Formative research for the development of an appropriate, acceptable and feasible intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa

presented for the Degree of DOCTOR OF PHILOSOPHY
in the Department of Medicine, Faculty of Health Sciences

LORREIN SHAMISO MUHWAVA
MHWLOR001

Academic Supervisors:

Associate Professor Katherine Murphy, Chronic Diseases Initiative for Africa (CDIA), University of Cape Town

Professor Christina Zarowsky, School of Public Health, University of Montreal (ESPUM), Canada and School of Public Health, University of the Western Cape

Professor Naomi Levitt, Chronic Diseases Initiative for Africa (CDIA), University of Cape Town

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Declaration

I, Lorrein Shamiso Muhwava, hereby declare that this thesis is my own original, unaided work. It is being submitted for the degree of Doctor of Philosophy (Medicine) at the University of the Cape Town, South Africa. This work has not been submitted before for any degree or examination at this or any other university or institution. I authorise the University of Cape Town to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

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Student Name: **Lorrein Shamiso Muhwava** Student Number: **MHWLOR001**

Publications

This thesis includes published papers, as per general provision 6.7 in the General Rules for the Degree of Doctor of Philosophy (PhD) of the University of Cape Town. I confirm that I have been granted permission by the University of Cape Town's Doctoral Degrees Board to include the following publications in my PhD thesis, and where co-authorships are involved, my co-authors have agreed that I may include the publications. The following four co-authored papers are formally included as part of the thesis:

i. **Muhwava, LS**., Murphy, K., Zarowsky, C., Levitt, N. 2018. Policies and clinical practices relating to the management of gestational diabetes mellitus in the public health sector, South Africa – a qualitative study. *BMC Health Services Research* 18:349

ii. **Muhwava, L. S**., Murphy, K., Zarowsky, C., & Levitt, N. 2019. Experiences of lifestyle change among women with gestational diabetes mellitus (GDM): A behavioural diagnosis using the COM-B model in a low-income setting. *PloS One*, *14*(11).

iii. **Muhwava, LS**., Murphy, K., Zarowsky, C., & Levitt, N. 2020. Perspectives on the psychological and emotional burden of having gestational diabetes amongst low-income women in Cape Town, South Africa. *BMC Women's Health,* 20(1), 1-12.

iv. **Muhwava, LS**., Murphy, K., Zarowsky, C., & Levitt, N. Women's perceptions and experiences of GDM health services in Cape Town, South Africa: A qualitative study (submitted to *Plos ONE*)

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Signed by candidate

Student Name: **Lorrein Shamiso Muhwava** Student Number: **MHWLOR001**

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Glossary

BANC: Basic Antenatal Care

CHC: Community Health Centre

COM-B model: Capability, Opportunity, Motivation – Behaviour model

COREQ: Consolidated criteria for Reporting Qualitative Research

GDM: Gestational Diabetes Mellitus

IGT: Impaired Glucose Tolerance

IINDIAGO: An **I**ntegrated health system **IN**tervention aimed at reducing type 2 **DIA**betes in disadvantaged women after **G**estati**O**nal diabetes in South Africa

LMIC: Low- and Middle- Income Countries

MMM Framework: Maternal Morbidity Measurement Framework

MOU: Midwife Obstetric Unit

OGTT: Oral Glucose Tolerance Test

PMTCT: Prevention of Mother to Child Transmissions

PPD: Postpartum depression

SA: South Africa

WHO: World Health Organization

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Abstract

Background

Gestational diabetes mellitus (GDM) is one of the most common obstetric complications, affecting 18.4 million live births globally. In South Africa, the high prevalence of GDM estimated to be up to 25.8%, is driven by the high rates of obesity. Women with a history of GDM have a seven-fold increased lifetime risk of developing type 2 diabetes. In addition, children born of women with GDM are susceptible to impaired glucose tolerance and obesity in adulthood. Prioritising GDM as a public health issue is critical for improving maternal and child health care services and non-communicable disease prevention efforts.

There is consistent evidence demonstrating that, in at-risk populations, lifestyle change can reduce the risk of developing type 2 diabetes and among women with GDM, continuation of lifestyle changes after a GDM pregnancy can prevent progression to type 2 diabetes. Understanding women's lived experiences and views around GDM is critical for the development of behaviour change interventions. Further, insights from women's experiences of the healthcare system for GDM care are important for informing health policy and improving the quality of care. At present, little is known about the policies and practices relating to the management of GDM in low- and middle- income countries and health systems interventions that support and facilitate continuity of care are lacking. This thesis constitutes the formative research for a complex intervention study aimed at developing and evaluating a novel health system intervention to reduce the subsequent risk of developing type 2 diabetes among women with GDM. The findings will inform the planning, development and

testing of an appropriate and innovative intervention for women with GDM, to be integrated into existing health services in South Africa.

Methods and Results

The **first study** used document reviews of policy documents and clinical practice guidelines for the management of GDM in South Africa and 11 key informant interviews with policy makers, health service managers from the Department of Health and clinicians working in the public health services to explore the existing policies and reported clinical practices relating to antenatal and postnatal care for women with GDM in the public health sector in South Africa and identified important factors in delivering an integrated mother - baby postpartum health service. We found that the management of GDM in South Africa is aligned with international standards, in addition to locally developed guidelines and protocols for clinical practice. Our findings also confirmed that postpartum follow-up for women with GDM is a significant problem in South Africa as a result of fragmentation of care and the absence of standardised postnatal care services. Key informants also raised patient – related challenges including lack of perceived future risk of developing type 2 diabetes and non-attendance for postpartum follow up, as barriers to postnatal care for women with GDM. The **second study** was a descriptive qualitative study which explored the lived experiences of 35 women with prior GDM using content analysis and the COM-B model to identify factors influencing lifestyle change during and beyond the GDM pregnancy. The results suggest that the COM-B model's concepts of capability (knowledge and skills for behaviour change), opportunity (resources for dietary change and physical activity) and motivation (perception of future diabetes risk) are relevant to lifestyle change among women with GDM in South Africa. The **third study** was an in- depth exploration of women's lived experiences of GDM, their context and perceived

needs. Women discussed the emotional and psychological burden of having GDM, highlighting (i) their initial emotional reactions to receiving a GDM diagnosis, (ii) their experience of adjusting to the constraints of living with GDM (iii) their feelings of apprehension about childbirth and their maternal role and (iv) their feelings of abandonment in the post-partum period once the intensive support from both health system and family ends. The **fourth study** further explored women's perspectives of and satisfaction with GDM care in the public health sector as well as their views on the feasibility and acceptability of the proposed intervention using the Donabedian's quality of care framework. Key sub-themes relating to 'structure' of care were the organisation of GDM health services, efficiency of the referral, efficiency of management practices, quality of hospital facilities and services and the availability of adequate healthcare resources. Overall satisfaction with GDM care processes was influenced by women's unmet need for education and behaviour change counselling, interpersonal support from health care providers and peers and the health services' capacity to enable them to actively participate in their care.

Conclusion

The management of GDM is currently foetal - centric and over-medicalised, focusing on clinical care processes to achieve glycaemic control and safeguard foetal health. There is a critical need for woman-centred approaches to be incorporated in the management of GDM in order to improve women's overall experiences of care. Behaviour change interventions for women with GDM should target factors within the physical and social environments, that influence women's capacity for lifestyle change. In addition, we recommend routine mental health and psychosocial vulnerability screening and monitoring for women diagnosed with GDM throughout pregnancy and postpartum to improve prognoses. Finally, holistic

interventions and health policies that directly support continuity of care are urgently needed if high rates of progression to type 2 diabetes in this population are to be avoided.

CHAPTER 1: BACKGROUND TO THIS THESIS

This first chapter provides the background to the thesis and a review of the current literature on gestational diabetes, risk factors, screening, diagnosis, and management of the condition. This was a narrative literature review to provide a broad overview of the barriers and facilitators of postpartum follow-up after GDM, from women's perspectives. The literature review intended to describe and discuss the literature on the management of GDM and therefore highlighted key issues, authors and findings relevant to the thesis, selected from among the full database of literature collected over the course of the research. This chapter also highlights important gaps in the literature, which provide motivation for this thesis.

1.1. Epidemiology of Diabetes

The increasing burden of diabetes is a major public health concern. Global estimates are that the number of people with diabetes will increase from 463 million people in 2019 to 700 million people by 2045 [1]. Low- and middle- income countries (LMICs) have the greatest burden of the disease and more than 80% of deaths from diabetes occur in LMICs [2, 3]. The high prevalence of diabetes is of great concern in Africa where the highest proportion is reported among people 40-59 years (43.2%) and where the burden of undiagnosed diabetes is very high (50.7%) [4]. South Africa is among the LMICs already facing a double burden of disease - an increase in non-communicable diseases (NCDs) whilst retaining the burden of infectious diseases (HIV/AIDS, tuberculosis etc.). This increase in diabetes and other NCDs in LMICs can be attributed to the epidemiological transition caused by uncontrolled

urbanization, a reduction in mortality and therefore aging populations and an increase in unhealthy lifestyle behaviours, such as unhealthy diet and physical inactivity [5-7]. The associated direct and indirect treatment costs of diabetes (e.g., medication and hospitalisations) place substantial financial strain on both patients and health systems [8]. Health systems in LMICs are not adequately resourced to cope with the rising prevalence of diabetes and other NCDs in addition to tackling communicable diseases [7, 8]. Data from the African region are limited, and therefore further research and evidence-based programmes are needed to effectively address this growing epidemic. Cost-effective public health interventions are urgently needed to improve the management of existing cases and more importantly, prevent new diabetes cases.

Type 2 diabetes is a metabolic disorder caused by the body's inability to effectively use insulin resulting in chronic hyperglycaemia. It is the most common clinical category of diabetes and accounts for 90% of diabetes cases compared to the rarer type 1 diabetes [7, 9-11]. People with type 1 diabetes require insulin for survival, whereas people with type 2 diabetes may be managed using non-insulin therapies. However, type 2 diabetes can also lead to serious complications including damage to the heart, eyes and kidneys and because symptoms appear gradually, most diabetes cases remain undiagnosed until the complications appear [11]. Given the complexity and chronic nature of the condition, the impact of type 2 diabetes is of particular concern in LMICs where health systems are overburdened, and resources are limited [4]. Health expenditure costs for type 2 diabetes are very high and in South Africa, are projected to reach at least 1.1 billion USD in 2030 [12].

Risk factors for type 2 diabetes include advanced age, ethnicity, family history of type 2 diabetes, high blood pressure, overweight, unhealthy diet, physical inactivity and history of gestational diabetes mellitus (GDM). Obesity (BMI>30kg/m^2) is the biggest lifestyle related contributor to type 2 diabetes. This is particularly so in South Africa, which has the highest rate of obesity and overweight in sub-Saharan Africa – up to 70% women are overweight or obese whilst the prevalence of obesity among women has risen from 30% in the 1998 (SADHS) to 42% in 2013 [13, 14]. Obesity is also a risk factor for gestational diabetes and studies have shown that women with a history of GDM have a seven-fold risk of developing type 2 diabetes in the future [10]. Large scale, community-based interventions in Europe, the US and India, which have targeted the modifiable risk factors for type 2 diabetes have proved effective in preventing new cases of the disease and in the management of existing cases of type 2 diabetes (DPP Research Group, 2006). Such interventions, which have focused on improving physical activity and diet, have succeeded in reducing type 2 diabetes incidence by about 50% among high-risk individuals [15-18]. In addition, lifestyle interventions for high-risk groups for type 2 diabetes (including obesity, IGT, IFG and GDM) have also been found to be cost-effective [19].

1.2. Gestational Diabetes Mellitus

Gestational diabetes mellitus (GDM) is defined by the WHO as “any degree of clinical glucose intolerance with onset or first recognition during pregnancy” [11]. This definition of GDM has been the subject of continued debate because it includes impaired glucose tolerance (IGT) and overt diabetes under one definition. The International Association of Diabetes and Pregnancy Study Groups (IADPSG) and American Diabetes Association’s (ADA) definition of

GDM clearly differentiate between overt diabetes that will not resolve after pregnancy and GDM [20]. On the basis of research evidence, the WHO has also made recommendations for the definition and diagnosis criteria to distinguish between overt diabetes and GDM [21]. GDM is currently defined as 'diabetes diagnosed in the second or third trimester of pregnancy and is not clearly overt diabetes' [22].

Although there is some indication that the prevalence of GDM is increasing, reliable global prevalence estimates of GDM are lacking or not easily accessible [23]. It has been estimated that up to 28% of pregnancies are affected by GDM globally [24]. In sub-Saharan Africa, on the basis of very limited data, the prevalence of GDM is estimated to range from 0% to 25.8% [25-28]. The paucity of GDM studies on the African continent may partially be explained by the lack of consensus on diagnostic criteria and screening practices for GDM, which differ from one setting to another. The true prevalence of GDM in South Africa is unknown, although it is currently estimated to be greater than 15% [26]. A small study [29] reported a combined prevalence of 8.8% for gestational impaired glucose tolerance (7.3%) and GDM (1.5%); another reported a very high prevalence of 25.8% GDM using universal screening and the IADPSG criteria, while another recent study reported a 7% GDM prevalence among black South African women using universal fasting plasma glucose [30].

Untreated GDM can have adverse effects on pregnancy outcomes, including shoulder dystocia, birth injuries, nerve palsies and stillbirth [31]. Women with a history of GDM have a significantly increased lifetime risk (≥70%) for developing type 2 diabetes [32, 33] with the highest risk occurring 3-6 years following the GDM pregnancy and among women younger than 40 years old [34, 35]. In addition, women with GDM also have a 3-fold risk of developing

metabolic syndrome and an increased long-term risk for cardiovascular disease, while GDM offspring are susceptible to impaired glucose tolerance (IGT) and obesity in adulthood [36-38]. Women with GDM therefore represent a unique high-risk target group for intervention during pregnancy, with long-term health benefits for both the mother and baby.

1.3. Screening, Diagnosis and Management of GDM

As GDM poses short-term and long-term health risks to the mother and child, early diagnosis is necessary to initiate treatment to ensure positive health outcomes for the mother and baby [39]. The diagnosis of GDM is usually made in the second trimester of pregnancy following prenatal screening. Although universal screening for GDM in all pregnant women is often regarded as best practice, it is not always feasible. In developed countries such as the USA where universal screening is practiced in some states, the overall screening rates for GDM are in the range of 87.5% - 96% [23, 40]. Where resources are more limited, pregnant women are selectively screened for GDM based on the presence of risk factors [41]. However, based on recent evidence from South Africa, universal screening using fasting plasma glucose ≥4.5 mmol/L has higher sensitivity and is more cost-effective in low-resource settings compared to selective screening on the basis of risk factors [30].

The WHO criteria for GDM diagnosis are accepted in many African countries although decisions on coverage are at the discretion of the health authorities [21]. In addition, some countries have national guidelines for screening, diagnosis and treatment for GDM. According to the Guidelines for Maternity Care in South Africa [42], the particular screening method used depends on the preference of the specialist referral centre. South Africa has adopted

selective risk-factor screening based on any of the following risk factors; repeated glycosuria, previous GDM, age>40 years, family history of diabetes (first-degree relative), history of stillbirths of unknown origin - previous congenital anomalies and suspicion of polyhydramnios in present pregnancy, history of high-birthweight infant (≥ 4.5 kg), obesity (Body Mass Index >30 kg/m2) and women of South-Asian descent [9, 42]. Similar to international WHO guidelines, women with any of these risk factors should be offered an Oral Glucose Tolerance Test (OGTT) and GDM is then diagnosed on the basis of a fasting plasma glucose level of 5.6mmol/litre or a 2-hour plasma glucose level of 7.8mmol/litre or above [21, 42, 43].

