noted in the findings of the video recorded education sessions and the encouragement of informal peer discussion in the GDM ward. However, various barriers to communication also appear to exist at the clinic, as suggested by findings across all three data sets. These barriers seem significant and thus deserve substantial discussion and exploration, as communication and the manner in which information is given have been noted to affect a number of patient outcomes, including physical and emotional wellbeing and adherence to treatment regimens (Falvo, 2011; Haskard Zolnierek, & DiMatteo, 2009; Hjelm, Berntorp, Frid, Aberg, & Apelqvist, 2008; Loh, Leonhart, Wills, Simon & Härter, 2007). In exploring the barriers to communication at the clinic, a more detailed discussion of what appear to be the most factors is necessary.

## **Inadequate information delivery**

Perhaps the most obvious barrier to communication at the GDM clinic is the lack or reportedly suboptimal quality of information-giving at the clinic. Many participants reported having received no information about GDM or its treatment at the clinic. Participants reported consulting sources outside of the clinic to learn about the condition.

The findings of this project suggest that patients are not receiving sufficient and relevant information during these education sessions, as confirmed by the analysis of the video recordings. Patients were noted to be passive throughout the education sessions, and diabetes nurse educators were observed to "dump" copious amounts of information, which was irrelevant at times, onto patients. Parker, Davis and Williams (1999) and Emory (2000) state that copious amounts of information given to patients in education sessions may result in patients feeling overwhelmed, uncertain, and as a result unable to ask questions. Larsson, Sahlsten, Segesten, and Plos (2011) also found that disengagement and disempowerment of patients in their care was associated with communication behaviours which included belittling statements, lack of support and lack of inclusion in treatment decision making. These are similar to the communication barriers that were noted in the video recorded education sessions. This suggests that the way that information is being given in education sessions is not facilitating optimal patient understanding and may leave patients feeling confused and anxious, as suggested by the uncertainty, frustration and dissatisfaction which was evident in the patient focus group data.

Based on patient reports, it is also possible that some patients are not receiving any education about their condition at all. This may be due to the lack of regular communication between the ward nurses and diabetes nurse educators may be resulting in patients slipping through the system without receiving education.

## **Cultural and linguistic diversity**

Cultural and linguistic diversity may impose difficulties within healthcare interactions and contribute as a barrier towards the limitations in communication and information giving at the GDM clinic, as suggested by previous literature (Browne, 2007; Fernandez et al., 2004; Mullins, Blatt, Gbarayor, Yang, & Baquet, 2005). Both nurses and patients reported language as a barrier to effective communication between nurses and patients at times, and the range of various cultures and language present at the GDM clinic is also evident from demographic features. It is likely that the mismatch of cultures and languages may be resulting in communication barriers in interactions, such as limited understanding of the information given to patients with GDM by the nurses.

It is interesting to note that the literature cited above speaks of language and cultural mismatch affecting minority groups. The patients at the GDM clinic are, however, a majority group in terms of South African demographics, highlighting that one should be cautious not to overlook the possibility of linguistic and cultural mismatch even in the absence of minority groups. This point also suggests that one should avoid generalising across African cultures and languages, as it is evident from the findings of this study that salient

differences exist between them. Ways of facilitating more trusting communication that facilitates culturally appropriate interactions are suggested to lessen the negative effects of socio-cultural differences in the healthcare context (Perloff, Bonder, Ray, Ray, & Siminoff, 2006). Ways of facilitating improved communication at the GDM clinic are discussed under implications.

#### **Resource difficulties**

Additionally, issues related to the environment and resource shortages may be hindering diabetes nurse educators from educating all newly diagnosed patients, as they are often short of time and expected to run other clinics within the maternity wards. This again highlights the difficulty faced by nurses within the South African government healthcare context, although a number of international studies have similarly documented the negative effects of resource shortages and understaffing on patient care, and patient and staff wellbeing (Aiken, Clarke, Sloane, Sochalski, & Silber, 2002; Aiken, Clarke, Sloane, Lake, & Cheney, 2008; Saxena, Thornicroft, Knapp, & Whiteford, 2007).

#### A lack of skills and knowledge

A further barrier to communication in nurse-patient interactions at the GDM clinic might also be the ward nurses' lack of knowledge and communication skills related to GDM (as reported during the nurse interviews). Nurses reported that they are not sufficiently equipped to provide patients with information about GDM when they are asked to do so by the patients. Optimal diabetes care has been linked to sufficient knowledge levels regarding

diabetes (Rubin, Moshang, & Jabbour, 2007). Furthermore, patients with diabetes who were managed by trained nurses have been found to yield better health outcomes than patients who were managed by primary care providers (Gabbay et al., 2006). This suggests the potential of the GDM clinic, If strategies were implemented to improve the nurses' (particularly the ward nurses') knowledge and skills related to GDM.

## **Different agendas**

Differing agendas may also form a reason for patients' negative perceptions of the quality of information giving at the GDM clinic. During the video recorded education sessions, it was often evident that the agendas of the patients and the diabetes nurse educators differed. Patients' agendas seemed to be to acquire relevant information about GDM and how it would affect them, in order to help them to live positively with it. The diabetes nurse educators, however, seemed to have the agenda of giving patients as much information as possible about GDM within a limited space of time. There was no tailoring of information according to patients' knowledge and needs. This relates to previous research which noted a disagreement between the goals of patients with diabetes and those of their healthcare providers, and an association between agreement of goals and patients' self efficacy (Heisler et al., 2003). This highlights the importance of devising strategies to match the agendas and goals of the diabetes nurse educators and patients with GDM. It also raises the importance of educating nurses with regard to information-giving and communication techniques and maintaining nurses' levels of job interest and motivation.

## **Negative attitudes**

A further barrier to effective communication at the GDM clinic appears to be negative attitudes. Both nurses and patients were noted to possess negative attitudes towards one another and towards GDM and its treatment. The majority of nurses described patients as difficult to communicate with and vice versa. The majority of patients and nurses were observed to describe one another negatively. It is likely that preconceived ideas of one another seem to be contributing a great deal to these negative attitudes, as Brown (2006) has documented that negative stereotyping in the healthcare context leads to negative attitudes. This appears to be creating a combative environment in which nurses and patients who have GDM are working against one another, instead of with one another. This issue highlights the importance of facilitating collaborative communication between the two groups, as collaborative relationships have been noted to foster increased self-management in patients who have diabetes (Nagalkerk, Reick, & Meengs, 2006).

Negative attitudes were also evident intra-professionally among the nurses, with reports of limited communication between nurses of differing professional levels, as a result of hierarchy and reported conflict. Limited communication between health care workers and a strong sense of hierarchy may result in professionals feeling anxious and reluctant to ask questions or even report poor performance of their peers and is likely to affect patient management (Rosenstein & O'Daniel, 2008; Tija et al., 2009). In a South African study, nurses were similarly found to report hierarchy within the medical health team, but highlighted collaboration and team work as an important predictor of patient care (Seedat, 2013). Randle (2003) explains the main reason for conflict and intimidating behaviour within

the nursing profession in the following manner: younger, newer nurses' observe conflict among older nurses and the subsequently internalise these norms. This was reported to result in reduced self-esteem among nurses, suggesting that increasing empowerment may be a way to prevent intimidation and bulling amongst nurses.

The importance of communication and delivering information and its association with increased treatment adherence, positive attitudes, reduced stress levels, increased empowerment and more practical expectations has been documented (Mills & Sullivan, 1999). A lack of information and communication may thus be contributing to patients' negative attitudes and emotions, as well as their lack of knowledge related to GDM and its treatment, which may well be forming a barrier to treatment adherence. Practical strategies thus need to be put into place to improve the frequency and quality of information giving at the GDM clinic.

## A paradox

In spite of all of the barriers to communication noted in this study, a salient phenomenon emerged from the data in the form of an apparent paradox. Despite the fact that diabetes nurse educators were noted to engage in communication behaviours which appeared to form possible barriers to optimal patient understanding of and attitudes towards GDM and its treatment (for example, patients took an extremely passive role and nurses were noted to dump information on patients and show little interest in patients' emotions of lifeworld) patients described their interactions with the diabetes nurse educators as highly satisfactory

and highlighted the diabetes nurse educators as effective communicators at the clinic. A number of reasons for this paradox appear to exist. These are suggested below.

Trust has been found to have a significant effect on patient satisfaction and treatment continuity (Thom, Ribisl, Stewart, & Luke, 1999). Trust has been documented to occur as a result of perceived competence or knowledge and the caring nature of the healthcare worker, as well as patient-centred care (Berrios-rivera et al., 2006; Jacobs, Rolle, Ferans, Whitaker, & Warnecke, 2006). It is evident that the patients with GDM trust the diabetes nurse educators, as they perceive them to be caring and have expert knowledge related to GDM and its treatment.

Watermeyer (2012) further highlighted that patients' belief that a clinic or healthcare facility is "life-saving" and has saved him or from dying appeared to contribute to patients' trust and positive regard of healthcare facilities, despite the fact that a facility may offer care that is of low quality standards. Patients in this study highlighted that fear is associated with GDM within their communities. The clinic has also reported positive health outcomes in 95% of women who have attended it. In this study some patients also compared the GDM clinic to other clinics that they had attended. For example, a participant in focus group three said "There is no other ward that is like this one... There hasn't been a day when I got upset since I came to this clinic" and "When I got here it was full but the nurses took care of me". It thus appears that patients may be associating the diabetes nurse educators with care that is

superior to that at other clinics, and vital to the survival of themselves and their children, hence adding to their positive regard of the diabetes nurse educators.

Berrios-rivera et al. (2006) further suggested that patients' trust in a health system influences their trust in a healthcare worker. The halo effect - the phenomenon where an individual's judgement of an item is affected by their previous judgements of related items (Powers & Knapp, 2011) - is important to consider as a possible contributor towards patients' trust in and positive attitude towards the diabetes nurse educators. Trust in a particular hospital or clinic may easily lead to trust in individuals who at the facility especially in new interactions (Buchanan, 2000).