The guidelines for the management of GDM vary from one country to the other depending on the health systems, resource availability, as well as disease burden; hence there is no uniformity in the screening and diagnostic criteria as well as GDM management practices across the world [24, 44]. In South Africa, the National Guidelines for Maternity Care in South Africa (Fourth Edition, 2015), the 2012 Society for Endocrinology, Metabolism and Diabetes of South Africa (SEMDSA) Guidelines for the Management of Type 2 Diabetes (Revised) and the provincially developed Western Cape 'Diabetes in Pregnancy' guidelines (adapted from the National Institute for Health and Care Excellence (NICE) 2008 guidelines) are followed in the management and care for women with GDM [9, 42, 45]. These guidelines were all developed in consultation with local experts and supported by evidence in the literature. According to the national and provincial clinical practice guidelines in SA, all women with GDM should receive antenatal care and deliver their babies at tertiary hospitals – where they will receive specialist care throughout the pregnancy from a diabetes-obstetric team. Management of GDM entails one or a combination of the following (i) counselling on lifestyle behaviour – particularly diet and physical activity, (ii) oral agents such as metformin and (iii)

insulin. At discharge, women with GDM should be counselled about their subsequent risk of developing type 2 diabetes in future and advised to undergo a 75g OGTT screening at 6 weeks. However, previous studies from high-income countries including a recent systematic review, have reported that some women perceive the management of GDM to be over-medicalised and focused on physiological aspects of care, without adequately engaging women in decision-making [46-48]. This finding highlights the importance of understanding the sociocultural context in which women experience a GDM-complicated pregnancy as well as identifying women's needs in order to improve GDM management and treatment practices. There is a need to re-frame messaging around developmental origins of health and disease to emphasise the role societal factors and not focus solely on the mothers [49].

1.4. Follow-up care after GDM

As mentioned, women with GDM have an increased risk for developing type 2 diabetes in later life. Studies have reported conversion rates ranging from 2.6% to 70% from 6 weeks to 28 years postpartum [50-52]. The initial diabetes prevention trials, which showed benefit in using intensive behaviour change interventions for people with pre-diabetes or IGT [53], were also found to be equally effective among women with and without self-reported prior history of GDM [38]. The high rates of undiagnosed diabetes cases in LMICs are indicative of a need for more effective screening practices in the post-partum period. International recommendations for post-partum follow up and care emphasize the need for women with a history of GDM to be screened for diabetes using an oral glucose tolerance test (OGTT) from 6-12 weeks postpartum [20]. The OGTT is also a good indicator for future risk of diabetes in women whose glucose levels are found to be elevated, but below the values of definitive type

2 diabetes diagnosis [54]. However, in many countries - including South Africa – screening for diabetes post-GDM is not routinely offered at primary care level. Once women are discharged from the hospital after delivery, there is no standardised system in place to ensure that women with recent GDM receive an OGTT post-partum.

1.4.1. Facilitators of postpartum follow-up

Childcare availability, good relationships with health care providers and the opportunity to ask questions and address concerns have been identified as facilitators of attendance to the follow-up visit among women with GDM [50, 55]. Health system interventions that support and facilitate follow-up for women with a history of GDM in the postpartum period are also needed. For example, in a study by Hunt and Conway [56], a case-manager nurse with specific responsibility to increase postpartum screening among women with GDM through individual follow-up achieved a 12% increase in attendance rates . Telephonic, text and postal reminders have great potential for improving attendance to postpartum screening. However, most of these methods have been used in the context of research settings where resources are specifically allocated, and sample sizes are manageable and have not yet been demonstrated to be feasible or effective in a resource limited setting.

1.4.2. Barriers to postpartum follow up

Despite its importance, post-partum follow-up for women with a history of GDM where available, is characterised by poor attendance. Although studies that have attempted to understand the barriers and facilitators to follow up care among women with GDM are limited, several factors have been linked to women's lack of attendance for postpartum follow-up care after GDM, as well as poor adherence to lifestyle changes in the postpartum

period (see Table 1). Poor understanding of the information on the diagnosis and lifestyle change recommendations may be contributing factors [57]. In some instances, women with recent GDM have reported personal and family adjustment to the baby and the demands of motherhood as some of the barriers [50]. These demands of motherhood including changes in sleeping patterns to accommodate the baby make it difficult to prioritize diet and exercise and may also affect a woman's mood and overall sense of wellbeing. A review of studies with ethnically diverse low-income women in the US found that the diagnosis and experience of GDM in itself may be linked to postpartum depression (PPD) [58]. Such psychological factors may impact on women's motivation to attend healthcare services for follow-up and sustain lifestyle changes. Furthermore, women's perception of risk of developing type 2 diabetes after a GDM pregnancy is an important determinant of postpartum follow-up. Women who perceive their risk of developing type 2 diabetes as high and immediate may decide not to attend the 6-week postpartum screening out of fear of a diagnosis of diabetes [50, 59]. On the other hand, perceived good health and a low perception of risk may also prevent women from seeking care. Even when women do attend for healthcare post-partum, many of them do not receive an OGTT [10, 39, 50, 60]. For example, in a US study, 77% of women with prior GDM attended postpartum follow-up, but only 45% received screening for diabetes [50]. Another study in Korea reported a similar postpartum glucose-testing rate of 44.9% [61]. Health care workers (HCWs) have cited patients not returning to the clinic, fragmentation of care and poor communication between HCWs delivering care as barriers to follow-up screening after a GDM pregnancy [58, 59]. These barriers indicate a missed opportunity for early intervention in order to prevent progression to type 2 diabetes.

Although lifestyle interventions for women with GDM through diet and exercise during pregnancy have proven effective in improving health outcomes for both the mother and baby, there is a need for postpartum interventions to support women in making positive behaviour changes that are sustainable in the long term [62]. The findings from systematic reviews confirm the effectiveness of postpartum lifestyle change interventions such as diet, physical activity and breastfeeding to reduce the long-term risk of type 2 diabetes among women with a history of GDM [63, 64]. However, a systematic review of lifestyle interventions also reported that lifestyle change among this high-risk population is a challenge and therefore further research on acceptable, feasible and effective lifestyle interventions is warranted [65].

The development of behaviour change interventions should be informed by behaviour and behaviour change theory and demonstrate an in-depth understanding of the cultural, social, and contextual factors that influence behaviour [62, 66]. Theories help researchers to understand why, when, and how behaviour change occurs [67] and while it can be challenging for researchers to select a single theory to guide their research, theoretical principles are fundamental to the development and evaluation of behaviour change interventions. The theoretical frameworks applied in this PhD thesis will be discussed in detail in the Methodology chapter (Chapter 3).

In conclusion, while much is known about the risk factors for GDM and subsequent risk of type 2 diabetes, there are gaps in the literature regarding the barriers and facilitators for lifestyle change during pregnancy and in the postpartum period. As demonstrated, the majority of intervention studies have been conducted in high-income countries and have not

yet been demonstrated to be feasible or effective in low-income settings. There is a need to further explore these factors, particularly in low-resource settings such as South Africa.

Table 1 presents a summary of the published literature presented in the literature review, and highlights the methods used, sample size and data on the barriers and facilitators as extracted from each of the included articles.

Table 1: Summary of of the published literature presented in the literature review highlighting barriers to and facilitators for post-partum follow-up for women with recent GDM

Author & date	Data collection	Barriers	Facilitators
Sunny *et al*., 2020 [62]	In-depth interviews conducted with 20 mothers with GDM	• Fear of the diagnosis and its consequences • Lack of childcare • Competing priorities • Unpleasant experiences with the OGTT	• Perceived risk of developing T2DM • Understanding the need for screening and the benefits of early diagnosis • Availability of childcare • Availability of emotional and peer support
Mathew *et al*., 2020 [63]	In-depth interviews with 6 women with a history of GDM, who did not attend follow-up	• Lack of prior appointment for mothers • Lack of adequate hospital facilities • Baby and concerns • Lack of knowledge or health education	• Not addressed in the study
Chang *et al.,* 2014 [64]	Telephonic interviews conducted with 2152 postpartum women with recent GDM	• Time constraints • No reminders/notifications from doctors • Low perception of risk • No symptoms • Hospital waiting times	• Family history of diabetes • Doctor Notification • Knowledge of risk of type 2 diabetes after GDM
Paez *et al*., 2014 [51]	Mixed methods study, In-depth interviews conducted with 22 women	• Difficulty fitting testing around work • Caregiver demands • Lack of reminders to reschedule missed visits • Perception that health care workers were not concerned about their diabetes risk •	• Consistent messages regarding long-term diabetes risk during pregnancy • Access to post-partum primary care • Convenient lab appointments and systematic reminders to providers and patients •

Bennett *et al*., 2011 [46]	Semi-structured interviews (in person and by telephone) with women with recent GDM	• Recent delivery experience • Baby health issues • Personal and family adjustment to the new baby • Concerns about postpartum and future health • Negative experiences with medical care and services	• Availability of childcare at time of visit • Desire to have check-up and clearance for return to work • Connection with clinical and office staff • Discussion of family planning
Doran & Davis, 2010 [56]	Individual semi-structured, face-face interviews with 11 women who had GDM in the past 12 months and 10 HCPs working in GDM	• Lack of childcare assistance • Preventative screening seen as a “foreign idea” among Tongans • Lack of resources to administer OGTT	• Health education • Health Promotion Programmes
Keely et al., 2010 [55]	A follow-up fax and telephone survey of 233 female patients with prior GDM and their primary care provider (PCP). Participants had taken part in RCT	• Time pressure given as reason by patients for not completing an OGTT • PCPs did not see patient in the post-partum period (Patient did not return for any reason)	• Reminder letters sent to patients and PCP

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CHAPTER 2: RATIONALE, SCOPE AND STUDY OBJECTIVES

This chapter provides the justification for and overview of the PhD thesis, highlighting how it fits in with a larger, ongoing study called IINDIAGO, an acronym for "An **I**ntegrated health system **IN**tervention aimed at reducing type 2 **DIA**betes in disadvantaged women after **G**estati**O**nal diabetes in South Africa". The scope, aims and objectives of the thesis are described below in reference to the main IINDIAGO trial.

2.1. Rationale

The South African public health system provides healthcare services to approximately 84% of the population [1, 2]. Only the minority have access to and can afford private healthcare services, which are typically far better resourced. The impact of poverty on health is well documented and in South Africa, the high levels of poverty continue to affect access to basic health care [2]. As part of efforts to increase access to health care, the free health care policy, was initially introduced in 1994 to offer free health care services to all people attending public sector primary care facilities, provided they do not have medical aid or health insurance [3]. At public hospitals, user-fees are charged based on annual household income and health services are free for those who cannot afford it (i.e., individual income <R70 000 per annum). It is on this basis that this study is situated in the public health sector setting and focuses on women from poor and previously disadvantaged communities, who would benefit from interventions to improve public sector health services.

According to Guidelines for Maternity Care in South Africa, women diagnosed with GDM should be referred from a primary care health facility to a district or tertiary level hospital with expertise in managing diabetes in pregnancy [4]. However, little is known about the current practices in the referral of women and the management of GDM in the public health sector. Anecdotal evidence suggests that the clinical care of women with GDM during pregnancy is of a high standard as it entails specialist care and medical management. Women should ideally be informed about their risk of developing type 2 diabetes in future and advised to attend a postpartum follow-up visit within 6 to 12 weeks to undergo an Oral Glucose Tolerance Test (OGTT) to determine their risk of type 2 diabetes. It is recommended that all women with GDM be provided with a discharge summary letter to present at the primary health care facility for the OGTT. However, exploratory interviews undertaken during the development of the IINDIAGO study protocol revealed that in practice, this is seldom done. Anecdotal reports indicate that the 6-week post-partum OGTT test is poorly attended, and screening tests are not routinely available to women with prior GDM at primary care level.

Despite the overwhelming evidence of women's increased risk of developing type 2 diabetes after GDM, the lack of postpartum follow-up in this high-risk population has not been explored in the South African context. Beyond the verbal reminders by health care providers and the handheld record on discharge from the tertiary hospital advising them to attend postpartum screening for diabetes, expert key informants consulted in the preparation of the IINDIAGO proposal indicated that most women with GDM in SA receive very little attention after pregnancy. This situation warrants a deeper understanding of the policies and guidelines for GDM management and the perspectives of healthcare stakeholders including policy makers, specialist clinicians and other health care providers regarding the management of

GDM and post-partum follow up and care. Furthermore, there is a need to undertake research to explore the opportunities and barriers within the health system for an integrated approach to the continuum of care that would fit within existing health services. Of particular interest is the potential for leveraging the scheduled visits at the 'Well Baby' primary care clinics, which mothers routinely attend for the child's immunization program. This primary care service may be an ideal opportunity to conduct diabetes screening and tests and to provide follow-up advice to women after a GDM pregnancy [5].

The majority of GDM studies on women's perspectives and experiences [6-8] as well as health care providers' views [9-11] have been conducted in high-income countries and may not be relevant or applicable in the South African context. To the best of our knowledge at this time, there are no South African studies that have investigated the potential for a more systematic approach to the postpartum care of women with GDM to facilitate them attending healthcare services for diabetes screening and provide women with continued support for lifestyle change. Women's perspectives on these issues are also yet to be established.

2.2. Scope of the thesis

2.2.1. The IINDIAGO Randomised Control Trial

The overarching aim of the IINDIAGO project is to develop and evaluate a novel health system intervention to reduce the risk of subsequent type 2 diabetes among women with recent GDM. The IINDIAGO objectives are the following:

i. Assess the feasibility and acceptability of the proposed intervention among both women and healthcare providers and managers, through formative research and evaluation

ii. Develop and implement a novel health system intervention package for women with recent GDM, that links existing public hospital-based antenatal care with postnatal community-based care at Well Baby clinics and which incorporates postpartum screening and evidence-based brief behaviour change counselling on the lifestyle risk factors for diabetes

iii. Evaluate the impact of the intervention on the type 2 diabetes risk profile of women with prior GDM in a randomised control trial

iv. Assess the process of implementation, including the possible system facilitators and barriers to integrating the intervention into routine, community-based primary healthcare services

v. Assess the cost-effectiveness of the proposed intervention package

These objectives conform to the four phases for development and evaluation of complex interventions recommended in the UK MRC framework namely, development; feasibility and piloting; evaluation and implementation [12]. The UK MRC framework and the theoretical and conceptual frameworks applied in this PhD thesis will be discussed in Chapter 3.

2.2.2. Outline of the PhD Study

This PhD thesis is a sub-component of the larger IINDIAGO randomized control trial and constitutes the formative phase of the overall project. The intent of this PhD thesis was to

develop and undertake formative research to gain an in-depth understanding of the situation and context in which the intervention would be initiated, as well as to assess the acceptability and feasibility of the potential intervention with its proposed implementers (healthcare providers and policy makers) and recipients (women with prior GDM). Formative research involving qualitative methods such as individual interviews, focus group interviews, and observations [13] is fundamental to the development of appropriate interventions [14]. The formative research process is therefore a critical component to intervention design as it allows for information gathering that will subsequently guide and inform the development of an intervention that best fits the targeted beneficiaries. Formative research methods have been applied in designing integrated interventions for maternal and child health in LMICs such as India [13], Ghana [15] and Malawi [16].