It is important to consider that the GDM clinic is one of the few specialist diabetes clinics in the area, and the qualified diabetes nurse educator has been working at the clinic for a long time. It is thus possible that patients' respect and positive regard for the diabetes nurse educators stems from patients' positive regard for the actual clinic itself and their negative experiences at other clinics and facilities which do not provide education and counselling for patients who have GDM. It is also possible that the diabetes nurse educators' long-term commitment to serving members of the community who are pregnant and suffering from a health condition has rendered them highly respected in spite of the fact that the way in which they communicate information is not always effective and optimal.

## **Effects of the barriers to communication**

Whilst patients appeared satisfied with the communication within their interactions with the diabetes nurse educators, the barriers noted in the video recorded education sessions and the limited communicative interactions with ward nurses seemed to be resulting in a number of negative consequences, as expected from previous literature. Patients were noted to demonstrate a lack of agency and empowerment and reported a strong desire for increased agency in managing their condition and taking treatment. This desire for agency was further demonstrated by their desire for increased peer group support and education. Furthermore, patients reported having a limited understanding, as well as lifeworld issues which appeared to impact negatively on their experience of living with GDM in the South African context. These effects are discussed in detail below alongside ways of tailoring communication practices to transform patients' negative experiences and emotions into positive ones.

#### Lack of empowerment

Empowerment and active involvement are vital facilitators of patient-centred care (Epstein & Street, 2011). Triangulation across datasets suggests that patients attending the GDM clinic lack empowerment and agency, despite their desire for it. During the video-recorded education sessions, patients appeared to be disempowered and passive in their communicative interactions with the diabetes nurse educators. The reasons for this lack of empowerment and agency at the GDM clinic require some exploration.

Whilst it has been documented that patients sometimes do not wish to play an active role in their management and treatment decisions (Arora & McHorney, 2000; Deber, Kraetschmer, Urowitz, & Sharpe, 2007), it is hypothesised that patients' acceptance of minimal involvement in learning about the condition in the context of this study may partially stem from the socio-political history of South Africa. Coovadia, Jewkes, Barron, Sanders, and McIntyre (2009) suggest that the challenges faced by the public health system in South Africa are to a large extent a result of the political history of the country, including discrimination based on race and gender, the separation of families, socioeconomic inequity, violence and the migrant labour system. Apartheid enforced that black South Africans take a disempowered stance and Thabo Mbeki, one of the post-apartheid South African rulers warned that black South Africans should not allow their struggle against apartheid to fade into a passive willingness to receive whatever is provided by the government (Ashforth, 2005). Based on the findings in this study it appears that patients may maintain a passive role as a result of being accustomed to disempowerment and passivity during apartheid, but also perhaps as a result of the perceptions of diabetes nurse educators as the experts who are committed to helping patients who have GDM.

A further contributing factor to the lack of empowerment amongst patients may also result from the lack of sufficient information provision at the GDM clinic as Funnell et al. (1991) state that patients are empowered when they have acquired adequate knowledge, skills, attitudes and self-awareness to control their behaviours and those of others to achieve a high quality of life. This corresponds with the lack of information which patients reported to have received and with the barriers noted during the video recorded education sessions where diabetes nurse educators were noted to provide information that was irrelevant and

overwhelming for patients upon their initial diagnosis. It also corresponds with the findings of the patient focus groups, which suggested that patients lack knowledge and a positive attitude towards GDM and its treatment. This appears to be preventing them from having full control over their GDM and achieving optimal quality of life and satisfaction. As Anderson and Funnell (2010) describe it, empowerment is not something that healthcare workers should do to patients, but rather foster by showing patients that they are the leaders of managing their condition through the ways that they educate and communicate with them. Whilst it is simplistic to argue that knowledge acquisition is the primary reason for reduced empowerment among South African patients, it must be considered as a contributing factor. This discussion highlights some important implications for practice.

The role of power and power relations forms a further possible cause for the lack of empowerment among patients who have GDM. Power relations may also form a reason why patients appeared comfortable disclosing their desire for empowerment to the researcher, but were not comfortable disclosing it to the nurses. Disempowerment may result from significant power imbalances between patients and nurses in interactions, causing patients to feel fearful and maintain a passive, disempowered role (Henderson, 2003). Henderson (2003) noted that this power imbalance occurred as a result of the nurses' perceptions that patients were less knowledgeable and their desire to maintain power in the healthcare context. Cultural attitudes towards doctors and nurses as authority figures may also result in patients feeling fearful, as suggested by Meeuwesen, Tromp, Schouten and Harmsen (2007).

Another suggested reason for this lack of empowerment among patients is that the nurses working at the GDM clinic may in fact be disempowered themselves, as Manojlovich (2007) has stated that disempowered nurses are often ineffective, dissatisfied and more at risk of experiencing burnout. This disempowerment may be resulting from unequal power relations between nurses and other professionals, such as doctors, which may be disempowering them, as suggested by the findings of Nugus, Greenfield, Travaglia, Westbrook, and Braithwaite (2010). The mismatch between patients' and healthcare providers' cultural backgrounds and beliefs has further been documented as a cause of disempowerment and lack of access to healthcare in South Africa (Rothberg, 2008).

As highlighted above, agency and empowerment are vital elements that need to be established and encouraged amongst patients who have GDM, as they have been associated with improved health outcomes and improved emotional wellbeing among patients (Pibernik-Okanovic, Prasek, Poljicanin-Flipovic, Pavlic-Renar, & Metelko, 2004; Tang, Funnell, Brown, & Kurlander, 2010). Furthermore, increasing empowerment and engagement within communities and amongst individual patients themselves has been found to prevent the occurrence of diabetes and other non-communicable conditions (Mohan et al., 2005). This suggests the need for strategies to facilitate increased empowerment levels among nurses and patients at the GDM clinic. Some recommendations to achieve this are discussed under the implications section of this dissertation.

### A desire for peer support and education

An indicator of patients' desire for empowerment and agency appears to be the desire for increased regular peer support and education as a means of learning about GDM and its treatment and dealing with negative emotions related to the condition. This links to the previous study at the site (Burkett, 2012) as well as other studies which have highlighted the positive effects of peer support and learning in the context of diabetes (Joseph, Griffin, Hall, & Sullivan, 2001; Keyserling et al., 2002). Broadhead et al. (2002) further suggested that peer support not only assists in providing socio-emotional support and improving health indices but also forms a successful method of grasping the tasks involved in managing the condition.

Smith et al. (2011) have alternately cautioned that peer support does not always have positive effects on health outcomes in the context of type II diabetes. This suggests that diabetes management should not consist solely of peer education and support programmes, which interestingly aligns with patients' desire for peer education and support in conjunction with other information provision methods. In advocating for peer support and education perhaps the work of Fisher et al. (2012) should be considered. These authors noted that peer education had a positive effect on health and socio-emotional outcomes for patients in various African countries, including South Africa when the following functions of peer support were met: assistance in day-to-day management of diabetes, socio-emotional support, association with medical care and continuous availability. This suggests that if peer support and education is formalised at the clinic and constructed to fulfil these four

functions, it may form an effective method of improving the health outcomes and quality of life of patients who have GDM.

A number of patients stressed their desire to learn about GDM from someone who has or has had the condition, suggesting that an 'expert patient' be employed or requested to volunteer to run education and support groups who patients who have GDM at the clinic. This raises discussion around the efficacy and previously documented effects of the use of the 'expert patient' to inform and support patients. The use of an expert patient or lay educator in educating supporting patients who have conditions of a chronic nature has been documented to have a positive effect by certain authors. For example, Griffiths et al. (2005) documented increased self-management, self-efficacy behaviours and psychosocial wellbeing in patients who regularly attended self-management programmes run by lay educators who, themselves, had similar condition. Similar findings were noted by Kennedy et al. (2007). However, it has also been documented that lay education by expert patients have had minimal effects on health outcomes, health related quality of life, and patients utilisation of healthcare (Barlow, Turner, & Wright, 2000; Buszewicz et al., 2006; Griffiths et al., 2005; Kennedy et al., 2007).

Within the South African context, expert patients or lay educators are commonly used in educating and caring for patients with HIV/AIDS and have been found to increase antiretroviral uptake and lessen the burden of care on nurses and doctors (Bedelu, Ford, Hilderbrand, & Reuter, 2007). However, difficulties have arisen due to the lack of

remuneration and incentive, resulting in expert patients or lay educators most probably being a short-term solution (Zachariah et al., 2009). Other recent work has also documented hierarchy and abuse of power as possible disadvantages of the expert patient (Walters, 2014).

The discussion above highlights various findings regarding the efficacy, sustainability and success of expert patients in the education of patients with conditions of a chronic nature. It is thus suggested that expert patients be used as an adjunct to other methods of patient education/counselling and support at the GDM clinic. This suggestion is in line with recommendations of Kennedy et al. (2007). Perhaps the government could consider budgeting for the remuneration of expert patients and lay educators or incentives could be provided for expert patients who have GDM to assist as lay educators at the clinic. The discussion above also highlights the need to consider peer support in a nuanced way according to the particular condition and care context.

#### Lack of understanding of GDM and its treatment and lifeworld difficulties

An additional significant effect of the limited communication at the GDM clinic appeared to be a lack of understanding of the condition and, subsequently, significant lifeworld difficulties related to GDM. The difficulty of understanding and adhering to the recommended diet and catering for family needs, for example, raises the discussion of living with GDM in the South African context and the importance of facilitating optimal

understanding of the condition and its treatment among affected communities but also considering the individual lifeworlds of patients which might make adherence a challenge.