2.3. Aims of this PhD thesis

i. To review the current policies and practices relating to the management of GDM, as well as the systems barriers to and opportunities for delivering the proposed integrated mother –baby service that extends beyond the first week post-partum, to the infant's first year of life.

ii. To explore the most effective means of delivering a feasible, acceptable and sustainable lifestyle modification intervention for women with GDM within the context of existing public health services taking into consideration the perspectives of different stakeholders notably policy makers, health care providers and women with GDM.

iii. To understand the context in which the proposed intervention is to be initiated, including cultural, social, and contextual factors, which influence health seeking and lifestyle related behaviour.

2.4. Objectives of this PhD thesis

a) To document and analyse the current policies and practices relating to the management of GDM, as well as the health systems barriers to and opportunities for intervention.
b) To describe and analyse the lived experiences of women with GDM with a focus on lifestyle modification and their overall experience of a GDM-affected pregnancy.
c) To explore the impact of GDM on women lives, experience of pregnancy and sense of well-being.
d) To assess women's experiences of GDM health services and determine their views around the potential intervention.

2.5. Manuscripts included in this PhD thesis

The following manuscripts are included as chapters in the thesis.

Manuscript 1 (Chapter 4): Muhwava, LS., Murphy, K., Zarowsky, C., Levitt, N. 2018. Policies and clinical practices relating to the management of gestational diabetes mellitus in the public health sector, South Africa – a qualitative study. *BMC Health Services Research* 18:349

Manuscript 2 (Chapter 5): Muhwava, L. S., Murphy, K., Zarowsky, C., & Levitt, N. 2019. Experiences of lifestyle change among women with gestational diabetes mellitus (GDM): A behavioural diagnosis using the COM-B model in a low-income setting. *PloS One*, *14*(11).

Manuscript 3 (Chapter 6): Muhwava, LS., Murphy, K., Zarowsky, C., & Levitt, N. 2020. Perspectives on the psychological and emotional burden of having gestational diabetes amongst low-income women in Cape Town, South Africa. *BMC Women's Health,* 20(1), 1-12.

Manuscript 4 (Chapter 7): Muhwava, LS., Murphy, K., Zarowsky, C., & Levitt, N. Women's perceptions and experiences of GDM health services in Cape Town, South Africa: A qualitative study (submitted to *Plos One*)

The findings of this formative research will inform the development of an appropriate integrated health system intervention targeting women with GDM, with the aim of reducing their risk of developing type 2 diabetes.

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CHAPTER 3: Methodology

This chapter provides an overview of the conceptual and theoretical frameworks that underpin the IINDIAGO study and describes the methodology used to address each of the study objectives of the formative research. The methods for each sub-study are described in greater detail in subsequent chapters (Chapters 4-7).

3.1. Conceptual Framework for IINDIAGO study

The United Kingdom (UK) Medical Research Council (MRC) Framework for the development and evaluation of complex interventions recommends that the development of complex interventions proceed through 4 main phases namely – (i) Development of the intervention, (ii) Piloting and feasibility, (iii) Evaluation of the intervention and (iv) Implementation [1]. These phases are non-linear and involve iterative processes throughout development and testing of the intervention (see Figure 1). This framework has been used successfully in the South African context in the development of an integrated chronic disease model [2] and an adherence support intervention for blood pressure control [3]. The 2008 MRC framework is therefore a suitable overarching framework for the IINDIAGO complex intervention trial as it provides a flexible approach to the development and evaluation of the intervention that conforms to current best practice. The formative research focused on the **Development** phase of the MRC framework. The development stage involved identifying the evidence-base and consulting appropriate theory for the design of behaviour change interventions [1]. The feasibility of the intervention was then assessed through consulting healthcare stakeholders (i.e. specialist clinicians, diabetes nurses, health services managers and policy makers) and

women with GDM, and soliciting their views, attitudes and ideas on the potential intervention and how it can best be delivered in the real-life setting. The results of this formative research provided the reference material for the designing of the intervention elements and the piloting of certain components prior to the trial.

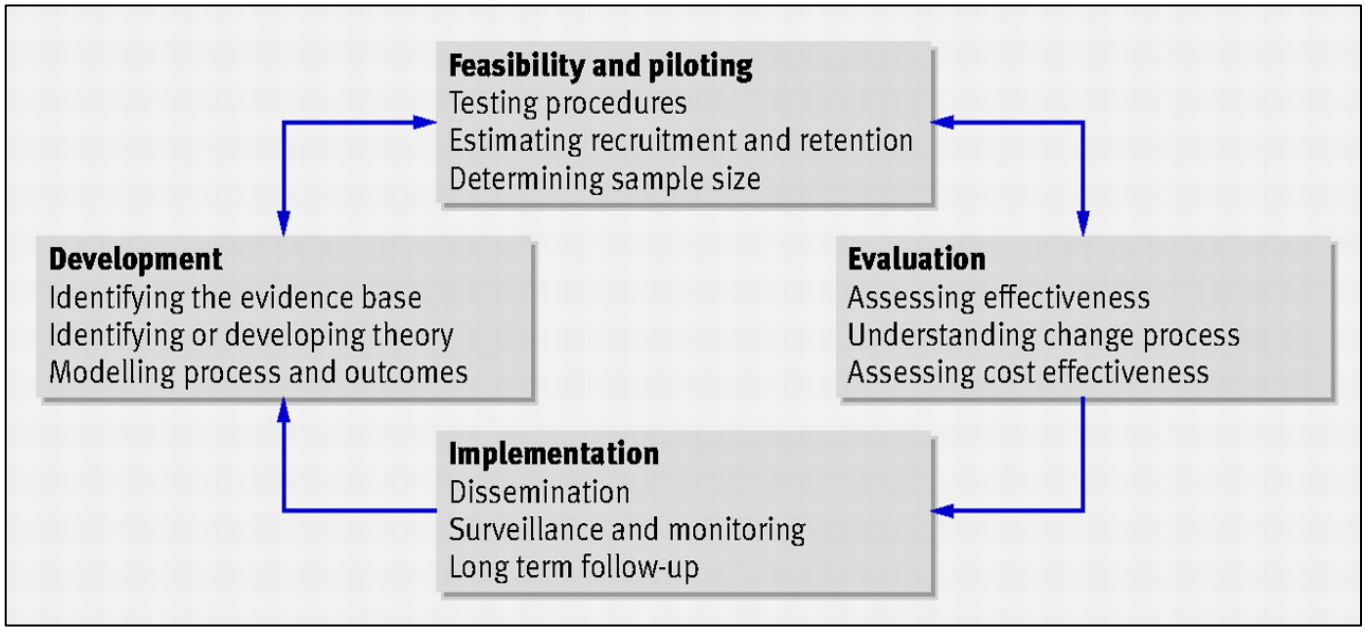

Figure 1: The UK MRC Framework for Complex Interventions [1]

(Image reproduced with permission of the UK Medical Research Council: https://www.bmj.com/content/bmj/337/bmj.a1655.full.pdf)

3.2. Theoretical Framework for IINDIAGO study

The development of behaviour change interventions should be informed by behaviour and behaviour change theory and demonstrate an in-depth understanding of the cultural, social, and contextual factors that influence behaviour [1, 4]. The MRC Framework recommends identifying appropriate theory in the early stages of the intervention development, drawing insights from existing literature and conducting empirical research, if necessary, to increase

the likelihood of developing an effective intervention [1]. The Behaviour Change Wheel (BCW) is an evidence-based and comprehensive theoretical framework (Figure 2a), which offers intervention designers step-by-step guidance through a systematic development process. The BCW framework and the COM-B model of behaviour change [5] provide a theoretical basis and structured methodology for analysing the target behaviours and characterizing interventions based on the behavioural diagnosis [6]. This framework has been used in the development of a diabetes prevention interventions for low-income Latina women with recent GDM in the USA [7] and to assess postnatal lifestyle among women with recent GDM in the UK [8]. The BCW and COM-B model will be used to guide the process of designing an appropriate behaviour change intervention for the IINDIAGO trial.

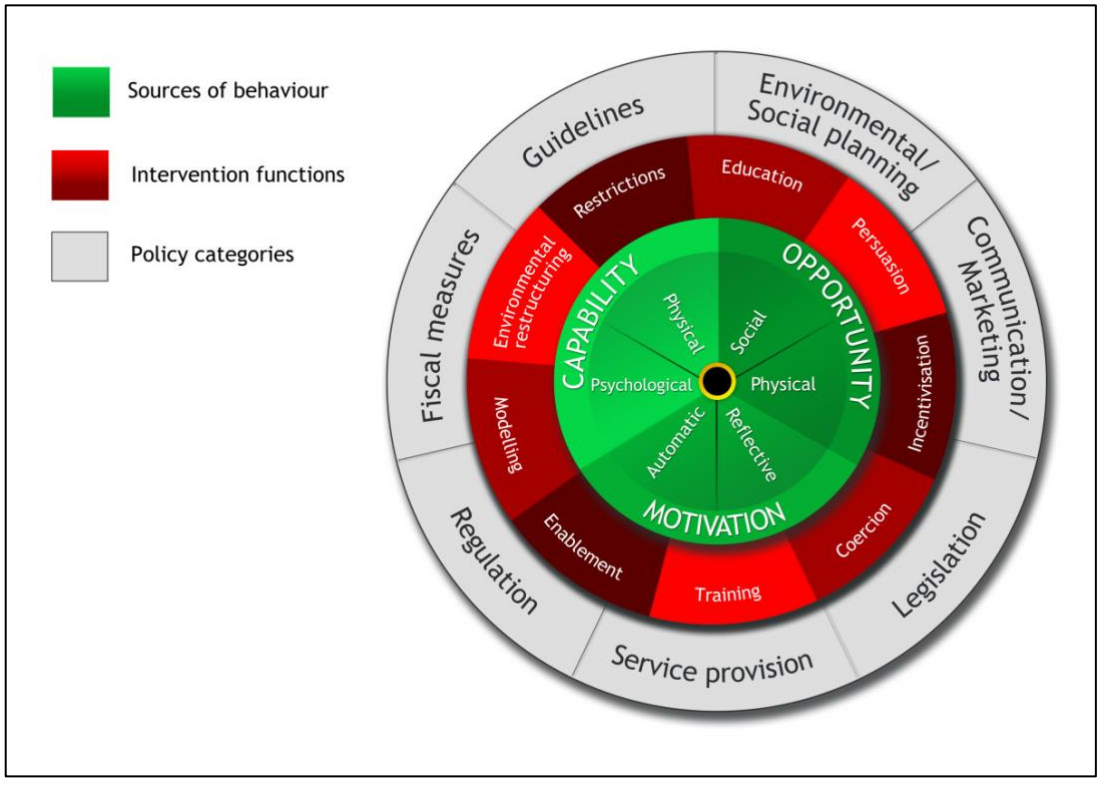

Figure 2a: The behaviour change wheel: a new method for characterising and designing behaviour change interventions.

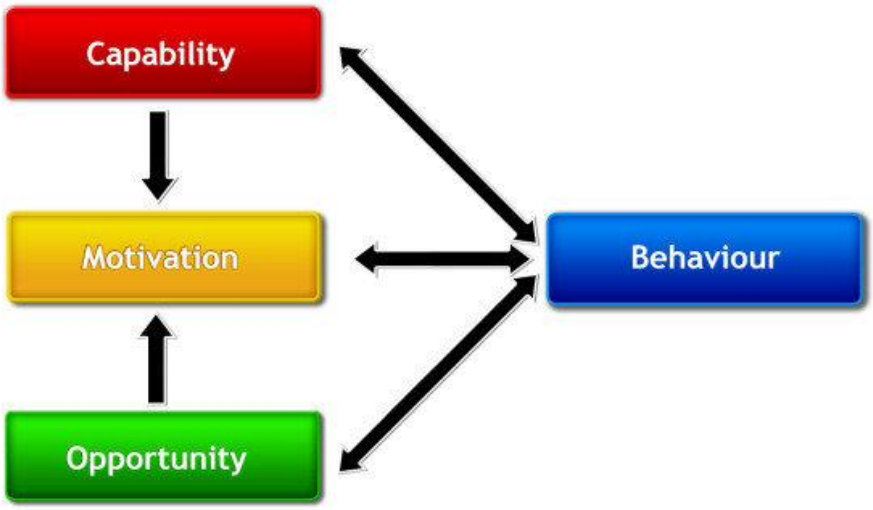

Figure 2b: The COM-B model framework for understanding behaviour [5].

(Image reproduced with permission from Professor Susan Michie: https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-6-42/figures/2)

3.3. Overall study design

Qualitative research is underpinned by philosophical assumptions about how knowledge is built, which inform the selection of theoretical or interpretive frameworks to guide the research [9]. Some common qualitative research designs used in formulating the research question, data collection, analysis and reporting include grounded theory, phenomenology, ethnography and narrative analysis [10, 11]. These approaches have increasingly been used in health research to explore, explain and understand health, health behaviours and to improve health services [12]. This body of work followed a phenomenological approach. This research methodology focuses on exploring the lived experiences of a heterogenous group of

individuals, providing a description of the lived experience (i.e., the phenomenon) and how the individuals make meaning of their experiences [9]. Factors underlying behaviour are best explored using qualitative research methods to capture beliefs, opinions and motivations [12, 13]. Unlike quantitative research which aims to objectively quantify or measure values, attitudes or behaviours, the goal of qualitative research is to gain an in-depth understanding of participants' subjective experiences [11]. Qualitative research generates data in textual form through various sources such as interviews, FGDs, observational methods or other documentary sources for analysis [12]. The analysis is conducted rigorously in a systematic and transparent manner. Further, because qualitative research seeks to understand participants' experiences and interpretation of their world [12], multiple viewpoints can be represented, often by including excerpts from the data in the findings to illustrate participants' voices [14]. This PhD thesis used qualitative research methods, guided by theoretical frameworks to explore the management of GDM in South Africa from healthcare stakeholders' perspectives and through the lived experiences of women with GDM in order and assess the barriers and facilitators for the implementation of a diabetes-prevention health system intervention. Focus groups enabled the collection of data on shared experiences and group norms around GDM in the context of a social group while individual in-depth interviews allowed exploration of the personal narratives of women in greater detail.

3.4. Theoretical and Conceptual Frameworks applied in this PhD thesis

The studies included in the thesis were descriptive qualitative studies that followed systematic data analysis processes, which is a characteristic feature of the phenomenology approach. The **COM-B model** (Figure 2b) was useful in structuring the analysis into the barriers to and enablers for behaviour change in our context. According to the COM-B

conceptual framework, behaviour is a result of the reciprocal interaction between the three fundamental components; Capability, Opportunity and Motivation [5]. Hence the COM-B model was used to guide the analysis of the focus group data and provide a theoretical framework for understanding women's capacity for lifestyle change and the available opportunities and barriers in their environments. The combination of a descriptive qualitative and theoretical framework (i.e., COM-B) approach to analyse focus group data enabled us to capture important insights into the lived experiences of women with GDM and the feasibility of lifestyle change in a low-income setting. Further, **Feminist insights** around maternal responsibility and mother-blaming (i.e., feeling blamed and maternal self-blame) provided some guidance for interpretation of the findings relating to the psychological 'burden' of having a GDM-complicated pregnancy [15, 16] while **Donabedian's Quality of Care model** [17] was applied in exploring women's experience of health services - these conceptual frameworks are discussed in more detail in the relevant manuscripts presented as Chapters 6 (Manuscript 3) and Chapter 7 (Manuscript 4) respectively.

3.5. Study setting

The larger IINDIAGO study is being conducted in the context of urban, public sector health services settings in Cape Town (Western Cape Province) and Soweto (Gauteng Province). Soweto is an urban township in Johannesburg with a population of about 1 300 000 (2011 census), with a predominantly IsiZulu, Sesotho and Setswana black African community. Cape Town has a population of about 3 800 000 (2011 census) with a predominantly 'coloured'

(mixed ancestry)[1] and black African community who speak English, Afrikaans and IsiXhosa. In both settings, the prevalence of diabetes and its risk factors are high and there are large hospital-based services for the management of GDM, where pregnant women are referred for antenatal care once the diagnosis of GDM has been made or suspected at primary care community maternity health centres. In Cape Town, Groote Schuur hospital (GSH) is the tertiary academic hospital servicing the Cape Town metropolitan district area. Chris Hani Baragwanath Hospital ("Bara") is the tertiary academic hospital servicing Soweto and its surrounding areas in the south of Johannesburg. It is also the largest hospital in Africa and third largest hospital in the world. The two settings share many commonalities, but also represent two very different provincial and municipal health systems, which are likely to have both common and divergent opportunities and barriers for potential integration and scale up.

3.6. Study participants

There were two groups of study participants for this PhD thesis, (i) key informants from Cape Town, Western Cape and Soweto, Gauteng as well as (ii) women who had been diagnosed with GDM and received antenatal care at Groote Schuur hospital in Cape Town between 2014 and 2015. It is important to note that at the time of data collection, our collaborating research team in Johannesburg had initiated a separate project with pregnant women diagnosed with GDM. The FGDs and in-depth interviews with women with a history of GDM reported in this thesis were only conducted in Cape Town with women who attended Groote Schuur Hospital. This decision was informed by findings from interviews with key informants who indicated

[1] A term commonly used in South Africa to describe historic mixed racial heritage

that although some women diagnosed with GDM would be referred to provincial/secondary level hospitals for treatment and management, the majority of women with GDM would be referred to Groote Schuur Hospital – a tertiary level hospital.

This PhD study therefore consisted of four components which are summarised in Figure 3 and described later in this chapter:

a) In-depth interviews with policy makers, specialist clinicians working in the public sector, health service managers, public health specialists) from Cape Town in the Western Cape province and Johannesburg in the Gauteng province.
b) A document review of policies, clinical practice guidelines and other available resources relevant to the management of GDM in the Western Cape and Gauteng provinces
c) A folder review to establish the numbers, characteristics and outcomes of women with GDM who attended the GDM clinic at Groote Schuur Hospital in Cape Town
d) FGDs and in-depth interviews with post-GDM women from the targeted geographic areas within Cape Town in the Western Cape province.

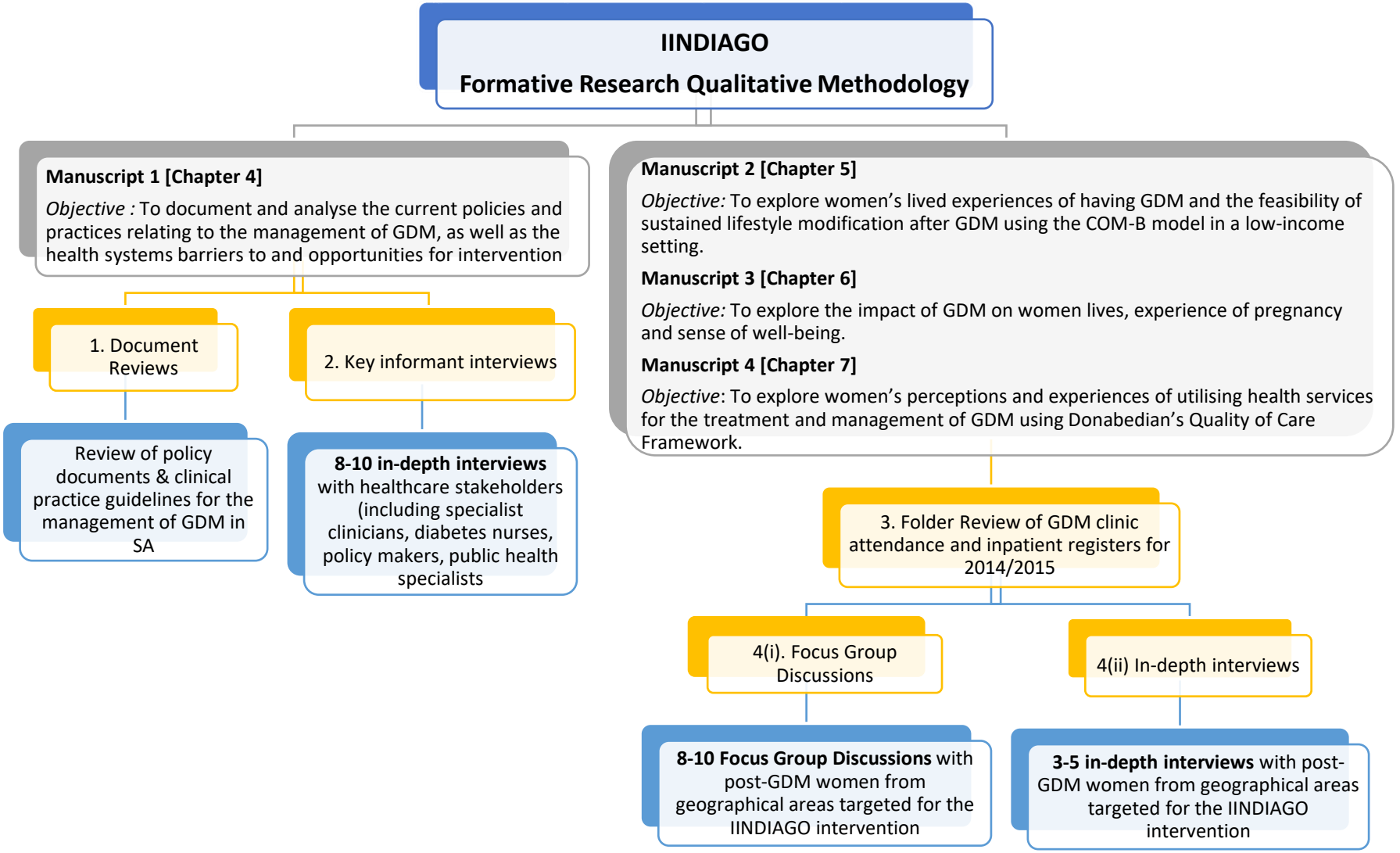

Figure 3: Summary of study components and data collection methods

3.7. STUDY OBJECTIVE 1

3.7.1. Document Review

Documents for review consisted of various policy documents, clinical practice guidelines for the screening, diagnosis and management of GDM in SA and educational materials provided to women with GDM. The key informants provided most of the documents during the interviews and others were sourced from the websites of the national and provincial Departments of Health. The document reviews therefore provided the background needed to contextualise the data from the key informant interviews.

3.7.1.1. Data collection

Documents for review consisted of various policy documents, clinical practice guidelines for the screening, diagnosis and management of GDM in SA and educational materials provided to women with GDM. The key informants provided most of the documents during the interviews and others were sourced from the websites of the national and provincial Departments of Health. The document search included protocols used in screening, diagnosis and management of GDM as well as any educational materials given to women with GDM.

3.7.1.2. Data analysis

Content analysis - a systematic and objective method for analysing documents to provide new knowledge and insights [15] was used to synthesize and summarise crucial information of relevance to the research question. This method was used to identify and summarise essential information from the sourced documents relating to the management of GDM and postnatal follow-up care for women after GDM. The data analysis process is discussed in

further detail and presented in Chapter 4. The document review also provided triangulation of information emerging from the key informant interviews with written health policies and clinical practice guidelines for the management and care for women with GDM during pregnancy and postpartum. Triangulation refers to the use of more than one data collection method to improve the rigour of the study and demonstrate internal validity [16].

3.7.2. Individual, in-depth interviews with key informants

The objective of the key informant interviews was to gain a clearer understanding of the current policies and practices relating to the management of GDM, as well as the systems barriers to and opportunities for delivering the proposed integrated mother-baby health service in the postpartum period. These interviews constituted the initial consultations with selected key individuals as part of the formative phase of the IINDIAGO project and therefore contributed to determining the most effective means of delivering a feasible and sustainable lifestyle modification intervention for women with GDM in the South African context. In addition, the interviews facilitated access to targeted health service facilities to conduct research through discussions with health policy makers, provincial health managers and HCPs about the IINDIAGO project and its objectives.

3.7.2.1. Participants and Sampling

Stakeholder criterion sampling was used to identify key informants - individuals with expert knowledge on clinical practice guidelines and policies on GDM in South Africa. This non-probability sampling technique identifies individuals with specific characteristics of interest that would enable the researcher to obtain information to answer the research question [16, 17]. Snowball sampling or sequential referral sampling – where individual participants are

asked to recommend other potential participants to be interviewed who in turn suggest names of others and so on, may also be used to follow up on important stakeholders recommended by others [12]. Contact details (i.e., email addresses) of key informants were obtained from publicly available records on the internet and from the department's administrative records. Key informants provided contact information of other potential participants, where these details were not available. Invitations to participate in the study were sent via email and followed up telephonically. Key informants included identified key policy makers and health service managers from the Gauteng and Western Cape departments of health, clinicians working in the public sector and other public health specialists. Informants were selected for their potential interest in the subject of the proposed study, their potential for influencing policy and disseminating the intervention if it is proved successful, and their insights into the current situation given their positioning in the field.

3.7.2.2. Data collection

Individual in-depth, interviews were conducted in English by a trained qualitative researcher (the PhD candidate) in a private location most convenient to the respondent. Prior to the interview, each key informant was given the draft study proposal and asked to subject it to critical review, as they were asked for their detailed comments on the proposal when interviewed. Each interview lasted between 45mins to 1 hour. An interview schedule was used, but the respondent had opportunities to raise other issues that may not have been anticipated by the researcher. The initial interview guide was informed by the literature and anecdotal reports from clinicians and policymakers. The interview guide was further developed in consultation with the IINDIAGO research team. The discussion guide included questions on the following topics: current policy and clinical practice guidelines for the

management of GDM, implementation and oversight of the policy guidelines, postpartum care for women after GDM, views on the proposed intervention and potential barriers to and opportunities for delivering the proposed integrated mother - baby intervention in the Well Baby Clinic. Each interview lasted between 45 minutes and 1 hour. The interview schedule was modified as the study progressed, and new issues arose from previous interviews. In addition, due to the diversity of their positions and roles, the interview guide was adapted for each interviewee to be more appropriate and relevant to achieve the purpose of the interview. All interviews were audio taped and transcribed verbatim. The findings of these interviews were useful for planning and developing a full and realistic study protocol and intervention.

3.7.2.3. Data Management and Analysis

All raw data were stored in a locked cabinet with restricted access. Electronic data such as audio recordings and word documents were de-identified (each participant was allocated a participant number) and stored on a password-protected computer. Access to the recordings and documents was restricted to the study team. A qualitative data analysis software package, NVivo 11, was used for data management. Qualitative methods were used to analyse the data [12, 18, 19]. Data from key informant interviews were analysed using qualitative content analysis [15, 20], which is commonly used in descriptive qualitative studies to identify and summarise data emerging from the interview transcripts. The qualitative content analysis process is dynamic and can be continuously modified as new information emerges from the data [20]. All transcripts were initially read to gain an overall impression of the data. Then, several interviews were closely read and annotated to identify initial codes and categories. A coding framework was then developed for application to the rest of the

interviews. This was iteratively developed as analysis proceeded. Two researchers (the PhD candidate and another researcher) coded the transcripts independently and met intermittently to compare their results and modify the coding framework. The data were then organised into key themes and recombined in the write-up. No identifying information was used in any research reports.

3.8. STUDY OBJECTIVES 2 and 3

3.8.1. Participants and sampling

3.8.1.1. Folder Review

We conducted a folder review of the GDM clinic attendance and delivery registers as well as patient folders to identify all women with GDM who had attended antenatal services and delivered at Groote Schuur Hospital during 2014/2015. The objectives of the folder review were threefold: firstly, to determine where most of the women come from so that informed choices can be made as to which 'Well Baby' clinics could be selected for the evaluation of the planned intervention; secondly, to establish the numbers of women with GDM in both settings during 2014/15 to enable the estimation of sample sizes for the evaluation, and thirdly, to compile the contact details etc. of a group of women with a history of GDM from which FGD participants could be recruited.

3.8.1.2. Focus Group Discussions (FGD) and in-depth interviews

The folder review was used to establish the numbers and contact details of women with GDM attending Groote Schuur Hospital. Potential participants were women who were diagnosed with GDM in the past 1-3 years (at least 1 year postpartum); received antenatal care at the

study sites; delivered a live baby and did not need treatment for diabetes at discharge. Purposive sampling was used in recruitment based on these pre-determined criteria. Potential participants who met the inclusion criteria were contacted telephonically and invited to participate in FGDs at the hospital study site or a community venue. Reasons for refusal were recorded. The aim of the FGDs was to understand women's experiences around the following areas:

i. Women's knowledge, attitudes, beliefs and experiences regarding lifestyle modification/health behaviour change (past achievements and difficulties; perceived barriers; factors that influence their health-related behaviour during pregnancy and in the post-natal period)
ii. Women's knowledge, belief and attitudes regarding GDM and the potential risks to themselves and their children
iii. Women's experiences of health services/health system (facilitators and barriers to attending community-based clinic sessions during their child's first year of life; their views on attending a combined mother-baby clinic for her health assessment, as opposed to attending mother only services; interactions with healthcare workers).

3.8.1.3. Data collection

Clinic attendance and delivery registers were used to collect data on date at ANC booking, gestational age, treatment, maternal complications, delivery and final pregnancy outcome and discharge medication. This information was useful in selection of participants who met the inclusion criteria. Data entry forms were developed in Microsoft Excel by the research team and piloted *a priori*. The CLINICOM patient administration system was used to extract demographic information and contact details of potential participants using patient names

and folder numbers obtained from 2014/2015 delivery registers. Data collected from the folder review was summarised and described in the findings.

The FGDs were led by a facilitator trained in qualitative research (PhD candidate) with the assistance of co-facilitators. A topic guide was used to guide the discussions and participants were encouraged to raise other issues of interest or concern to them that relate to the broad topic of the discussion. The topics for discussion were developed through a series of consultations with the broader IINIDIAGO project and aimed at filling the knowledge gap on women's knowledge, views and experiences regarding GDM, lifestyle change and GDM health services. The COM-B model concepts were also covered in the topic guide to enable assessment of women's capability, motivation and opportunity for behaviour change and how the intervention could help them in all these three areas. The FGDs were conducted in simple English, but a second co-facilitator, a diabetes nurse educator fluent in isiXhosa and Afrikaans was present to assist participants who needed to express themselves in their mother tongue. Their responses would then be translated into English for the benefit of the wider group. The co-facilitator was also responsible for taking notes, observing group dynamics and ensuring that the audio recorder was working. Participants received a telephonic reminder (or an SMS text if unreachable) prior to the scheduled FGD to confirm their attendance.

We ensured that the recruitment process was flexible in order to accommodate women's schedules. Reasons for refusal were recorded to enable the research team to strategize on how to maximise recruitment. As a result, some of the FGDs and interviews were conducted over the weekend to accommodate women who had work commitments during week or

could not make childcare arrangements. Participants could select the most suitable date from available options and could bring their infant if they could not make childcare arrangements. In addition, we scheduled FGDs at community venues to overcome transport barriers. Challenges with recruitment necessitated over-sampling. Despite this, when less than three participants showed up for a scheduled FGD, we had to resort to in-depth individual interviews. These interviews however had the advantage of enabling a deeper exploration of women's individual experiences and motivations and allowed women to discuss aspects of their personal experiences that they may have been reluctant to share in the context of a group. The topic guide remained the same for both the in-depth interviews and focus groups for consistency. However, there was flexibility to further explore dominant issues of specific areas of interest that came up in both the focus group and interview setting.