In this study, both nurses and patients suggested that the community's understanding of GDM is limited. Whilst the diabetes nurse educators at the GDM clinic may attempt to facilitate patients' understanding at the clinic, perhaps they should also focus on facilitating understanding of the condition amongst community and family members, as patients' views and understanding are likely to be affected by those of their families, social networks and cultural beliefs, as suggested by Siminoff (2013). The diabetes nurse educators were not observed to consider each patient's individual lifeworld when explaining the condition or its treatment to them at the GDM clinic. Increased attention thus needs to be given to the socio-cultural backgrounds of the patients, particularly patients' beliefs, values, social and financial contexts when patients are educated about the condition at the clinic.

Broadbent, Donkin and Stroh (2011) have additionally highlighted that patients' perceptions influence their adherence to medication, diet and exercise in diabetes. Patton (2011) also highlighted the importance of considering community related factors, in conjunction with personal factors in understanding the reasons for dietary non-adherence in diabetes. Increased emphasis should thus be placed on exploring patients' individual perceptions of a healthy diet and negotiating with patients to achieve a treatment regimen that is practical, effective and in line with patients' individual beliefs.

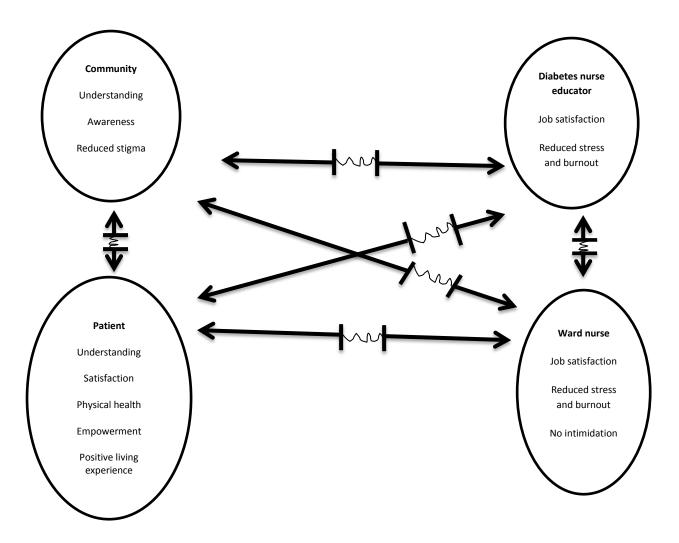
In addition to patients having to cope with the rigid treatment recommendations imposed on them, patients also have to cope with stigmatisation as a result of GDM having been neglected by the South African healthcare system. As highlighted by the patients, the understanding of GDM in their communities is generally poor and community members frequently liken GDM to HIV/AIDS. This results in patients with GDM feeling isolated and marginalised, most likely as a result of the stigma that has been documented in relation to HIV/AIDS (Bond, Chase, & Aggleton, 2002; Brown, Macintyre, & Trujillo, 2003; Simbayi et al., 2007).

According to Carr and Gramling (2004) significant stigma is attached to HIV/AIDS within the South African context which has been found to affect women's adherence levels, access to medical care and social well-being and support. The fact that women with GDM and community members are comparing an unrelated condition to HIV/AIDS highlights the dominance of HIV/AIDS in the South African context and suggests that patients and community members are using HIV/AIDS as a benchmark. The fact that the majority of patients with GDM reported that HIV/AIDS was less burdensome to live with than GDM implies that policy and health campaigns in South Africa have focused too narrowly on HIV/AIDS and neglected other prevalent health conditions. This finding aligns with those of Burkett (2012) and calls for increased awareness-raising and community education related to GDM and diabetes in general.

Based on the points discussed above, it is evident from this study that patients find GDM a highly complex and difficult condition to live with for a number of reasons including financial constraints, cultural and family beliefs, social support, community perceptions and understanding, the dominance of HIV/AIDS in the South African context and resulting stigmatisation. It is also evident that communication practices at the GDM clinic are not optimal and appear to be contributing to a number of negative effects experiences by both patients and nursing staff at the clinic. Work thus needs to be done to mediate these negative effects. It is suggested that improved communication practices may facilitate a more positive experience of living with the condition in South Africa and improved socioemotional and physical wellbeing for patients at a clinic and community level, as well as a more positive working environment for the nurses.

The diagram below (Figure 4.) demonstrates the barriers and lack of communication that have been noted during this study, and illustrates how gaps in communication are creating breaks in the flow of information, and hence not achieving the goals of each of the parties (patients, their communities, ward nurses and diabetes nurse educators). It is suggested that these breaks may be closed through improved communication, which will lead to more positive outcomes for patients who have GDM and the nurses caring for them. Methods of improving this communication are discussed below under implications for practice, along with other important recommendations from this study.

Figure 4. Gaps in communication at the GDM clinic and in the community



## **Implications**

All of the issues discussed above inform a number of implications in the areas of practice, research, policy and theory. These implications are provided in the table below (Table 11) and then discussed in further detail thereafter.

Table 11. Implications of this study

| Implications for       | Implications for       | Implications for        | Implications for       |
|------------------------|------------------------|-------------------------|------------------------|
| practice               | research               | policy                  | theory                 |
| Nurse training         | An expanded study      | The creation of         | Communication          |
| workshops related to   | including other staff, | healthcare policies     | appears to have a      |
| GDM and                | such as doctors and    | related specifically to | significant effect on  |
| communication skills   | dietitians             | GDM care, as this is    | patients'              |
|                        |                        | in line with the        | understanding,         |
| Increased              | Research methods to    | millennium              | satisfaction and       |
| collaboration          | establish accurate,    | development goal.       | treatment adherence    |
| between nurses at all  | updated figures of     |                         |                        |
| levels and between     | the treatment          | Increased               | Communication          |
| ward nurses and        | adherence of           | consideration of        | appears to hold        |
| patients with GDM      | patients with GDM      | communication,          | potential as a tool to |
|                        |                        | counselling and         | mediate the social,    |
| Changes related to     | Research into the      | empowerment in          | emotional and          |
| how information is     | understanding and      | existing policies on    | physical effects of    |
| given to patients and  | experience of living   | GDM                     | GDM                    |
| how patients learn     | with GDM and other     |                         |                        |
| about GDM and          | chronic conditions,    | The creation of         | Provision of an        |
| treatment              | other than HIV/AIDS,   | policies to advocate    | expanded               |
|                        | in South Africa        | for GDM awareness       | understanding of       |
| Changes related to     |                        | raising within          | adherence in the       |
| staffing and logistics | Research into the      | communities             | context of chronic     |
| of the GDM clinic      | effects of improved    |                         | conditions.            |
|                        | communication          | Policies to advocate    |                        |
| Increased              | practices on patients' | for increased funding   |                        |
| awareness-raising in   | physical and           | to decentralise GDM     |                        |
| communities            | emotional outcomes     | services around         |                        |
|                        | and knowledge          | South Africa            |                        |
|                        | related to GDM         |                         |                        |

### Implications for practice

Barriers to effective communication at the GDM clinic are evident from the practices noted in this study. The implications discussed below have been devised based on the communication barriers which were noted to be the most salient from the findings of this study. It is suggested that these recommendations may improve the communication at the GDM clinic, and possibly lead to improvements in patient satisfaction and health outcomes, as well as staff satisfaction.

The site may wish to implement a training programme or workshop for nurses working at the GDM clinic, involving teaching related to the condition itself (the content) and ways of effectively communicating about the condition with patients. This is informed by nurse and patient reports of limited GDM knowledge and communication skills among nurses working in the GDM ward. Positive effects of communication training in the field of diabetes and other health conditions have been documented (Gysels, Richardon, & Higginson, 2004; Moore, Wilkinson, & Mercado, 2009; Wilkinson, Perry, Blanchard, & Linsell, 2008). The implication of communication training for nurses is thus of high importance, as healthcare providers with better communication skills are able to detect difficulties earlier and provide more support to their patients during the treatment process (Ha & Longnecker, 2010).

Increased collaboration is a related implication to the above. Findings across the data sets suggested a lack of collaboration at different levels, that is between nurses and patients and intra-professionally. Nurses, including the diabetes nurse educators should collaborate more

closely with patients to identify their own beliefs, difficulties and goals and set common agreed upon goals, as improved collaborative decision-making between patients and healthcare workers is thought to achieve better patient outcomes related to health, social and emotional wellbeing (Ha et al., 2010). This may be done by discouraging preconceived views and fostering a stronger sense of unity and commonality between nurses and patients, so as to eliminate the negative attitudes towards each other. Nurses also need to collaborate more closely on an intra-professional level, to reduce the sense of hierarchy and segregation that was evident from the findings of the nurse interviews. Increased collaboration might be achieved via the implementation of increased group activities related to patient care. For example, ward rounds involving ward nurses and diabetes nurse educators, or weekly meetings for ward nurses and diabetes nurse educators to discuss patient care and set joint goals.

Another implication, which may also assist with fostering increased nurse-patient collaboration, is that of changing the structure and methods used to provide patients with information about GDM and its treatment. The following changes are suggested, based on the findings of this study:

A change in the approach of diabetes nurse educators to the patient education sessions.
 Diabetes nurse educators could consider the following suggestions, based on the findings of this project:

- Having more than one education session with patients to allow time for patients to process information and allow for the information given to be split over a number of sessions.
- Providing the most relevant information to patients initially and allowing patient questions and concerns to govern the type and amount of information given.
- Providing multimodal information to patients e.g. verbal and visual (by means of pamphlets or even a webpage) to facilitate patients' understanding
- Showing an increased consideration of patients' perceptions and individual lifeworlds when explaining GDM and its treatment to them, in order to facilitate increased understanding and empowerment among the patients who have GDM.
- Finding out about the patients' own goals and desires related to the outcome of their condition, in order to facilitate joint goal setting and increased self-efficacy and agency among the patients who have GDM
- The implementation of a more formal and regular peer education and support group at the GDM clinic. This could perhaps be run by an expert patient. The clinic would need to ensure incentives for the expert patient and find ways of sustaining these education and support groups.

A further important implication which emerged from the findings is the allocation of increased dedicated ward staff for patients who have GDM, either via the employment of more specialised staff or the training of existing staff. The site may also wish to consider eventually finding a ward space that may be completely dedicated to treating patients who have GDM, as this may reduce stress and anxiety related to staff, space and resource

shortages which were reported to form a barrier to optimal patient care and the emotional wellbeing of nurses working with GDM patients.

The final implication suggested is the implementation of increased awareness-raising related to GDM, particularly within the patients' communities, as community members were reported to lack an understanding of the condition and hence stigmatise those affected by it. GDM clinic staff should perhaps consider campaigns which include regular community contact and education in the form of flyers, pamphlets and workshops. Community engagement in the context of health conditions has in fact become a primary goal of many international foundations, such as the Wellcome Trust. It is suggested that an increase in community understanding will reduce the stigma associated with GDM and make patients' experience of living with the condition less stressful.

### Implications for research

This study informs a vast number of implications for future research in the field of health communication, particularly work related to GDM. The most salient of these implications will be focused on below for the purpose of this paper.

A clear implication of this project for further research is perhaps an expanded research project which explores the communication practices at the GDM clinic in a similar manner to this project, but includes all other staff who work at the clinic, such as doctors and

dietitians. This may generate even more new data and findings which could be used to inform useful and practical implications and recommendations for future practice, policy and theory.

Research to obtain accurate up to date statistics on patients' adherence levels at the clinic is also suggested. This may involve analysing patient statistics and documenting patient outcomes in terms of delivery and maternal health and diagnosis of GDM after pregnancy. This is an important implication, as patients' adherence to treatment is suggested to be a direct indicator of their understanding and satisfaction with the care and communication (Haskard Zolnierek & DiMatteo, 2009). It is thus important that accurate, up-to-date figures are available. Research to obtain data regarding adherence would also need to include a way of measuring patients' adherence to lifestyle changes, such as diet and exercise. This may be difficult to track accurately and would thus form a highly relevant topic for future research.

Participants in this study described high levels of stigmatisation and limited understanding of GDM among community members in their contexts. Investigations of lay persons understanding and perceptions of GDM in the South African context is also implied, so as to gain increased insight into community members' understanding and perceptions of the condition and how this may be contributing to stigmatisation of patients living with GDM in these communities. Research into the experience of living with a chronic condition other than HIV/AIDS is also suggested, based on the comparisons that participants drew with

between this condition and GDM. As highlighted by Macaulay, Dunger, and Norris (2014), GDM within Africa needs to be better understood given the increasing burden of type 2 diabetes and the lack of African research related to GDM.

Another important implication of this study in the area of future research is research into the effect of improving the communication practices at the GDM clinic on outcomes such as patient knowledge, satisfaction, physical health (e.g. glycaemic control) and emotional state. Future research might for example, wish to measure the effects of a nurse training programme related to communicating with patients about GDM. This type of research is particularly important, because if certain changes are found to affect patient outcomes positively, they might be applicable at other healthcare facilities for GDM within South Africa, and could thus be rolled out and inform formal treatment protocols countrywide.

### Implications for policy

Policies related to GDM and caring for those diagnosed with the condition exist both internationally and locally. However, international policies and guidelines appear to be more numerous. This suggests that GDM requires further study and consideration within the context of South African policy, because the condition relates closely to the millennium development goals. The policy implications of this project are in line with those suggested by Mollentze et al. (2009) who recommends policies related to diabetes which will assist with the establishment of new healthcare plans, treatment empowerment groups similar to those for HIV/AIDS, development of a training programme for diabetes educators, increased

awareness of diabetes in communities and the formation of task teams to oversee the enforcement of diabetes strategies in the different provinces.

Local policies that relate to GDM include a manual created by the Department of Health of South Africa (2007) to direct health workers in the field of maternity care in South Africa, as well as a guideline for the management of diabetes in pregnancy (Department of Health of the Western Cape, n.d.). The guidelines for the care of women with GDM are concise in nature. The description of 'management' is dismissive of the social aspects of the condition, such as empowering patients and facilitating positive experiences of living with the condition. There is no indication to suggest that patients should be informed of their diagnosis or counselled with regards to their diagnosis. The importance of communication in delivering information regarding patients' diagnosis and treatment appears to have been dismissed entirely. Research projects such as this one provide a justification for the consideration of the social aspects of the condition and the importance of communication in helping patients to live positively and achieve optimal health outcomes with GDM.

A further implication of this study is the creation of GDM awareness-raising policy guidelines, given the limited understanding of the condition within communities reported by participants. A GDM policy which may be applied successfully in South Africa might be one similar to the *Diabetes Action Now* programme. It is a joint effort of the WHO and IDF (2004) to raise awareness on the causes, risk-factors effects and prevention of diabetes amongst middle- and low-income communities in developing countries. The programme highlights

the importance of considering patients' needs, and facilitating patient education and empowerment. The data obtained in this study speaks greatly for the development of such a policy or programme within the South African context. The implementation of a similar policy might increase patient- and community understanding of GDM, and in turn result in improved health outcomes, increased understanding of GDM and reduced stigma associated with the condition.

Policymakers and government health officials should also consider the effects of decentralising GDM specialist services within South Africa, so as to make these services more accessible. The findings of this study highlight the need for strategies such as decentralisation to reduce staff burnout and environmental difficulties related to resource and availability. The decentralisation of health services has assisted and been hypothesised to assist with improved rollout of treatment and health resources and reduce staff stress and burden in the context of a number of health conditions in South Africa, including HIV/AIDS and TB (Nyasulu, Muchiri, Mazwi, & Ratshefola, 2013; Padayatchi & Friedland, 2008). It is thus suggested that GDM specialist services be offered at other healthcare facilities in the vicinity of the research site.

Despite the lack of South African policies and guidelines related to GDM, it is encouraging to note that a South African project is currently being run by the World Diabetes Foundation. Women in South Africa will be screened between 2014 and 2018 with the aim of gathering evidence to strengthen and create more comprehensive guidelines and protocols for GDM

care and screening in South Africa (World Diabetes Foundation, 2014). This research project provides additional evidence for the need to construct in-depth South African protocols related to the condition, as it provides insight into what it is like to live with the condition and receive care in the South African context.

### Implications for theory

This research project was exploratory in nature. Communication practices noted at the GDM clinic were observed and analysed in relation to existing literature. Whilst no theories have been directly tested or examined, some of the findings of this study lend themselves well to certain theoretical stances highlighted in the literature review. Some new ideas to consider in analysing and understanding nurse-patient communication in the field of gestational diabetes have also been highlighted by the project.

Perhaps the most obvious theoretical implication of this study is that communication appears to be closely linked with health outcomes and attitudes of patients who have GDM, as previously suggested by research (Haskard Zolnierek & DiMatteo, 2009; Hjelm et al., 2008; Thompson & McCabe, 2012 Watermeyer & Penn, 2009a). Health outcomes seem to be the result of the interaction between medical and social aspects of GDM and GDM care at the clinic, and the manner in which the nurses communicate with patients appears to be having a significant effect on patients' understanding and emotions related to GDM. This provides additional support for theories which link communication and health outcomes mentioned in the studies cited above.

Furthermore, and perhaps most importantly, this study suggests that communication may be a powerful tool to mediate the medical and social difficulties experienced by patients living with GDM in the South African context, as suggested by Barry et al. (2001). This study appears to propose that the establishment of more collaborative relationships between patients and nurses, in which patients are empowered and communicated with in a trusting manner may improve patients' understanding of the condition and its treatment, and create a stronger sense of agency among patients, hence facilitating more positive attitudes towards the condition and treatment adherence. This links to the stance taken by numerous authors (Anderson & Funnell, 2010; Schneider et al., 2004 Street et al., 2009). In addition, improved communication about GDM and its treatment within communities may reduce the stigma associated with the condition, as suggested by the findings of Raingruber (2002) and Pinto-Foltz and Logsdon (2009). It is suggested that improved communication between nurses at the clinic may also foster increased job satisfaction and reduce stress among nursing staff working with patients who have GDM, as highlighted previously by Amos, Hu, and Herrick (2005) and Seedat (2013).

Finally, this study has expanded on our understanding of adherence in the context of conditions that are of a chronic nature. It has confirmed the complexity of the treatment regimens imposed by these conditions that were documented by Wagner et al. (2001). This suggests that all theory related to chronic conditions should consider the complex factors which play a role in patients' adherence to treatment and their experience of living with the condition.

## Chapter summary

This chapter has drawn on the findings from the previous chapter to present a detailed discussion of relevant issues pertaining to communication between the patients and nurses at the GDM clinic. The chapter highlights significant gaps in communication at the clinic and describes the effect of these gaps on patients' empowerment levels, desires for future education and experiences of living with GDM in South Africa. These discussion points have been used to formulate important implications related to the areas of practice, research, policy and theory. This is to be followed by a concluding chapter in which all salient finings and implications are summarised.

# **CHAPTER 6: CONCLUDING COMMENTS**

This chapter provides a consideration of the methods used in this study and reflection upon their efficacy and shortcomings. It then concludes with a summary of this study, its pertinent findings and the significant implications which these have.

### **Methodological reflection**

Upon reflecting on this research study as a whole, it appears that the chosen methods worked successfully and generated a large amount of useful and relevant data, which have informed a number of practical implications in the areas of practice, research, policy and theory.

The efficacy of a qualitative research design deserves some exploration and reflection. Whilst the quantitative work done in the area of diabetes suggests that much is known about the condition and the medical aspects of it, the qualitative methods used in this study have demonstrated that there is still a great deal that we do not yet know or fully understand about the condition, particularly in developing countries such as South Africa, where a diverse range of sociocultural and linguistic backgrounds interact within the healthcare setting. This lack of knowledge and research in GDM in South Africa appears to relate specifically to the social aspects of the condition and what it actually feels like to live with the condition in the South African context. In this respect, the qualitative methods used allowed the researcher to gain a deep insight into some of the difficulties that patients

experience with living with the condition, as well as the facilitators and barriers to communication that exist at the GDM clinic. The qualitative methods used were, in fact, also reported to be cathartic by some of the patients who participated in the focus groups.