3.8.1.4. Data Management and Analysis

The FGDs and in-depth interviews were audio taped and transcribed verbatim by an experienced transcriber for accuracy and in order to maintain integrity of the data. The transcripts were kept secured in a locked cabinet while electronic versions were stored on a password-protected computer and only accessed by the research team. Participant IDs (e.g., Focus Group 1, Participant 24) were allocated to each participant to protect their identity. No names have been used in the research reports and manuscripts.

Data analysis followed thematic analysis procedures as described in Braun et al [21]. Thematic analysis offers flexibility in that it can address a wide range of research questions across various datasets including interviews, FGDs and secondary data sources. It is usually aligned with a theoretical or other interpretive framework to explore 'lived experiences' of social

groups and to understand factors that influence behaviours and shape their views [21]. The analysis process was both inductive and deductive, following a "six-phase" reflexive approach involving familiarisation with the data, coding, searching for themes, reviewing themes, defining themes and finally writing up the findings [21, 22]. Data analysis ran concurrently with data collection to allow for refining of the questions and further exploration of particular themes. The methods are described in detail in the relevant chapters (Chapter 5-7). In Chapter 5, we used thematic analysis to understand women's lived experiences of GDM and how they interpreted it using the conceptual categories of the COM-B model as a lens to view and interpret the data [5]. In Chapter 6, thematic analysis procedures were followed to understand the impact of GDM on women's experience of pregnancy and sense of well-being using feminist insights around maternal responsibility and mother-blaming [23, 24]. In Chapter 7, we used thematic analysis to assess women's experiences of GDM health services using the three elements of Donabedian's quality of care framework (i.e., structure, process and outcomes) [25] to organise and interpret the findings.

3.9. Rigour

Several strategies were employed throughout the research to ensure rigour as described by Mays and Pope [17]. These included using the appropriate sampling strategies, taking steps to ensure reliability of the analysis and minimising researcher bias [26]. Our purposive sampling approach ensured that participants would be selected based on specific characteristics and their potential to contribute meaningfully to the research. Methodological triangulation: which refers to using multiple data collection tools to maximize validity of findings [18] was applied; we conducted document reviews to contextualise and verify

information from key informant interviews regarding the policies and guidelines followed in the management of GDM. The folder review also provided triangulation of some aspects of the data from the FGDs and in-depth interviews such as demographic data, treatment regimens and pregnancy outcomes. Recruitment for each study continued until saturation was achieved when no new themes emerged from further data collection. Inter-rater reliability was ensured by using two trained qualitative researchers to independently to conduct data analysis, thereby minimising researcher bias. However, due to time-frame constraints, we were unable to conduct respondent validation for key informant interviews and FGDs following data analysis to increase credibility of the findings. However, in each of the empirical chapters (Chapter 4-7), the results are presented as direct quotes from the original data along with detailed commentary to further minimise researcher bias. Quoting participants verbatim gives them an opportunity to speak directly to the reader and allows readers to interpret what they say. The study findings have been reported in accordance with the recommended Consolidated criteria for Reporting Qualitative Research (COREQ), which provide a comprehensive checklist for reporting on qualitative interviews and focus groups [27].

3.10. Reflexivity and Reflections

Reflexivity in qualitative research relates to the researcher's position and potential influence, intentionally or unintentionally, on the research findings [28, 29]. This critical process of awareness and continual self-reflection throughout this PhD was necessary to enrich my understanding of the data. In this section, I reflect on the research process, highlighting

particular elements of each of the studies included in this PhD thesis as well as my academic and personal positioning and their potential influence on the research findings.

3.10.1. Study 1 - Document Review and In-depth interviews with key informants

Key informants comprised healthcare stakeholders, who held senior and potentially influential roles. One of the challenges I faced during the recruitment process related to scheduling of appointments to conduct interviews with key informants, due to their demanding schedules. Careful planning was essential to increase likelihood of participation; potential participants received emails with a brief summary of the study, a copy of the interview guide and suggested dates for the interview. As part of preparation for the interviews, I researched information on participants' professional biographies to be able to relate their previous and current roles, and any relevant accomplishments, as a way to establish rapport during the interview and demonstrating that I was well-informed about the topics. Due to the diversity of their positions and roles, the interview guide was modified for each interviewee to be more appropriate and relevant to achieve the purpose of the interview. As I had no prior experience interviewing senior officials, my academic supervisor conducted the first two interviews as part of my training and attended subsequent interviews as a co-interviewer and observer. We had informal debriefing sessions where she provided critical feedback following each interview and suggestions on areas of improving my techniques. This process was valuable for me to reflect on my style of interviewing and refine interview questions for subsequent interviews.

3.10.2. Study 2, 3, 4 - FGDs and in-depth interviews with women with a history of GDM

The research team comprised females of diverse ethnicity and age i.e., the facilitators; my academic supervisor (white, 50+ years) and myself (black African, 20+ years), assisted by a diabetes-nurse educator (black African, 50+ years) and a research assistant ('coloured' (mixed ancestry), 20+ years) who were fluent in isiXhosa and Afrikaans. It was important to create a safe environment for women to be able to speak freely about their experiences with GDM and health services. My youth and inexperience with pregnancy and motherhood may have initially limited my ability to connect with participants who were mostly multiparous and relatively older (30+ years). Fortunately, in the group context of the FGDs, I played a less prominent role in the discussions as a facilitator while women generally conversed among themselves. However, in the in-depth interviews, while I maintained professionalism, I occasionally found it challenging to withhold emotion while listening to very personal stories, particularly the traumatic details around labour and childbirth. I was also aware that participants, who were mostly South African, would perceive me as an "outsider' based on my foreign nationality, and in light of the unfortunate current context of xenophobia in South Africa. As a result, I felt ethically obligated to declare my Zimbabwean nationality during the discussions. However, my foreignness did not seem to affect how participants responded to me and was instead a point for informal conversation with some participants. However, having lived in South Africa for well over a decade, and interacted with local communities in different capacities, I have become sensitized to social and cultural nuances in the local communities. To some extent, I have also been integrated into the Xhosa community through social ties (i.e., marriage and religion). To overcome some of the potential barriers, a co-facilitator with more personal experience as well as extensive experience in facilitating FGDs around sensitive topics in the SA context, was present in the discussions. The diabetes nurse educator and research assistant also present were isiXhosa and Afrikaans-speaking South

Africans. We started off each FGD or interview with informal introductions, refreshments and ice-breaker activities to build rapport with participants. Women responded well to the research team; they opened up and were willing to share very personal stories. The facilitators also encouraged the few less confident women to participate by asking them directed questions concerning their experiences.

My personal positioning as an educated, postgraduate research student situated in a research unit that is affiliated with the hospital in question may have created dynamics of unequal power and privilege and potentially introduced social desirability bias. However, because of my inexperience with GDM, pregnancy, childbirth and motherhood, I considered the participants as 'experts' on the topics of interest and positioned myself as one willing to learn from them. This enabled me to gain their trust and respect as they recognised the importance of their role in this study. I was also able to approach the study from an objective viewpoint and gain valuable insights around the various topics. My personal experiences with pregnancy and motherhood during the latter course of this PhD prompted me to reflect on the data analysis process and contributed towards a more enriched and relatable perspective of women's lived experiences and understanding of the data as a whole. I related more personally to women's experiences of maternal morbidity, the fears and anxieties concerning the health of the unborn baby and the importance of social support. I was also able to understand the challenges with committing to a healthier lifestyle in the immediate postpartum period, while balancing motherhood and other responsibilities. **Chapter 6** is a result of this reflective process as it focuses on highlighting the importance of women's mental wellbeing during pregnancy in order to improve the likelihood of adherence to

treatment regimens (e.g., lifestyle change and medication) for pregnancy complications such as GDM.

3.11. Ethical considerations

The following ethical approvals were obtained from the research ethics committees of the University of Cape Town (HREC: 946/2014) & University of Witwatersrand (Ethics No: 150628)). In addition, permissions were obtained from all relevant health authorities; National Department of Health (WC_2015RP3_38); City of Cape Town (ID No: 10543); CEOs of Baragwanath Hospital, Mowbray Maternity and Groote Schuur Hospital. Ethics approvals for the overall IINDIAGO project were also obtained from the University of Montreal and the University of Montreal Hospital Research Centre (CR CHUM: 2018-7091, 17.128-ID). The risk of improper disclosure of information was addressed by strict protocols so as to protect the participants' privacy and confidentiality at all stages. The study was conducted in accordance with the Declaration of Helsinki and the laws of the Republic of South Africa.

Written consent was obtained from each participant prior to the interviews and FGDs and filed for safekeeping. All participants were able to read and write and therefore signed the consent form at the start of each focus group discussion and interview. Each research participant was fully informed as to the purpose and procedures of the research study and were assured that their names would not be used in the write up of research findings. Participants were informed of the importance of confidentiality and urged to refrain from divulging information shared in the discussions with anyone outside of the focus group. Information sheets were made available in English and verbally explained in vernacular

languages where necessary. The contact details of the research team as well as the institutional ethics committee were on the information sheet and participants were encouraged to contact any one of these people if they had any concerns about their participation in the study. Potential participants were informed of their right to withdraw from the research at any time without any prejudice. The researchers also had the ethical responsibility to refer women to additional support services, where necessary. The need for a tape recorder during the discussions to store data for reference purposes during the analysis was explained and permission was obtained before it was used. Participants taking part in FGDs and in-depth interviews were given a R100 supermarket voucher and R50 towards their transport costs. Healthy refreshments and snacks (i.e., unprocessed foods and non-sugar-sweetened beverages) were provided during all FGDs and interviews with women to demonstrate healthier food options.

3.11.1. Risks

As the study involved voluntary participation in in-depth interviews and FGDs with the research team, there were minimal risks for participants. However, given the sensitive nature of some of the topics in the FGDs, we were prepared to refer women who experienced distress during the interviews/FGDs or had additional questions or other concerns to the Principal Investigators of the IINDIAGO project, who would either address their concerns or further refer women to appropriate services. The risk of misconception of the study being directly linked to health services at the tertiary hospital was addressed during the informed consent process to avoid confusion and prevent unrealistic expectations.

3.11.2. Benefits

For healthcare stakeholders, the benefits included a sense of satisfaction from being consulted regarding the development of the proposed intervention and having the opportunity to influence policy and clinical practice. The potential benefits for women participating in the study included a greater awareness of GDM and the associated risks as well as the experience of social support from being part of the discussions with researchers and peers. Qualitative methods such as FGDs and in-depth interviews can be therapeutic in that they provide a platform to be heard, encourage expression of opinions, thoughts and feelings in a context where one is a valuable informant and having a worthy contribution to make to the improvement of health services [30]. The diabetes nurse-educator was also available after the FGDs to answer any questions that women had regarding GDM and type 2 diabetes. Each participant also received a recipe book for preparing healthy meals.

3.12. Dissemination

The findings of this study have been written up in fulfilment of the requirements for the University of Cape Town doctoral degree. Four peer-reviewed journal articles have been published or submitted for publication, as products of the research to add to the body of knowledge on gestational diabetes and health systems research. In addition, the findings of each sub-study have been presented at academic seminars and conferences including the African Doctoral Dissertation Research Fellowship (ADDRF) Scientific Writing Workshop in Nairobi, Kenya; the Annual Scientific Meeting for the Global Alliance for Chronic Diseases (GACD) in Sydney, Australia and the NCD Research Symposium in Cape Town, South Africa, as a means to network and share information with other researchers in the field.

This study provides the formative research for the IINDIAGO complex intervention trial that commenced in 2018. We assembled a stakeholder group and convened intervention development workshops to present the findings and their implications for the intervention to be developed; what messages were important to incorporate into the intervention and what factors needed to be considered carefully for the format and planned implementation. This PhD thesis reports the formative research for the IINDIAGO complex intervention trial. The PhD candidate designed, implemented and analysed the work presented in the thesis. The preliminary findings presented in this thesis have been used systematically in the planning and development of the IINDIAGO study complex intervention trial which is currently underway and in determining the detailed individual components of the intervention according to BCW and COM-B model for behaviour change. Further, educational materials have now been developed for use in the IINDIAGO trial and have been distributed to women with GDM attending public sector hospitals. Part of the process evaluation for the trial will involve further engagement with policy makers, health service managers and HCPs on their views regarding the implementation of the intervention in comparison to the protocol. Once the effectiveness of the RCT is established, a policy brief will be prepared to advocate for the provision of integrated health services for women with a history of GDM in the postpartum period to help prevent or delay the onset of type 2 diabetes.

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CHAPTER 4:

Study 1: Policies and clinical practices relating to the management of gestational diabetes mellitus in the public health sector, South Africa – a qualitative study

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Contributions of the candidate:

Lorrein Shamiso Muhwava conceptualised this sub-study and developed the protocol for the study. She developed the data collection instruments, conducted the interviews and data analysis with guidance from A/Professor Katherine Murphy (main supervisor). Lorrein Muhwava wrote the first draft of the manuscript. The supervisors: A/Professor Katherine Murphy, Professor Christina Zarowsky and Professor Naomi Levitt provided critical input in reviewing drafts of the manuscript. All authors read and approved the final manuscript for publication.

Abstract

Women with a prior gestational diabetes have an increased lifetime risk of developing type 2 diabetes. Although post-partum follow-up for women with GDM is essential to prevent progression to type 2 diabetes, it is poorly attended. The need for health systems interventions to support postpartum follow-up for women with GDM is evident, but there is little knowledge of actual current practice. The aim of this study was to explore current policies and clinical practices relating to antenatal and post-natal care for women with GDM in South Africa, as well as health sector stakeholders' perspectives on the barriers to -- and opportunities for -- delivering an integrated mother - baby health service that extends beyond the first week post-partum, to the infant's first year of life. Following a document review of policy and clinical practice guidelines, in-depth interviews were conducted with 11 key informants who were key policy makers, health service managers and clinicians working in the public health services in South Africa's two major cities (Johannesburg and Cape Town). Data were analysed using qualitative content analysis procedures. The document review and interviews established that it is policy that health services adhere to international guidelines for GDM diagnosis and management, in addition to locally developed guidelines and protocols for clinical practice. All key informants confirmed that lack of postpartum follow-up for women with GDM is a significant problem. Health systems barriers include fragmentation of care and the absence of standardised postnatal care services for women after GDM. Key informants also raised patient - related challenges including lack of perceived future risk of developing type 2 diabetes and non-attendance for postpartum follow up, as barriers to postnatal care for women with GDM. All participants supported integrated primary health services but cautioned against overloading health workers. Although there is alignment between international guidelines, local policy and reported clinical practice in the

management of GDM, there is a gap in continuation of care in the postpartum period. Health systems interventions that support and facilitate active follow-up for women with prior GDM are needed if high rates of progression to type 2 diabetes are to be avoided.

4.1. Background

Gestational diabetes mellitus (GDM), that is diabetes diagnosed in the second or third trimester of pregnancy, affects up to 28% of pregnancies globally [1,2]. Women with GDM have a significantly increased lifetime risk (≥70%) for developing type 2 diabetes, a 3-fold risk of developing the metabolic syndrome and an increased long-term risk of developing cardio-vascular disease (CVD) [3,4]. In addition, children born of women with GDM are susceptible to impaired glucose tolerance and obesity in adulthood [5,6,7,8]. International recommendations for the management of GDM emphasise the need for post-partum follow up and care, including an Oral Glucose Tolerance Test (OGTT) from 6-12 weeks postpartum and continued support for lifestyle change [9]. However, compliance with these recommendations is reported to be low [10]. In South Africa, as is the case elsewhere, most women with GDM are lost to follow-up after delivery [11,12].