It is possible that if quantitative methods were used, a less clear illustration of the communication practices and patients' and nurses' experiences of dealing with the condition may have been obtained, as Curry, Nembhard, and Bradley (2009) highlight that qualitative methods are more favourable in exploring the causal factors of complex phenomena which are difficult to measure quantitatively. The qualitative methods used allowed the patients and nurses to voice their feelings and thoughts in a comfortable and confidential environment, and as highlighted by Pope, Ziebland and Mays (2000), this study produced large amounts of rich data which fulfilled research aims and objectives. Such an expression of emotions and thoughts would not have been possible if quantitative methods had been used instead. Furthermore, the use of qualitative methods allowed for a large amount of data to be generated from a fairly small number of participants within a relatively short period of time, adding to the feasibility of the current study. Data saturation was reached within all data sets, suggesting that enough data was collected. This advocates for value of qualitative methods in the field of health communication and examining the social aspects of patient care.

The success and importance of methodological and data triangulation is also highlighted by the current study. The use of multiple methods and sources of data allowed the researcher

to obtain information and draw findings and conclusions that are of a higher level of credibility and rigour. A comprehensive picture of the communication practices at the GDM clinic was provided. The value of triangulated methods is perhaps illustrated by the paradox which was noted in the analysis of the data, where the researchers' observations of the communication behaviours in the nurse-patient interactions conflicted with patients' reports of diabetes nurse educators as demonstrating good communication skills. The absence of data and methodological triangulation would not have revealed such.

Whilst the methods used in this project seem to have been efficacious, it should be noted that the Hawthorne effect may have occurred at times during the study. Although the nurses and diabetes nurse educators did not seem to change their behaviour during ethnographic observations or education sessions, it is possible that a change in behaviour may have occurred as a result of an awareness of observation. This needs to be considered and future studies of a similar nature should perhaps consider methods of preventing the Hawthorne effect to a greater extent. This forms a methodological consideration rather than a limitation.

A further methodological limitation is the absence of a formal measure to ensure the reliability of the translation of video recorded and patient focus group data. An unqualified individual was used to check the reliability of the translations, as a result of time constraints and data that was linguistically diverse. It was difficult to locate an individual who competently understood and spoke as many languages as the research assistant and also

impractical to hire several other translators to verify translations which appeared to be accurate, as suggested by the researcher's analyses and triangulation of the data by the researcher, and the translation of the data by an additional individual (although unqualified).

The management and triangulation of large data sets formed another methodological challenge. However, these large data sets allowed for a more comprehensive understanding of the communication practices at the GDM clinic.

### **Conclusion**

The South African healthcare context is an environment which is confounded by a number of factors unique to South Africa as a country, including linguistic and sociocultural diversity of staff and patients, resource and staff shortages, a large burden of other health conditions such as HIV/AIDS, limited funding and historical norms entrenched in racial oppression and segregation. The South African healthcare context may thus be viewed as a complex interaction of these factors. In addition to such complexity, conditions such as GDM further complicate the interaction, as GDM is also a highly intricate condition which requires an understanding of an adherence to a complex treatment regimen and lifestyle changes. The merge of two such complex situations thus creates an extremely difficult, multifaceted circumstance, for both patients and the healthcare workers involved in treating and caring for them. This complexity has been highlighted by the current study.

The primary aim of this study was to explore the communication practices of the nurses and patients at the chosen GDM clinic. In addition to shedding light on the complexity of caring for patients with GDM in South Africa, the current study has provided evidence which suggests that the current communication practices around the condition at the chosen site are suboptimal, and significant barriers to communication exist, in spite of some facilitatory factors and reportedly high levels of treatment adherence at the clinic.

This study has demonstrated that patients with GDM at the research site are lacking information, feel overwhelmed and are disempowered. All of these negative attributions seem to be linked with the gaps in communication practices at the clinic. Hence, communication barriers appear to be contributing to patients' disempowerment, negative attitudes and experiences of living with GDM and adhering to treatment, in addition to limiting their understanding of the condition and fostering stigma related to the condition among patients individually and their communities. Whilst patients report instances of facilitatory communication behaviour, it is evident from closer observation that patient reports are not always completely indicative of a situation and a deeper exploration of social factors and contributors is required in understanding paradoxes that exist within the healthcare setting.

In addition to the apparent negative effects on patients, nurses too seem to be negatively affected by the contextual and communication barriers noted. Resource shortages, understaffing, hierarchy and intra-professional tension seem to be causing nurses to feel

anxious, overworked and uncomfortable. The likely negative effect that this may be having on patients cannot be neglected.

This calls for interventions at the GDM clinic to foster more positive staff and patient attitudes towards GDM and dealing with the condition on a daily basis. A number of these interventions were discussed under implications for practice. It is interesting to note that communication seems to underpin the majority of these interventions, and thus may form a powerful tool to mediate patients' experience of GDM, particularly in the South African context where a number of previously discussed social issues exist.

Whilst this exploratory study has highlighted communication a powerful tool, further scientific research is required to demonstrate a definite positive effect if any on patients' health and socio-emotional outcomes, such as treatment adherence, glycaemic control, attitudes towards living with the condition, knowledge and understanding, empowerment levels. Effects of improved communication should also be measured on nurses' emotional wellbeing and job satisfaction and community understanding and stigma related to the condition. Once such research has been conducted, communication can be scientifically recognised as having a truly positive effect on healthcare in the context of GDM in South Africa and effective communication methods and training programmes may be rolled out at a national level.

It is thus vital that more research be conducted in this area to demonstrate its effect and work towards highlighting in further detail the importance of communication in treating GDM at the chosen site, and other similarly run facilities in South Africa. This may provide support for increased consideration of the condition in South African health policy. Perhaps the potential of communication in helping patients come to terms with the physical, social and emotional burdens of the condition are best captured by this concluding quote: "When you are talking about the things you are facing, it's beautiful" (participant from focus group 2). Only further research in this area can assist to reveal this potential.

#### **Chapter summary**

This chapter has provided a methodological reflection and a concise summary of the study that was conducted, as well as its results and the way forward in terms of implications, with a specific emphasis on the importance of future research into GDM and communication in the South African context.

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## Appendix 1: Ethnographic description of the GDM clinic

The icy wind bites at my hands and face as I walk from my car to the maternity building. A large sign that reads 'admissions' sits above the entrance to the building. People stand around the entrance looking like they are waiting for something or someone. As I push the heavy metal gate open the calm and silence of outside is drowned by chatters of a large crowd of women sitting on benches and standing in queues, many of whom are heavily pregnant and struggling to waddle and shuffle as they make their way to the front of the queue to see the nurses. This is the antenatal clinic. I carry on walking to get to the ward, the ward where the GDM patients are admitted and from where the GDM clinic is run. The corridors are dark and fairly quiet with the odd chatter or shout from passing nurses. The ceiling is low and a chilling wind drifts through the corridors as I continue my walk to the ward. Eventually I come to a long, wide passage. I start to notice ward numbers above doors on both sides of the passage. As I come to the ward, I notice drops of water leaking from the roof into a plastic bucket placed on the floor. I push the large wooden swing door open ad notice a "welcome" sign accompanied by a cheerful looking cartoon pasted onto the door.

The ward is bright, stiflingly warm and in a way welcoming, despite the fact that it is inhabited by women who are unwell. The sun drifts through the windows and the eerie silence of the corridors is drowned out by chatting and the clanging of food trolleys. As I enter the ward, I immediately notice the patients in cubicle A, some of whom have GDM. All except one patient are seated around a table at the centre of the cubicle and dunking chunks of brown bread into paper cups which appear to be filled with tea, chattering as they

do so. One of the patients is lying down, looking rather sombre as she shifts her gaze between the patients eating around the table and the floor.

There are doctors who appear to be doing their rounds. They stride sternly and swiftly from bed to bed, writing notes in each of the patients' files. The kitchen lady wheels a heavy steel trolley loaded with two large steel pots and a pile of bread loves towards the kitchen, which is positioned just behind the nurses' station. As the kitchen lady passes cubicle A, she come to a standstill to greet and chat with two nurses who are passing by. At this moment I notice a thick layer of posters on the wall that read "Batho Pele" which translated into English means "People First". This carpet of posters is broken by some black and white sheets of paper which read "Patients' Rights", "Complaints" and "Infant Feeding Policy". On the adjacent wall there are some large posters about HIV/AIDS and Antiretroviral therapy. I then notice a few A4 posters about diabetes and one large poster that reads "Promoting Healthy Lifestyle". The diabetes posters are all written in English, unlike the others, which have been translated into other African languages.

My viewing of the posters is suddenly interrupted by a ward nurse who shuffles into cubicle

A and begins to make the beds. While she does this, all of the patients are still seated

around the table and begin to measure their sugar levels together, watching each other and

chatting about their readings as they do so. The patient who was initially lying down

waddles to the table to measure her sugar levels too. At this moment one of the diabetes

nurse educators walks into the cubicle. She sits at the table and begins to watch and explain

to the patients how to measure their blood glucose levels. The diabetes nurse educator and patients chuckle together as the nurse shifts off the bench to check one of the patients' drips. She then turns to me and shouts "Spoilt they are! Patients don't see that they are well taken care of." She then turns to the patients and says "I'm watching you" with a big smile on her face, as she escorts one of the patients out of the ward to collect diabetes test results. The patients chuckle.

About an hour later the dietician arrives to check if there are any patients who need to be counselled about a diabetic diet. The other diabetes nurse educator then arrives. She approaches the dietician and seems rather impatient. She begins questioning the dietician about one of the patients and sternly says "I need to tell you how I work here with my patients". After their discussion, the dietician grabs her sling bag and file and hastily advances out of the ward. Over the next two hours, cubicle A becomes strikingly silent.