The sparse data available from 11 of the 55 countries in Sub-Saharan Africa (SSA) reveal a wide range in the prevalence of GDM, from 0% to 14% [13,14]. While South Africa's exact prevalence is unknown, it is currently estimated to be greater than 15% [13]. A recent SA study reported a GDM prevalence of 25.8% with universal screening and 15.2% with selective risk factor screening using the International Association of Diabetes in Pregnancy Study Groups (IADPSG) criteria [15]. The lack of uniformity in GDM screening and diagnosis practices in SA is concerning. Anecdotal reports indicate that GDM screening is not consistent and many

women remain undiagnosed. However, the feasibility of universal screening for GDM in SA, given resource constraints, is yet to be established. In addition, the reported high rates of GDM are likely to be driven by the fact that the country has the highest rate of obesity and overweight in sub-Saharan Africa: up to 70% of women are estimated to be overweight or obese and the prevalence of obesity among women has risen from 30% in 1998 (SADHS) to 42% in 2013 [16,17]. Given the expectations of increasing rates of GDM in SA and the high risk of progression to type 2 diabetes among this group, there is an urgent need to develop interventions with women with GDM to prevent or delay progression to type 2 diabetes.

The South African public health system provides healthcare services to approximately 84% of the population and is overwhelmed by the multiple disease burden including chronic infectious diseases and NCDs [18]. A minority of the population has access to and can afford private healthcare services, which are typically far better resourced. The proposed IINDIAGO project – an acronym for "An integrated health system intervention aimed at reducing type 2 diabetes in disadvantaged women after gestational diabetes in South Africa", is therefore situated in the context of the public health sector and focuses on women from disadvantaged communities, who would benefit from interventions to improve health services.

Several studies and systematic reviews show that lifestyle interventions for women with prior GDM, through diet and exercise are effective in reducing their risk of developing type 2 diabetes, improving health outcomes for both the mother and baby [8,19,20]. In addition, lifestyle interventions for high-risk groups for type 2 diabetes (including people with obesity, impaired glucose tolerance, and impaired fasting glucose and GDM) have been found to be cost-effective [21]. Where interventions have had little success, this has been attributed to inadequate post-partum follow up and support and a poor understanding of context in the

development of interventions. However, many of these intervention studies have been conducted in developed countries and have not yet been demonstrated to be feasible or effective in a resource limited setting [8,19,20].

Formative research is increasingly recognised and undertaken as an essential process in the development of health behaviour change interventions [22,23,24,25,26]. The formative research process is a critical component to intervention design which allows for context-driven information gathering that will subsequently guide and inform the development of an intervention that best fits the targeted beneficiaries [22]. This paper reports on one component of the formative research for the IINDIAGO project, which aims to develop and evaluate a novel health system intervention to reduce the risk of subsequent type 2 diabetes among women with recent GDM, that can be integrated into existing health services in South Africa. The formative research for the IINDIAGO project will assist the project team to understand the context in which the proposed intervention is to be initiated, including cultural, social, health system and contextual factors, which influence health seeking and lifestyle related behaviour [23, 27].

As little was currently known about the policies and clinical practices relating to the management and care for women with GDM in South Africa, the purposes of this study were two-fold. The first objective was to explore the existing policies and reported clinical practices relating to antenatal and post-natal care for women with GDM in the public health sector in South Africa. The second objective was to identify the barriers to -- and opportunities for -- delivering the intervention - an integrated GDM mother - baby health service that extends beyond the first week post-partum, through the infant's first year of life.

The results from this study will contribute to the design and implementation of a feasible and sustainable intervention for women with GDM postpartum, within the context of existing public health services in South Africa.

4.2 Methods

Study design

We conducted a qualitative study consisting of; (i) a document review of policy documents and clinical practice guidelines for the screening, diagnosis and management of GDM and (ii) semi-structured in-depth interviews with key informants on the management and care for women with GDM during pregnancy and postpartum within the context of public sector health services in South Africa. The use of qualitative methods allowed for an in-depth assessment of the barriers and facilitators for implementation of the proposed intervention from the perspective of those with responsibility for GDM care and policy.

Study Setting

The study was conducted in the context of three urban public sector hospitals in Cape Town (Western Cape province) and Soweto (Gauteng province), South Africa, which are classified as secondary (Level 2) and tertiary (Level 3). The secondary hospital is a regional hospital, which provides health services to women with complicated pregnancies referred from Midwife Obstetric Units (MOUs) around Cape Town. The two tertiary hospitals have dedicated antenatal diabetes clinics and provide health services to patients referred from primary and secondary health facilities mainly within the Western Cape and Gauteng provinces but not limited to provincial boundaries. Due to the recognized high standards of

care at these hospitals, it is common for pregnant women from rural areas to migrate to these provinces for the duration of their pregnancy, to access antenatal care services.

Study sample

Criterion-based and sequential referral sampling were used to identify key informants who had expert knowledge on clinical practice guidelines and policies on GDM and/or had experience in providing clinical care for women with GDM in the three public sector hospitals in Cape Town and Soweto, South Africa. Criterion sampling identifies individuals with specific characteristics of interest that would enable the researcher to obtain in-depth information to answer the research question [28,29]. Informants were therefore selected based on their positioning in the field and/or their potential for influencing policy. Key informants comprised policy makers, health service managers from the Department of Health and clinicians working in the public health services. Sequential referral sampling was used to follow up on other important key informants recommended by respondents. Participants were recruited until saturation was reached. Invitations to participate in the study were sent via email and followed up telephonically.

Data collection

Data collection was conducted in two phases. Firstly, a document review of international and local guidelines pertaining to the management of GDM was conducted. Documents for review consisted of various policy documents, clinical practice guidelines for the screening, diagnosis and management of GDM in SA and educational materials provided to women with GDM. The key informants provided most of the documents during the interviews and others were sourced from the websites of the national and provincial Departments of Health. The

documentary reviews provided the background needed to contextualise the data from the key informant interviews.

Following the document review, interviews were conducted by a trained qualitative researcher, in a private location most convenient to each respondent. These were typically in their offices at the hospital, clinic or health departments. Prior to the interview, each key informant was given the draft project proposal and asked to subject it to critical review. A discussion guide (Supplementary File 1) was used, but each respondent was also given opportunities to raise other issues that may not have been anticipated by the researcher. The discussion guide was slightly modified as the study progressed on the basis of new issues arising in previous interviews. The discussion guide included questions on the following topics: current policy and clinical practice guidelines for the management of GDM, implementation and oversight of the policy guidelines, postpartum care for women after GDM, views on the proposed intervention and potential barriers to and opportunities for delivering the proposed integrated mother - baby intervention in the Well Baby Clinic. Each interview lasted between 45 minutes and 1 hour. All interviews were audio recorded and transcribed verbatim. All audio recordings were stored in a locked cabinet with restricted access.

Data Analysis

Content analysis was used to identify and summarise essential information from the sourced documents relating to the management of GDM and postnatal follow-up care for women after GDM. The documentary reviews provided triangulation of much of the information emerging from the key informant interviews.

Data from key informant interviews were also analysed using qualitative content analysis [30,31]. Firstly, all transcripts were read to get a general overview of the data. They were then re-read closely to identify codes, categories and themes. A qualitative data analysis software package, NVivo 11, assisted in managing and organising the data. The data was scrutinised for both deductive and inductive codes/ categories (i.e., predetermined issues relating to the research questions, as well as unanticipated, emergent issues). Once a certain number of transcripts had been analysed, a coding framework was then developed and applied across the rest of the data set, with various revisions. Two researchers were involved in analysing the data and reviewing final categories. The overall coding process moving from the focus areas to categories and key thematic areas is illustrated in Figure 4.

Ethics approval

Ethical approval was granted by the Faculty of Health Sciences Research Ethics Committees of the University of Cape Town, University of Witswatersrand as well as the relevant hospital authorities. Written informed consent was obtained from each participant prior to the interviews and filed for safekeeping. Each participant was fully informed as to the purpose and procedures of the research study and assured that their names would not be used in the write up of research findings. The need for a digital voice recorder was explained and permission was obtained before it was used.

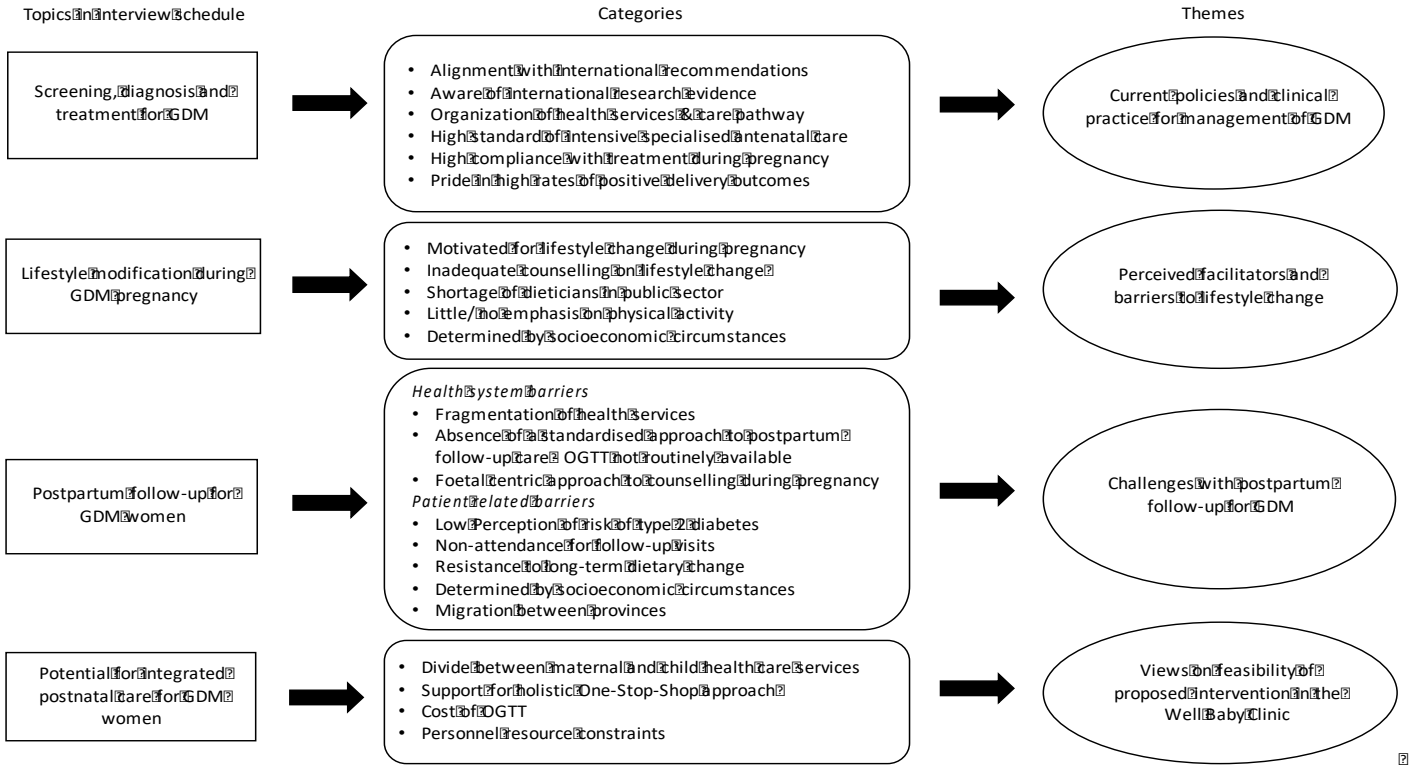

Figure 4: The coding process illustrating focus areas, categories and key thematic areas. A summary of the overall coding process moving from the focus areas in the interview schedule, to categories and key thematic areas.

4.3 Results

Between July and November 2015, in-depth interviews were conducted with a total of 11 key informants: 2 key policy makers, including 1 health service manager from the Department of Health; 2 public health specialists and 7 clinicians working in the public health services. All those contacted consented to participation in the study. The results from the interviews are described under four main headings, which follow the key areas of investigation outlined in the discussion guide.

i. Current policies and clinical practice for the management of GDM

The review of documents found that the three hospital sites follow the WHO criteria [32], as well as the UK National Institute for Health and Care Excellence (NICE) [33] guidelines for GDM diagnosis and management during pregnancy. In addition, there are national and provincial guidelines for screening, diagnosis and treatment for GDM i.e., the National Guidelines for Maternity Care in South Africa [34] and the provincial Western Cape 'Diabetes in Pregnancy' guidelines [35]. The National Department of Health has adopted selective risk-factor screening based on the presence of risk factors which include obesity (BMI > 30 kg/m^2), repeated glycosuria, previous GDM, age>40 years and family history of diabetes (first-degree relative) [36]. Consistent with the international WHO guidelines [37], women with any of these risk factors should be offered an OGTT and GDM is then diagnosed on the basis of a fasting plasma glucose level of 5.6mmol/litre or a 2-hour plasma glucose level of 7.8mmol/litre or above. Antenatal clinics at the primary care level also have specific protocols developed from the overarching national policy guidelines, which are used in clinical practice. The guidelines in South Africa have been developed through consultation with clinicians and

other experts and are based on international research evidence. Participants highlighted the importance of research evidence in policy development and clinical practice and made reference to landmark empirical studies [38,39] that have influenced practice.

Organisation of health services and the care pathway

The organisation of health services and the referral pathway for women with GDM in the public health services in SA is summarised in Figure 5 According to the document review and interviews; pregnant women first present for antenatal care either at a local MOU or Basic Antenatal Care (BANC) clinics, which are birthing units based in the community and run by midwives (Figure 5). The MOU and BANC clinics provide similar primary health care services under provincial or local municipal governance respectively. Cape Town, like several other urban settings in South Africa has dual authority over health services – provincial Department of Health and the local municipal government – each providing somewhat independent governance over a number of community-based health services with their own set of guidelines. In both the MOUs and BANC clinics, the pregnant woman is screened for GDM on the basis of the presence of risk factors described above. Upon diagnosis, the pregnant woman with GDM is referred for her remaining antenatal care and delivery at the nearest secondary or tertiary level hospital. At the tertiary level, women receive intensive specialist care and medical management from a team of obstetricians, endocrinologists, dieticians and nurses (Figure 6. The Soweto study site also has a team of diabetes nurse educators who provide counselling and health education. In the Cape Town setting, women with Impaired Glucose Tolerance (IGT), receive antenatal care, including delivery at a secondary level hospital. The primary form of intervention for women with GDM is lifestyle modification. According to the key informants, antenatal care for women with GDM is of high standard with

positive foetal and maternal outcomes. At discharge, women are counselled by their health care provider about their risk of developing type 2 diabetes in future and are advised to attend a follow-up visit at their nearest clinic or community health centre (CHC), within 6 to 12 weeks for an OGTT to determine whether they have type 2 diabetes postpartum. However, there are inconsistencies in the referral process from tertiary to primary care level and the OGTT is seldom offered at primary care level to women with prior GDM.

Although the management and care for women with GDM is in line with international guidelines, continuation of care in the postpartum period is problematic. In the first ten days postpartum, the mother and baby typically receive care (e.g., wound care after delivery through Caesarean -section and breastfeeding advice) at the MOU or BANC clinic, where she originally registered for antenatal care. Thereafter, the baby receives care at the Well Baby Clinic, which provides baby-feeding counselling, development assessment, weight monitoring and immunization, whilst the GDM mother is expected to receive any further care at her nearest primary health care clinic. Some clinicians felt their hospitals did not have the capacity to offer women with GDM an OGTT postpartum; hence they follow policy recommendations by referring women to primary level clinics within their local communities for postpartum follow-up care.

The following section provides a summary of the results of the key informant interviews as depicted in Table 2 and Table 3 below.

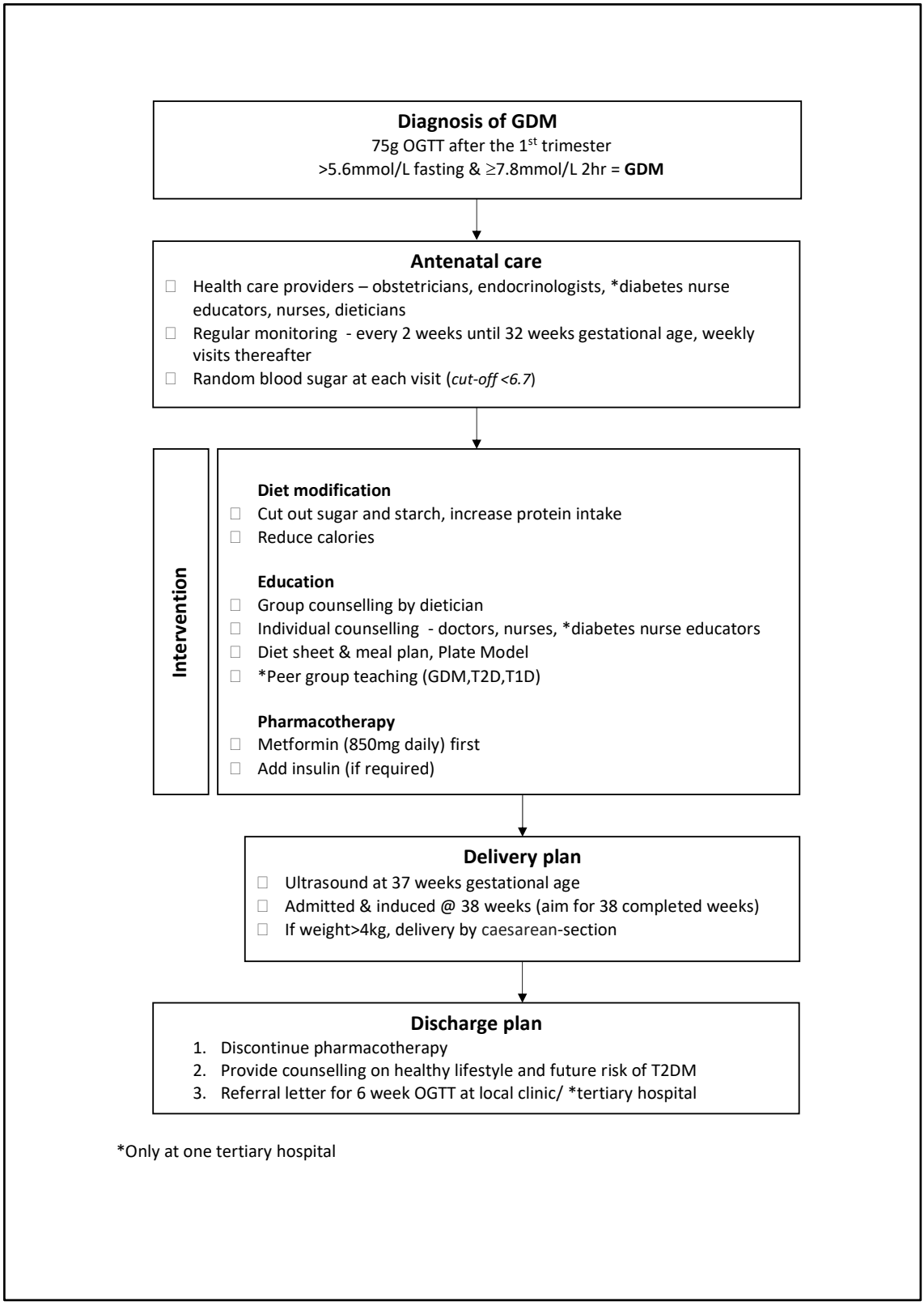

Figure 5: Management and care plan for women with GDM at 2 tertiary and 1 secondary hospital in South Africa. A summary of the management of GDM in the study settings, which entails one or a combination of (i) counselling on diet and physical activity by the doctors,

nurses (and a dietician where available), (ii) oral agents such as metformin and (iii) insulin where necessary.

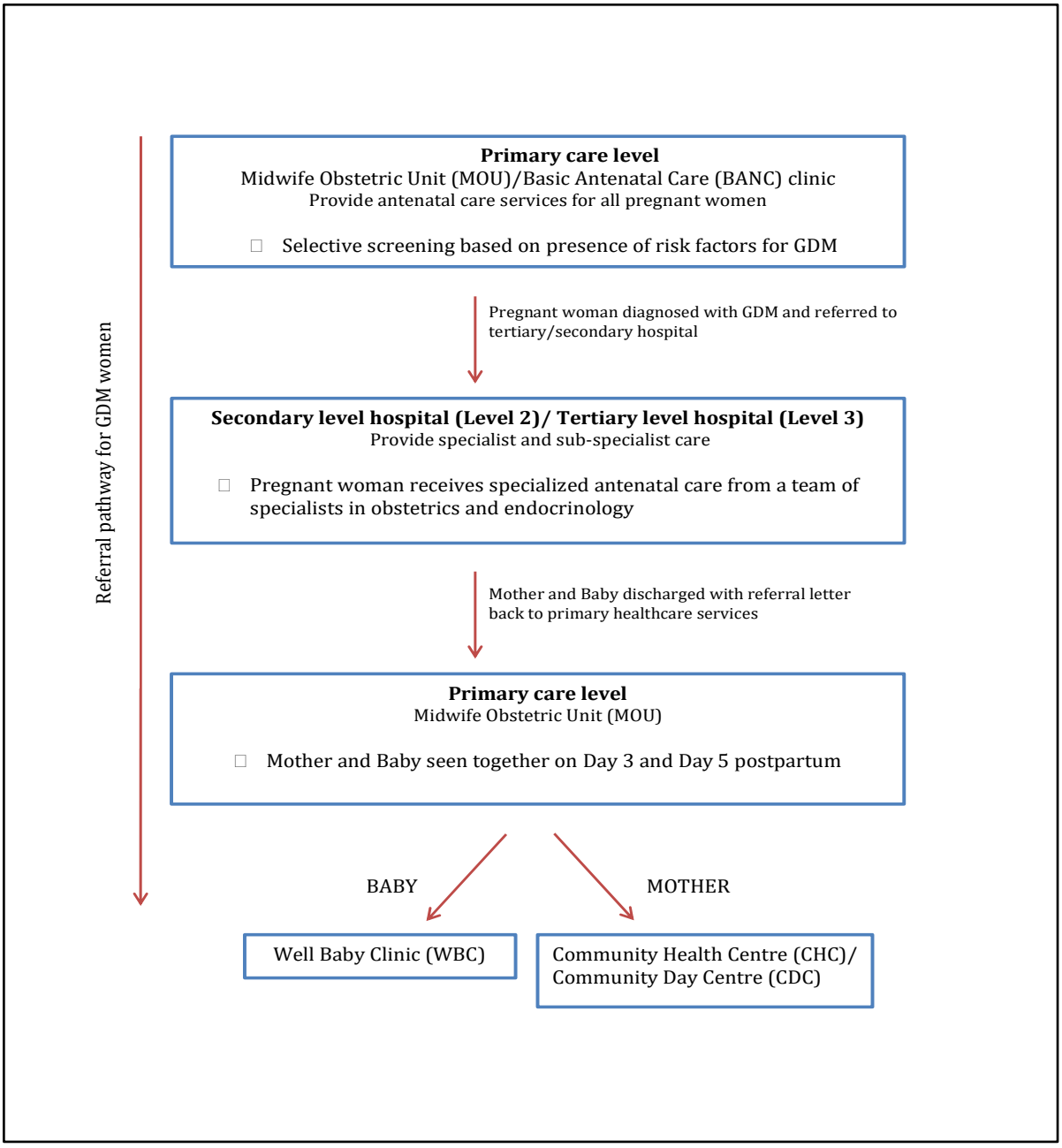

Figure 6: Levels of care and referral pathway for women with GDM in South Africa. An overview of the organisation of health services and the referral pathway for women with GDM in the public health services

Table 2: Results of key informant interviews by categories and illustrative quotes

Key findings	Quotes from key informants
Theme 1: Perceived facilitators and barriers to lifestyle change	
Facilitators of lifestyle modification (i) Concern for the health of the unborn baby	*"The patients are well motivated in pregnancy, they do change because they want a live baby" - Diabetes nurse educator* *"Their compliance for the very reason that they want a healthy baby is much higher. It doesn't mean that it stays like that postpartum" – Professor, Obstetrician 1* *"Pregnancy is a really good time to intervene because they are so worried about the baby and sometimes a bit shocked that something they can do or not do can harm their baby" – Professor, Obstetrician 2*
Barriers to lifestyle modification (i) Inadequate dietary counselling due to shortage of dieticians in the public sector	*"Ideally they should see a Dietician, but not everybody has access to a Dietician, and there are too many patients" – Obstetrician 3* *"Actually the people that should control nutrition are nurses because there are so few dieticians. They (dieticians) are either at a hospital or at a sub-district level but day to day, it's the nurses who are encountering patients" –Professor, Public health specialist 1* *"Dieticians are a rare and scarce resource in this hospital and most of them do not have time to go into pregnancy work" - Professor, Obstetrician 4* *"If the dietician is not available, we take over, but the Dietician comes to do her part as well. The Dieticians come and go, they train, qualify, work for a bit, and then they usually go into private practice, I guess." – Professor, Obstetrician 1* *"In discussions with the Department of Health around this, I think there is a sense that it was slightly ambitious to expect the nursing staff to do a full, kind of, dietary counselling intervention, and that actually the Dietician needs to be doing that..." – General practitioner, Medical Anthropology Researcher* *"It's group counselling because we are limited, which is unfortunate - Obstetrician 5* *"We give them general advice but of course that probably isn't enough –Professor, Obstetrician 1*
(ii) Lack of full understanding of healthy diet requirements	*"A lot of the patients I don't think actually understand what needs to be done in terms of the diet to be able to deal with this" – Obstetrician 5*

(iii) Lack of interventions for physical activity	*"I don't think there is enough spoken about exercise actually, I think it could be useful" – Professor, Obstetrician 2*
(iv) Affordability of healthy food	*"We've got two groups of women, one who has resources and can try to follow the advice, most of those women do, they've really taken up the idea that vegetables are important, you shouldn't drink alcohol and you should avoid sugar but the rest of the women, cost is the main factor in what they can do" – General practitioner, Medical Anthropology Researcher* *"I think also it's just the reality of going home to limited financial resources" – Obstetrician 5* *"It's really expensive to eat healthy; you can't do it, because all the cheap food you can afford is junk food" – Professor, Public health specialist 1* *"I am just quite pessimistic about how much people can acquire a healthy diet, if they are below a certain income" –Professor, Public health specialist 2*
Theme 2: Challenges with postpartum follow-up for women with GDM	
Health system barriers (i) Absence of a standardized postnatal care approach for women with women	*"You are probably going to find that the policy (management of diabetes during pregnancy and postpartum) is not being implemented at primary care level. Part of the problem is that the diabetes policy is aimed at the doctors at the hospitals and the health care providers at the primary care clinic don't read the diabetes policy" – Obstetrician 6, Policy maker 1*
(ii) Lack of communication between tertiary and primary care levels of care	*"The gap in the communication between a delivery unit and where the patient has to go to is one of our main concerns. So, this was meant to be the communication between the Delivery Unit and the primary healthcare facility where the mum and the baby are followed up" – Health services manager, Policy maker 2* *"They get a discharge summary in which we advise them to go to their local clinic in 6 weeks' time to have their sugars checked but we don't have any way of checking that it's happened" – Professor, Obstetrician 2*
(iii) Inconsistencies in completion of referral letter (iv) Fragmentation of care	*"What we've discovered was that A it [the referral letter] doesn't get completed very well and B for one or other reason, it doesn't reach the primary healthcare clinics" – Health services manager, Policy maker 2* *"The key obstacle is that there's such a divide between maternal and child care in the clinic setting, and the sisters are so habituated to that. They are either working on the maternal side, or they are working in the baby side" - Health Services manager, Policy maker 2* *"So certainly not all MOUs are going to be accessible to the patient, the community health centres might be the best place to do it [postpartum OGTT], but you've got to find out, can they cope?" – Professor, Obstetrician 4* *"To my knowledge, the Community Health Centre's are not set up for it [postpartum OGTT]. The patient has to arrive early in the morning fasting. She's then supposed to have a fasting blood sugar, and then two hours afterwards, she's supposed to have the two hour blood sugar" Professor, Obstetrician 3*

(v) A foetal – centred approach to antenatal care	*So the understanding that this is more of a lifestyle thing for the long-term future maybe isn't there enough. It's been very much geared around the pregnancy. I would say, our focus is the pregnancy, keep the sugar down, try and have a healthy baby and a mother that's not injured during the birth. And we don't think too much to the afterwards" – Professor, Obstetrician 2* *"I think it's a good idea because this is a particular at risk population, who get good care during pregnancy and child birth and then often just disappear from the system" -Professor, Public health specialist 1*
Patient – related barriers (i) Perception of future risk of developing T2DM	*"Because they don't feel ill so they tend not go to the clinic or the doctor when they don't have an issue. So I don't know what the barriers are but the clinics are available it just that they don't go" – Obstetrician 6, Policy maker 1*
(ii) Non-attendance for postpartum OGTT	*"They are not lost to the system, they lose themselves from the system I would say. Each person has a responsibility to her own health. If you get all the information and you get the appointment, then the onus in on you" – Obstetrician 3* *"We do attempt to get them back for OGTTs, a small number do come back, but not all" – Professor, Obstetrician 1*
(iii) Resistance to long term dietary change	*"So there is quite a lot of resistance to dietary intervention and that's probably the reason they don't go back because they know somebody will just talk about their diet again" – Obstetrician 6, Policy maker 1* *"I can tell you, it happens here in hospital already, once that baby is born you'll find the bottles of cool drinks, and then you tell her, you are promoting yourself to Insulin" - Diabetes Nurse*
(iv) Lack of time and cost of transport for postpartum follow-up visits	*"It might also be pie in the sky [expecting women to attend postpartum follow-up visits], because once you have a small one (a baby) at home, it's very difficult to give up your time" – Professor, Obstetrician 4* *"It's quite expensive when you think of what taxi fares they probably have to pay and they are all the ones that are the most at risk. The ones that haven't got money for the transport to get back, and we invariably lose the most at risk 20, 25% of the people "– Professor, Public health specialist 2*
(v) Lack of agency to make lifestyle changes	*"If you're an incredibly poor woman in a township with few choices, with a patriarchal man who takes control of your life and you have no choices, what's your incentive to eat healthy and exercise? Really, it's hard. So you must go home now, and don't put sugar, don't put salt, cut the gravy, no potatoes or whatever. They can't do that: their husbands will have a hernia!" – Professor Public health specialist 2*
Theme 3: Views on integrated postnatal care for women with GDM	
Concept of 'One-Stop-Shop'	*"I think that integration in general is a really good idea. It is a no-brainer that we've missed for the past 100 years!" - General practitioner, Medical Anthropology Researcher*