As twelve o'clock approaches, the patients' energy levels seem to decline progressively as they await their lunch. The mood suddenly lift a bit when one of the ward nurses comes in to announce to the patient who was initially lying down in the corner of the ward that she is going to be taken to the delivery ward to deliver. The nurse drips this patient speedily and another patient helps the patient in labour to take her blood glucose levels before she leaves the ward. "7.2" she announces to the nurse who scribbles this down onto the patient's HGT sheet and continues filling in the charts at lightning speed. The nurse retreats to retrieve a blood pressure monitor. In the meantime, the patient calls one of her relatives

to update them on her delivery. Once the nurse has taken the patient's blood pressure she takes the patient's file and shuffles to the nurse's station. The patient now lets out occasional whimpers and sighs as she holds one hand over her face and clutches her cell phone with the other. At this exact moment, the heavy steel lunch trolley is wheeled through the wall and the smell of hot food wafts through the cubicle. The patients do not look enticed and seem indifferent to the arrival of lunch. A new patient who has diabetes and is pregnant trudges laboriously into cubicle A, lugging her blankets and belongings with her from cubicle B next door. She places her belongings in the cabinet that sits next to the bed of the patient who is in labour and sits on one of the benches around the wooden table at the centre of the ward. She breaths heavily over her swollen belly as the nurse draws the curtain around the bed of the patient in labour.

In the corridor I hear one of the doctors instructing a patient "wee and take to sister, ok" in a slow, high-pitched voice as he waves the urine dipstick at the patient who stares at him and nods. He then turns to one of the ward nurses and asks loudly "Where is the dietician? Who is it?" The ward nurse attentively nods and assures "I will call her doctor". From behind the curtain I can hear the nurse giving the patient in labour slow, calm instructions and she opens and rustles packets and packaging of medical equipment. The nurse then shouts to the new patient seated on the bench to bring her sheet and place it on the bed of the patient who is going to be transferred to the labour ward. The nurse then emerges from behind the curtain and leaves the ward. In the meantime the new patient chats to the patient who is in labour and asks how she is feeling. About ten minutes later, the nurse returns with a wheelchair. She shouts "Let's go" to the patient in labour and helps her into

the wheelchair, as the patient clutches her phone and catheter bag. The patient in labour slumps into the wheelchair and waves at the other patients in cubicle A and says "sharp" with a smile. The others wave goodbye and wish her good luck. The nurse takes the sheets of the bed and upon finding three sheets on the bed shouts "This one is rich rich rich". The other patients laugh and the new patient begins to place her linen neatly over the now empty bed while the nurse takes the dirty linen away. A diabetic patient who had recently delivered now enters the cubicle and announces that she gave birth to a boy. The patients in cubicle A greet her warmly and congratulate her. As she leaves the cubicle, the nurse returns and wheels the patient in the wheelchair to the labour ward. Cubicle A is silent. The new patient settles into her bed and snacks on a banana. Lunch has still not been served, despite having been brought to the ward over half an hour ago. Another twenty minutes later, one of the diabetic pregnant patients who is lodging in cubicle B pops her head around the wall and says "ukudla" or "eat".

The patients unwillingly drag themselves to the food trolley and return carrying white polystyrene packs. They open the packs and stare at the grated carrots, rice and mince disdainfully. Before attempting to eat what seems a disappointing meal, all of the patients measure their sugar, in a similar way to how they did earlier in the morning after breakfast. One of the patients helps another with measuring her sugar and clarifies that they need to test their sugar levels six times a day. The patients then begin to eat their lunch in a slow, reluctant fashion. Some eat around the table, while others sit in their beds and eat. One of the patient leaves her food next to her bed and appears to have decided to take a nap instead. The patients measure their sugar levels together again after lunch and all retreat to

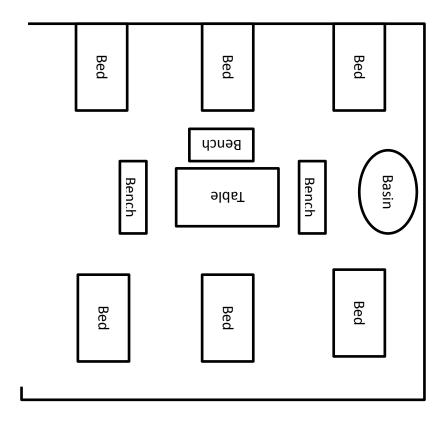
their beds. The cubicle is quiet as the duller afternoon sun stretches its long bronze fingers across the ward. About an hour later, visitors arrive at the cubicle for two of the patients. As the patients chat with their relatives and friends, the rest of the ward becomes silent, despite intermittent chatters from nurses and clerk sitting at the nurses' station or the wheeling a machine around the ward to measure each patient's blood pressure levels.

After this some of the patients disperse to their beds, whilst others remain seated around the wooden table, chatting to each other occasionally. One of the patients lying in bed quietly browses through a 'Baby City' catalogue, whilst another is hooked onto a machine for foetal heart monitoring by one of the ward nurses.

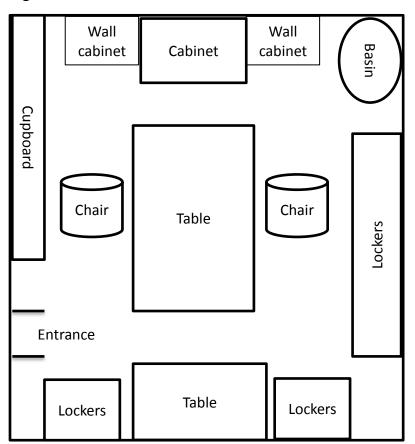
# The ward where the GDM clinic is held and where in-patients with GDM stay

| Cubicle E                 | Cubic             | Cubicle D |  | le C    | Cubicle B | Cubicle A           |
|---------------------------|-------------------|-----------|--|---------|-----------|---------------------|
|                           |                   |           |  |         |           |                     |
| Entrance  Nurses' station |                   |           |  |         |           |                     |
| Patient toilets           | Equipment<br>room | Kitchen   |  | Nursery | Side ward | Counselling<br>room |
|                           |                   |           |  |         |           |                     |

**Cubicle A** 



## The counselling room



## **Appendix 2: Clinic procedures**

## How is GDM diagnosed at the clinic?

At the GDM clinic patients are diagnosed with GDM using the following methods:

A patient is usually referred to the GDM clinic if she presents with the following risk factors

- Glycosuria (glucose detected in her urine)
- GDM in a previous pregnancy
- A first degree relative who has diabetes
- Poor obstetrical history
- Polyhydraminos (an excess of amniotic fluid in the amniotic sac) in her current pregnancy
- A previous child whose birth weight was above 4kg
- Maternal obesity (body mass index of above 30kg/m²)
- The patient is of South Asian descent (this ethnicity is a risk factor for GDM)

The following measurements are then taken:

- Random blood glucose: This is a pin prick test in which blood is taken from the patient at
  any time. This measurement should not exceed 11.0mmol/l. If it does, GDM is suggested
  and a fasting blood glucose test and possibly an oral glucose tolerance test should be
  done
- Fasting blood glucose: The patient is required to fast for eight hours, after which the blood glucose level is measured using a glucometer. The blood glucose level should fall between 5.1 and 6.9mmol/l and should not exceed this range. If a fasting blood glucose

levels falls at or above 7.0mmol/l, GDM is suggested and an oral glucose tolerance test should be done.

- Oral glucose tolerance test: During this test, the patient is required to drink a mixture consisting of 200ml water and 75g sugar or glucose. Her blood sugar levels are then measured 1 hour and then 2 hours after drinking the mixture.
  - At 1 hour the patient's blood glucose level should not exceed 10mmol/l
  - At 2 hours the patient's blood glucose levels should not exceed the range of 8.5-11.0mmol.

At the clinic, GDM is diagnosed if one or more of the above measures exceed the specified range (excluding the random blood glucose measure). Overt GDM is suggested in cases where fasting blood glucose is greater than or equal to 7mmol/l, the 2 hour oral glucose tolerance test measure exceeds or is equal to 11.0mmol/l and the random glucose test measure in greater than or equal to 11.0mmol/l. Patients who are diagnosed with GDM are admitted to the ward for counselling and education about GDM, its treatment and how to control their blood glucose levels.

## How do patients learn about GDM and its treatment?

Patients who have been newly diagnosed with GDM receive an education session in which one of the diabetes nurse educators provides them with information about the condition and its treatment. The diabetes nurse educators reported that these sessions are done individually or in groups depending on how many patients there are to counsel. One of the diabetes nurse educators reported a preference for group counselling as she expressed that

patients "pretend to understand" when they are counselled individually. This raises questions around the way in which the patients are counselled and the importance of checking for patients' understanding.

The diabetes nurse educators also reported that patients are sometimes given pamphlets about GDM, its causes, symptoms and treatment, when there are pamphlets available. The GDM patients also reportedly receive counselling and education from a dietician related to the dietary recommendations for persons living with GDM. The dietician liaises with the nurses in the ward and is reported to generally visit the GDM ward at least once a week to counsel patients on a diabetic diet. Other than the education sessions, patients are encouraged to learn about their treatment from one another, whilst they are admitted in the ward. Patients are encouraged to test their sugar levels together and take their treatment together so that they may learn via observation and peer discussions with other patients in the ward who have GDM. The difficulty, however, is that not all of the patients in the diabetes cubicle present with GDM specifically. Some of the patients present with type 1 or type 2 diabetes and thus may be on different regimens of treatment or have different goals regarding their blood glucose levels.

#### Glucose monitoring

Once patients have been admitted to the ward and diagnosed with GDM, they are provided with sheets on which they are required to record their blood glucose levels six times per day, from the time that they are admitted to hospital and diagnosed with GDM up until they deliver their baby. The patients are required to check their glucose levels at one hour before

and one hour after breakfast, lunch and dinner every day. The process involves the following:

- The patient is to prick her finger with a lancet to draw a drop of blood
- The patient should place the test strip over the drop of blood
- The edge of the test strip where the drop of blood was placed is then inserted appropriately into the glucometer
- The patient is to hold the test strip in this position until the glucometer produces a blood glucose level reading
- Patients are then to record this reading of their glucose monitoring on a Hemo Glucose
   Test (HGT) sheet

Nurses indicated that patients' sugar levels should fall between 4 and 7 mmol/l. However, this may vary with the severity of each patient's condition.

### **Treatment regimens**

Once patients have been diagnosed with GDM, they are either prescribed oral medication (Metformin) or injectable insulin. Before medication is prescribed, the patients' blood glucose levels are monitored for approximately one day. If patients present with sugar levels of between 8 and 9mmol/l after one day of monitoring they are prescribed metformin (oral treatment). If their sugar levels after one day of blood glucose monitoring fall above 11.0mmol/l, they are put onto insulin (injectable treatment).

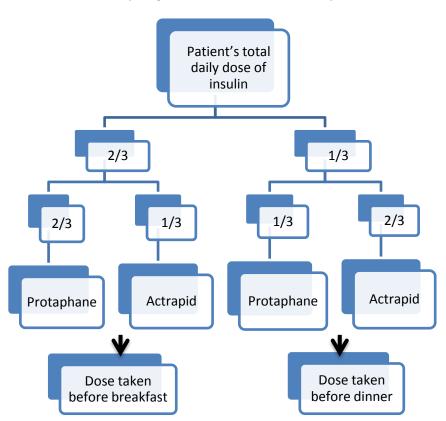
## Metformin

Patients who are prescribed metformin are instructed to take an 850mg tablet in the morning before breakfast, and an 850mg tablet in the evening before dinner. However, patients are allowed to take the tablet after each of these meals if they complain of nausea when taking the tablet before meals. If Metformin does not appear to be controlling patients' sugar levels sufficiently, they may be switched to the injectable insulin regimen of treatment.

## <u>Insulin</u>

The insulin regimen of treatment consists of two drugs, namely protaphane (slow acting insulin, which acts over an 8 hour period) and actrapid (fast acting insulin, which acts over a 6 hour period). Patients are required to take an injectable dose in the morning 30 minutes before breakfast. This dose consists of 2/3 protaphane and 1/3 actrapid. Patients are also required to take an injectable dose of insulin in the evening 30 minutes before eating dinner. This consists of 1/3 protaphane and 2/3 actrapid. The dose of insulin for patients who have GDM is calculated in the following way (Figure 5):

Figure 5. Method used to calculate dose of insulin



#### Patient's bodyweight x 0.6 = Patient's total daily dose of insulin

#### Ways of checking and facilitating adherence at the GDM clinic

The diabetes nurse educators explained that patients' adherence is checked every time the patients attend the out-patient GDM clinic on Tuesdays. The nurses keep a register of patients that are due to attend the clinic every week. At every visit, the patients' HGT monitoring sheets are checked so that the sugar levels may be observed and the diabetes nurse educators may identify whether they are controlled or uncontrolled. The levels that have been recorded by the patients are then cross-checked by the physicians who compare the written levels with the levels recorded in the memory of the glucometer. This acts as a method of verifying patients' reports. Uncontrolled or high sugar levels, or written levels

that conflict with levels recorded by the glucometer are suggestive of poor treatment adherence.

Each of the patients with GDM also have their HbA1c level tested once a month at the GDM clinic. This measurement provides an accurate and stable indication of the patients' blood glucose level over the past two to three months and is thus also used as a way of checking patients' adherence.

# Appendix 3: Language history of the research assistant

| D.O.B: 1988/10/23  |
|--|
| Place of birth: North West   |
| Highest level of education achieved:BA Honours                             |
| Please list the languages that you were educated in:Tswana, English        |
| Please describe any previous experience with interpreting and translating? |
| Transcriber for NHLS, Wits University                                      |
| What is your home language? <u>Setswana</u>                                |

# Please list other languages that you speak/understand:

| Language | Where and when did  | Who do you use this                 | How long have you |
|----------|---------------------|-------------------------------------|-------------------|
|          | you learn this      | language with                       | spoken this       |
|          | language?           |                                     | language for?     |
| English  | School              | Colleagues, friends                 | 20 years          |
| Sesotho  | Home (19 years ago) | Colleagues, friends, family members | 20 years          |
| isiZulu  |                     | Colleagues, friends,                |                   |

|          | School (10 years ago) | neighbours           | 19 years |
|----------|-----------------------|----------------------|----------|
| isiXhosa | School (10 years ago) | Colleagues, friends, |          |
|          |                       | neighbours           | 10 years |
|          |                       |                      |          |
|          |                       |                      |          |
|          |                       |                      |          |
|          |                       |                      |          |
|          |                       |                      |          |
|          |                       |                      |          |

# Please list any other languages that you have been exposed to:

| Language | Where are you exposed to this language? |
|----------|---|
| N/A      | N/A                                     |
|          |   |
|          |   |
|          |   |
|          |   |
|          |   |
|          |   |
|          |   |
|          |   |

## Appendix 4: Focus group question guideline (patients)

## **Demographic information**

- 1. How old are you?
- 2. What languages do you speak?
- 3. Tell me about your illness and how you got to this clinic?

#### **Communication with nurses**

- 1. How did you find your counselling session with the nurses when you were diagnosed with GDM here?
- 2. Did you understand everything that the nurse told you? Why or why not?
- 3. Did the nurse tell you everything that you wanted to know?
- 4. Do you feel comfortable asking the nurses questions? Why or why not?

#### **GDM** and its treatment

- 1. Can you explain GDM and your treatment to me?
- 2. What should your blood sugar levels be?
- 3. What do you find difficult about taking the treatment?
- 4. Do you feel comfortable asking the nurses about your treatment?

### Appendix 5: Semi-structured interview guideline (nurses)

#### **Demographic information**

- 1. How old are you?
- 2. What languages do you speak?
- 3. What is your qualification and where did you obtain it?
- 4. What is your work experience and how long have you worked in this clinic?
- 5. What are your main responsibilities when caring for patients with GDM?
- 6. Have you ever had training on communicating with patients who have GDM?

#### **Communication with patients**

- 1. What information is important to give to the patients who have GDM?
- 2. What is it like communicating with the patients at this clinic?
- 3. Do you feel that the patients understand all of the information that you give them?
- 4. What questions do the patients ask you about GDM?
- 5. Do you find it easy to answer patients' questions? Why or why not?
- 6. Do you think that the patients feel happy with the care and communication at this clinic?
- 7. How do you find the patients' adherence to GDM treatment?
- 8. What would you like to learn more about when communicating with patients who have GDM?

# Appendix 6: Ethical approval from HREC(Medical)



# HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL) **CLEARANCE CERTIFICATE NO. M140353**

NAME:

Ms Bianca Burkett

(Principal Investigator)

DEPARTMENT:

Speech Pathology and Audiology

PROJECT TITLE:

The practice and perceptions of nurses and patients regarding

communication at an urban clinic for gestational diabetes

mellitus

DATE CONSIDERED:

28/03/2014

**DECISION:** 

Approved unconditionally

CONDITIONS:

SUPERVISOR:

Prof Claire Penn

APPROVED BY:

Professor PE Cleaton-Jones, Chairperson, HREC (Medical)

DATE OF APPROVAL: 16/05/2014

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 Secretary in Room 10004, 10th floor, Senate House University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned researc 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 the application to the Committee. I agree to submit

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

#### Appendix 7: Information sheets and consent forms

#### **Nurse information sheet**

Hello,

My name is Bianca Burkett. I am studying for my master's degree at Wits University. I am studying how nurses and patients talk to each other about gestational diabetes.

I would like to invite you to participate in this study. I will be observing the gestational diabetes ward and the gestational diabetes clinic that runs every Tuesday morning for one to two months. While I observe I will be looking at how the nurses are educating and counselling patients about gestational diabetes and how the nurses communicate with the patients. I will also be watching and video-recording the sessions where the nurses educate and counsel patients about gestational diabetes. I will use the video-recording to get information about the communication between you and the patients, because I will not be able to remember all of it.

I would also like to invite you, the nurses, to participate in individual interviews or focus groups so that you can tell me about the methods that you use to teach patients about gestational diabetes. You will also be able to talk about things that are easy and difficult for you when communicating with patients who have gestational diabetes. If you feel uncomfortable about questions that I ask you, do not have to answer them. What is said in the interviews will be tape recorded so that I will not have to remember everything that was said when I write my results. The interview should take thirty minutes to an hour.

You might be worried about who will be able to watch the video recordings of you or listen to the tape recordings of you. However, this information will be kept completely private. No one that you work with will be able to see the videos or listen to the recordings. I will not tell anyone about you or about what happened. The only people who will see the video-recordings and listen to the tape recordings will be me, my supervisors and my research assistants and they will not have access to any of your personal information like your name. They will keep all of your information private. After I have gotten all of the information from the video-recordings and tape recordings, I will keep it locked away where no one will be able to access it except me.

After I have finished doing the study, I will write the results in a report which I will hand in to Wits University. I might also publish the results of the study. None of your personal information will be available in the report or in the publication. Your privacy will be respected and protected at all times. After the study has finished, I will also give you feedback and training.

By participating in this study, you will be helping me to learn about how the nurses and gestational diabetes patients are communicating with each other. This might help in training nurses about communication, which might make patients feel more positive about taking their treatment for gestational diabetes.

You do not have to participate in this research if you do not want to. If you do choose to participate and then later on decide that you do not want to participate anymore, that is alright. You will not have to do anything else and I will not ask you why you have asked to stop. You will not be in any trouble.

If I find out that a patient has not understood information that you have given to her, I will bring this to your attention in a way that is sensitive and respects the patients' privacy, so that you may make the information better understood to the patient.

If you have any questions about the study now or later on please contact

- Me (Bianca Burkett) on (011) 717 4585 or 0724416503
- My supervisor (Prof. Claire Penn) on (011) 717 4579
- My co-supervisor (Dr. Jennifer Watermeyer) on (011) 717 4578
- The chair of the Human Research Ethics Committee (Medical) (Prof. Peter Cleaton-Jones) on (011) 717 2635.

If you agree to participate in this study, please read and sign the consent form that has been given to you.

Thank you for your time.

| Nurse's informed consent to participate in study  |  |  |
|---|--|--|
| I, agree to participate in the study, investigating   |  |  |
| the communication between patients and nurses.  |  |  |
| I understand the contents of this form.   |  |  |
| I confirm that I have been informed about the study, what will be done, its benefits and risks.   |  |  |
| I understand that my responses will be kept anonymous and that none of my personal information will be shared.  |  |  |
| I understand that my participation is completely voluntary and I can stop participating in the study at any time, without facing negative consequences. |  |  |
| I confirm that I have had sufficient opportunity to ask questions and have chosen to take part in this study of my own free will.                       |  |  |
| I understand that when I speak with the patients and with the researcher, this information will be (video and/or audio) recorded.                       |  |  |
| I understand that confidentiality in the focus groups cannot be guaranteed.   |  |  |
| Signed: Date:   |  |  |
| Witness:  |  |  |

| Nurse's informed consent to audio recording                    |  |  |
|--|--|--|
| I,the communication between patients                           | agree to participate in the study, investigating s and nurses. |  |
| I understand that my interview with t<br>this.                 | the researcher will be audio-recorded and I consent to         |  |
| I understand that all information will will be made available. | be kept confidential and none of my personal details           |  |
| Signed:  | Date:  |  |
| Witness:   |  |  |

| Nurse's informed consent to video recording                    |  |  |
|--|--|--|
| I,the communication between patients                           | agree to participate in the study, investigating and nurses. |  |
| I understand that my conversation wi this.                     | th the patients will be video recorded and I consent to      |  |
| I understand that all information will will be made available. | be kept confidential and none of my personal details         |  |
| Signed:  | Date:  |  |
| Witness:   |  |  |

## **Patient information sheet**

Hello,

My name is Bianca Burkett. I am studying for master's degree at Wits University. I am studying how nurses and patients talk to each other about gestational diabetes. I would like to look at how the nurses teach and talk to you about gestational diabetes and how you feel about the education that you get from the nurses.

I would like to invite you to participate in this study. In this study, I will be observing the gestational diabetes ward and the gestational diabetes clinic that runs every Tuesday morning. While I observe I will be looking at how the nurses are educating and counselling patients about gestational diabetes and how the nurses communicate with you, the patients. I will also be watching and video-recording the sessions where the nurses educate and counsel you about gestational diabetes. I will use the video-recordings to get information about the communication between the nurses and you, because I will not be able to remember all of it.

I would also like to invite you, the patients, to participate in discussion groups for one to two hours, where you will be able to tell me how you feel about the education that the nurses give you and how you feel about communicating with the nurses. You will also be given the opportunity to talk about things that are easy and difficult for you when communicating about gestational diabetes with the nurses. I will not ask you any embarrassing questions. If you feel uncomfortable about questions that I ask you, you do not have to answer them. There will be an interpreter to help you in the discussion if you prefer to speak in Zulu, Tswana, Sotho or Xhosa instead of English. The interpreter has been trained by myself and does not work at the hospital. The discussion will take about one to two hours. What is said in the focus group will be tape recorded so that I will not have to remember everything that was said when I write my results. Although I cannot guarantee confidentiality or anonymity during our discussion group, I will try my best to ensure that your details are kept private. I will not ask you for your name or any other personal information. I will also set ground rules before our discussion to ask that no one share anything that we talk about outside of the discussion group.

You might be worried about who will be able to watch the video recordings of you or listen to the tape recordings of you. This information will be kept completely private. No one at the hospital will be able to watch the videos or listen to the tape recordings. I will not tell anyone about you or about what happened. The only people who will see the video-recordings and listen to the tape recordings will be me, my supervisors, and a translator, and they will not have access to any of your personal information like your name. They will keep all of your information private. After I have gotten all of the information from the video-recordings and tape recordings, I will keep it locked away where no one will be able to access it, except me.

After I have finished doing the study, I will write the results in a report which I will hand in to Wits University. I might also publish the results of the study. None of your personal information will be available in the report or in the publication. Your privacy will be respected and protected at all times.

By participating in this study, you will be able to talk openly about the communication at the clinic and how you feel about having gestational diabetes and taking your treatment.

You do not have to participate in this research if you do not want to. If you do choose to participate and then later on decide that you do not want to participate anymore, that is alright. You will not have to do anything else and I will not ask you why you have asked to stop. You will not be in any trouble and your treatment will not change in any way because you asked to stop.

If you do not understand something about gestational diabetes or your treatment, or you have questions about it, I will have to tell the nurse about this so that the nurse can talk to you and help you to understand better. You do not have to talk to the nurse if you do not want to. If you are happy to talk to the nurse I will not give her any of your personal information or share any of your responses.

If you have any questions about the study now or later on please contact:

- Me (Bianca Burkett) on (011) 717 4585 or 0724416503
- My supervisor (Prof. Claire Penn) on (011) 717 4579
- My co-supervisor (Dr. Jennifer Watermeyer) on (011) 717 4578
- The chair of the Human Research Ethics Committee (Medical) (Prof. Peter Cleaton-Jones) on (011) 717 2635.

If you agree to participate in this study, please read and sign the consent form that has been given to you.

Thank you for your time.

| Patient's informed consent to participate in study                              |   |  |
|---|---|--|
| I,the communication between patient   | agree to participate in the study, investigating ts and nurses.                 |  |
|   |   |  |
| I understand the contents of this for   | m.  |  |
| I confirm that I have been informed risks.                                      | about the study, what will be done, its benefits and                            |  |
| I understand that my responses will information will be shared.                 | be kept anonymous and that none of my personal                                  |  |
| I understand that my participation is study at any time, without facing ne      | s completely voluntary and I can stop participating in the gative consequences. |  |
| I confirm that I have had sufficient o<br>part in this study of my own free wil | opportunity to ask questions and have chosen to take                            |  |
| I understand that when I speak with will be (video and/or audio) recorde        | the nurses and with the researcher, this informationed.                         |  |
| I understand that confidentiality in t  | the focus groups cannot be guaranteed.  |  |
| Signed:   | Date:   |  |
| Witness:  | _   |  |

| Patient's informed consent to audio re                                   | ecording  |
|--|---|
| I,the communication between patients a                                   | agree to participate in the study, investigating nd nurses. |
| I understand that my discussion with the recorded and I consent to this. | e researcher and other patients will be audio-              |
| I understand that all information will be will be made available.        | kept confidential and none of my personal details           |
| Signed: D  | Date:   |
| Witness:   |   |

| Patient's informed consent to video                            | recording  |
|--|--|
| I,the communication between patients                           | agree to participate in the study, investigating and nurses. |
| I understand that my conversation wi<br>this.                  | th the nurse will be video recorded and I consent to         |
| I understand that all information will will be made available. | be kept confidential and none of my personal details         |
| Signed:  | Date:  |
| Witness:   |  |

# Appendix 8: Sample of translated data from video recorded education session

Nurse: Ok o rata la X (name of other nurse)

[Translation: ok you love the X (name of other nurse) one]

Patient: Hmmn. ((nods head))

Nurse: Ok ba o testile today?

[Translation: ok did they test you today?]

Patient: No.

Nurse: Ok habao tester today, ok si ready, taba tsa rona di gala mo. Wantseba akere hore ke

sister mang?

[Translation: ok they didn't test, ok we are ready, our talk will start here. You do know

who I am right?]

Patient: Sister Y (name).

Nurse: Y (name) akere okase lebale kahore ke salona akere.

[Translation: Y(name), you won't forget it because it's yours]

Patient: Eee.

[Translation: Yes].

Nurse: Akere bago boleletse maabane gore onale tsukiri?

[Translation: They told you yesterday that you have sugar right?]

Patient: Eee ((nods head))

[Translation: Yes]

Nurse: Ba bone jwang gore onale tsukiri?

[Translation: How did they see that you have sugar?]

Patient: Bang chekile.

[Translation: They checked me.]

Nurse: Bao chekile akere, baochekile moroto ebe ba bona gore moroto wagago onale shukiri.

[Translation: They checked you right? They checked your urine and they realized from the urine that you have sugar.]

Patient: Eee.

[Translation: Yes.]

Nurse: And then ha ke sheba mona mo famaling ha hona motho onang le shukiri, ke bona mo history ya gago hahona motho onang le shukiri and then baile bago tester mo letsogong ebe ba thola gore...

[Translation: And when I look at the family history there is no one with sugar, I can see from your history that there is no one with sugar, and then they tested you on the hand and found out that...]

Patient: Ke positive.

[Translation: Am positive.]

Nurse: He harebe positive mo tsukiring re bitsa ka di number bathola ere 10 haere 10 hake tsebe hore nesetse ele nako ekae o fetsa hoja, nele nako e kakang o fetsa hoja?

[Translation: No we don't test positive with sugar, we distinguish it using numbers, if they find that its 10, and when it says 10, am not sure how long it was after you have eaten, how long was it?]

Patient: Ke jele vroug ebe ke tester.

[Translation: I ate in the morning and then I tested.]

Nurse: Nele kgale o jele motlhomong, hour nesetse e fitile neh

[Translation: Was it long after you had eaten, had an hour passed by then?]

Patient: Hmm. ((nods head))

Nurse: Ok keabona gore tsokere ya gago nele kodimo, so gonanong gawe tester nereng?

[Translation: I see your sugar was high and what were the results when you tested now?]