Potential of leveraging an existing health service (i.e.; WBC)	*"It's such a good example of something of the ongoing care that's needed and maybe it could even be applied to other areas like blood pressure or heart or whatever. It's a really good concept" – Professor, Obstetrician 2* *"There isn't a 6-week visit for the mum at the moment; it's just for the baby. So we are trying to integrate that maternal and child health visit" – Obstetrician 6, Policy maker 1* *"I think today the emphasis is on holism, and a holistic approach to everything, and not just to concentrate on a single item which really upsets you"- Professor, Obstetrician 4* *"It makes a lot of sense. It's very nice that it's integrated into something that exists and is standard practice" - Professor, Obstetrician 1* *"Excellent idea, because she will go for her baby..." – Obstetrician 3* *"Currently their focus postpartum is mainly on the baby. They do a developmental screening, immunise the baby, weigh it and check on nutrition; how's the baby feeding and things like that. They tend to forget the mom, and that is what we specifically want to do with this postnatal policy" – Health Service manager, Policy maker 2* *"In my experience, the mother would rather take the baby for the 6-week visit than to go herself for anything if she is feeling well" – Professor, Obstetrician 2* *"Now, whether that can be done, I don't know, to emphasise just the baby, and to then to say, well, you know, you're a Diabetic,, we'll do an oral GTT at the same time, I'm not quite sure whether that's the right approach. I think the idea is at least a step in the right direction, but whether she will come fasting is another question" - Professor, Obstetrician 4* *"I think it's a good idea, if the mother didn't have the baby, she wouldn't go, but for the baby's sake, she will go" – Diabetes nurse*
Theme 4: Feasibility of integrated postnatal care for women with GDM in the WBC	
Resource constraints given the current clinic structure in the WBC	*"One of the core issues is that you've got a resource constrained situation, community health workers, nurses and even doctors are full to the brim. I mean their job is 120%, so anything else you give them, is a problem" – Professor, Public Health specialist 2* *"The OGTT is a 2hour test that involves administering glucose and that involves taking blood at those intervals. Quite simply, the primary care clinics are not going to cope with that. There are challenges in terms of staffing and costing and deficiencies need to be sorted out" – Obstetrician 5* *"I think one's going to have to be careful with this integrated visit not to give too many tasks" – Professor, Obstetrician 2*

	"It's not that people are not aware that OGTTs need to be done, it is because the environment will be challenging for people to be doing OGTTs. That's associated with human as well as financial resources" – Obstetrician 5
Role of nurses	*"Ideally, to deliver the intervention, that person should be trained to do all of those things, so that it's a kind of one-stop shop. I don't know if it would be better to have an additional person [dietician]to do that nutrition counselling element who's got some dietetics training but I don't think we can have a dietician doing that, because we don't have enough Dieticians to go around."– General practitioner, Medical Anthropology Researcher* *"The nursing staff do the OGTT in any case. So the nursing staff at the Well Baby Clinic should be able to it" – Obstetrician 3* *"All nursing staff in South Africa, have been through General Nursing where they are exposed to all those things. So they are able to do it." – Diabetes Nurse* *"I think a primary care nurse should be able to do it." - Professor, Obstetrician 2*

Table 3: Key informant views on policies and clinical practice guidelines for the management of GDM

Available guidelines	Key Informant comments
A: International guidelines	
➢ National Institute for Health and Clinical Excellence (2015). Diabetes in Pregnancy: Management of Diabetes and its Complications from Preconception to the Postnatal Period. NICE Guideline NG3. ➢ World Health Organization. (2013). Diagnostic Criteria and Classification of Hyperglycaemia First Detected in Pregnancy. Geneva, World Health Org. (WHO/NMH/MND/13.2).	*"We follow international guidelines, I suppose more the NICE Guidelines from the UK but we adapt them for local context. The therapies we use are used internationally and then we try and adapt everything. You can't use a London diet for our patients from Soweto" – Professor, Obstetrician 1* *"From the beginning of 2014 we've been using the WHO criteria. We used to use the 100 gram test, which was the United States test, but we changed in January last year, to 75 grams" - Professor, Obstetrician 1* *"The new definition has made it easier. It said any altered carbohydrate metabolism, which included Impaired Glucose Tolerance; and then we used the WHO criteria from 1990" - Professor, Obstetrician 4* *"Everybody knows what to do with GDM - we all follow international standards, and we all follow international protocol and recommendations within the resource constraints" – Obstetrician 5*
B. National guidelines	
➢ Guidelines for Maternity Care in South Africa. A manual for clinics, community health centres and district hospitals. 4th Ed. Pretoria: NDoH 2015: 172.	*"There would be something on diabetes and there is a national maternity care guideline" - Professor, Obstetrician 2*
C. Provincial guidelines	
Western Cape Department of Health policy guidelines ➢ Diabetes in Pregnancy, Provincial guideline of the Western Cape, for the management of diabetes and its complications from pre-conception to the postnatal period. (2010	*"We have very little to do with implementation of services, but at our level, we do policies; we've got to write policies. We assist with guidelines and protocols, and what we do, is we monitor and evaluate the implantation of these guidelines and policies" – Health service manager, Policy maker 2* *"We do have a provincial policy - Circular 124 of 2010 which is due for review" – Health services manager, policy maker 2* *"Yes, there is a Western Cape province policy for diabetes in pregnancy which we put together. It's about 5 years old so I think it needs revision but there haven't been major changes so it will be minor revisions" –*

	Obstetrician 6, Policy maker 1 *"So this would then be management of Diabetes during pregnancy. The policy speaks a little bit about what happens postnatally but not much,. We know that is where the gap is. We are currently busy doing a postnatal policy for the province" - Health services manager, Policy maker 2*
➢ Metro West Protocols for Basic Antenatal Care ➢ Midwife Obstetric Units (MOU) Protocols for clinical practice at level 1 maternity care facilities in the Metro West (PMNS)	*"So you will find in the City BANC Clinics, that they use our BANC protocols as well" – Health services manager, Policy maker 2* *"There are the provincial guidelines and the protocol for each of the facilities is based on the overarching guideline" – Health services manager, Policy maker 2*
D. Hospital – clinical practice guidelines	
(i) Selective screening criteria for Gestational Diabetes (ii) Postpartum management of diabetic patients (iii) Information sheet and Meal plan	*"..there is a guideline for the tertiary hospital and that's the one we follow in terms of management" - Professor, Obstetrician 2* *"…we just go with the guidelines that were produced by our department by our Professor, which I think he bases on some international opinion" – Obstetrician 5*
E. Evidence from empirical studies	
➢ ACHOIS study (Crowther et al; 2005) ➢ HAPO study (HAPO Study Cooperative Research Group, 2002)	*"We follow international guidelines on the management of Gestational Diabetes. It's been proven in many studies, the HAPO and the ACHOIS studies, that you have to actually follow up people with just gestational or milder form of Gestational Diabetes as well, as this has an impact on the outcome of the baby" – Obstetrician 3* *"We are influenced quite a lot by recent research – such as the ACHOIS study, which was looking at GDM. For quite a long time, people didn't think that impaired glucose tolerance was going to have a negative impact on the pregnancy" – Professor, Obstetrician 2*

ii. Perceived facilitators and barriers to lifestyle change

The majority of key informants felt that the mother's concern for the health of the unborn baby was the single strongest facilitator for adherence to lifestyle modification during pregnancy. In particular, clinicians reported that in their experience, women with GDM were motivated to commit to lifestyle modification in order to deliver a healthy baby without complications, whilst others felt that fear of hospitalization for observation due to uncontrolled blood glucose also contributed to adherence to lifestyle modification.

Despite these facilitators, some clinicians, viewed their own counseling on dietary and lifestyle change during pregnancy as insufficient. While the three hospital study sites each have a dietician, whose role is to provide dietary education to women with GDM, the informants bemoaned the high turnover and shortage of dieticians in the public health sector. As a result, doctors and nurses provide some dietary counseling during consultations, but high patient numbers and time constraints limit their ability to provide detailed educational information to each individual woman. In one of the hospitals, women have access to a dietician upon diagnosis of GDM. In another hospital, the dietician is only available once a week to provide group counseling to women with GDM who are admitted to a hospital ward. Only one of the hospitals has diabetes nurse educators who are tasked with continuous counseling and patient education for this group of patients. Informants expressed a need for more updated and appropriate educational material on lifestyle modification, which they could use with women with GDM.

Regarding physical activity as part of lifestyle intervention, many respondents commented that there was a greater focus on diet modification than the importance of increasing physical

activity during pregnancy. Affordability of healthy food was recognised as a major challenge for women from low socioeconomic backgrounds, regardless of their desire to eat well. According to the public health specialists, unhealthy highly refined foodstuffs are often cheaper and more satisfying than the healthier options such as unprocessed starches and vegetables. Overall, despite these barriers, there was consensus among informants that women with GDM make a considerable effort towards lifestyle modification during pregnancy, although they suspected that these efforts were not usually sustained once the baby was born.

iii. Challenges with postpartum follow-up for women with GDM

Health system barriers

Health service managers admitted that post-partum follow up for women with GDM was problematic. They expressed concern over the fragmentation of health services (Figure 6 and the absence of a standardised approach to postpartum follow-up care for women with GDM. Postpartum care for the GDM mother and health care for the baby are currently available as two separate health services, which are not always located within the health facility. This inconvenience, they believed, posed a barrier to women attending for post-partum care. In addition, the OGTT is not routinely offered at the primary care level and no specific lifestyle advice is being delivered by these services to women with prior GDM. Our interviews revealed that only one of the hospitals in our study offers the 6 weeks postpartum OGTT in an effort to make it more convenient for women to access the OGTT. Even then, not all women attend, our key informants reported on average less than 50% attendance. Although it is standard practice to discharge the woman with a referral letter to a primary care clinic for an OGTT,

this appears to be inconsistently done and there are no communication channels between the different levels of service that enable clinicians to verify whether a woman has had a post-partum OGTT.

Patient-related barriers

Because the majority of women who have had GDM are not on any diabetes medication when discharged, some participants believe they do not perceive themselves to be at risk and so fail to attend for postpartum follow-up care. They also noted that while women are highly motivated to eat more healthily during pregnancy, they were resistant to the idea of permanently altering their lifestyle. Two of the public health specialists were sceptical about achieving long term dietary change in this group of women in the context of patriarchal households where women have very little agency to make lifestyle changes for themselves, let alone the family.

One of the clinicians felt that where women were informed about the importance of the OGTT post-partum, they needed to take more responsibility for their own health and attend the follow-up visit. However, other key informants suggested that non-attendance could be due to lack of time, the cost of transport for postpartum visits and the fact that women may have returned to their rural home in another province. It is common for women residing in the Eastern Cape to migrate to the Western Cape province for the duration of their pregnancy and return home after delivery. Similar patterns of migration between urban and rural areas were reported by key informants in Gauteng. Key informants attributed this to the perception that women would have access to better quality of health services in the Western Cape. In light of these barriers to follow-up care and sustained lifestyle changes, we elicited key

informant views on potential integrated postnatal care for women with prior GDM and their babies.

iv. Views on feasibility of proposed intervention in the Well Baby Clinic

In general, all key informants supported the idea of integrated health services for all women after pregnancy. Policy makers reiterated that there is a need to bridge the divide between maternal and child health care services by means of a holistic approach to postnatal care. They were also in support of our proposed intervention which would potentially leverage the scheduled 6-week immunisation visit at the Well Baby clinics as an opportunity to conduct the OGTT and provide follow-up advice to the GDM mothers. At the time of the interviews, the provincial Western Cape Department of Health were in the process of finalising a postnatal care policy for all women. This new Western Cape Postnatal Care Policy [40] aims to provide integrated postnatal care (up to 6 weeks postpartum) for the mother and baby at the same visit, same site - in particular, the Well Baby Clinic, and by the same health provider.

Most participants felt that integrated care for mother and baby in the Well Baby Clinic would be feasible, if additional resources were made available. There was some concern about the cost implications (e.g., human resources, medical supplies) for offering an OGTT in the Well Baby clinics. Some clinicians did not feel that the current set-up (i.e., space and clinic operations) in the Well Baby clinics could accommodate and attend to the health needs of both the mother and baby. Key informants also cautioned against overloading nursing staff and compromising the quality of care and affect morale. However, most were of the view that with resources, primary care nurses would be the ideal personnel to conduct the OGTT at the

Well Baby clinics. Some suggested training community health workers or health promoters to provide counselling on lifestyle changes, whilst others insisted that nurses should trained to offer dietary counselling since they have frequent contact with patients. Due to the shortage of dieticians, none of the key informants felt that relying on a dietician would be a feasible option.

4.4 Discussion

This study explored the policy guidelines and reported clinical practices relating to antenatal and post-natal care for women with GDM in South Africa, as well as health sector stakeholders' perspectives on the patient and health systems barriers and opportunities for intervention. The health services in our study, adhere to international guidelines for screening, diagnosis and management of GDM– in particular, the WHO guidelines and an adaptation of the NICE guidelines. Further, antenatal care for women with GDM in the two provinces is intensive and in line with health policy, but postpartum care for women with GDM appears to be poorly structured and misaligned with existing policy.

There is considerable international debate regarding the best approach to screening and diagnosis of GDM. The IADPSG criteria have been adopted by the WHO, which has different thresholds for diagnosis compared to the updated UK NICE guidelines [41]. As a result of the lack of consensus on screening and diagnostic criteria, there is no uniformity in screening practices [42,43]. The WHO diagnostic criteria are generally accepted globally, including by many African countries such as Nigeria and Ethiopia [13,44]. The WHO recommends that a GDM diagnosis be made at any time during pregnancy on the basis of a fasting plasma glucose

value between 5.1- 6.9mmol and a 2-hour post 75g oral glucose load value of 8.5 - 11.0mmol [37]. In low-resource settings, one of the challenges of this approach, aside from the costs associated with the actual OGTT, is that women may not always remember to come fasting for their ANC visit [45]. In most LMICs, including South Africa, where resources are limited, pregnant women are selectively screened for GDM on the basis of the presence of risk factors. Universal screening is not practiced in all high-income countries. For example, in the USA only some states follow this practice. [46,47]. Further, a recent study found that universal screening for GDM in the UK was not cost-effective and of no added value in comparison to risk factor-based screening [41]. At this stage, there is no conclusive evidence as to which method is best practice, in fact, a recent review describes the GDM screening and diagnostic criteria as disorderly and chaotic [44].

According to our key informants, all primary care facilities providing antenatal care services should already have in place protocol guidelines for screening procedures and referral pathways for women at high risk for GDM. However, the extent to which this screening actually takes place and the sensitivity of these risk factors for identification of GDM is not known. It is possible that a proportion of likely women with GDM either remain undiagnosed and therefore untreated, or are only diagnosed late in the pregnancy with possible adverse pregnancy outcomes. Sustainable Development Goal (SDG) 3 prioritises 'strengthening the capacity of all countries, in particular developing countries, for early warning, risk reduction and management of national and global health risks' [48]. For women of reproductive age, effective screening for GDM during pregnancy is necessary in order for them to receive appropriate antenatal care and ensure positive pregnancy outcomes. In addition, improving postpartum screening and follow-up care for women after GDM is critical to delaying or

preventing progression to type 2 diabetes in this particular high-risk population [49, 50].

Our key informants reported that women with GDM are consistent in their attendance of antenatal care visits and make considerable effort towards lifestyle modification during pregnancy. However, a few key informants felt that women with GDM did not always demonstrate a clear understanding of what constituted a healthy diet. They expressed concern that they could not provide women with adequate counselling and educational information to empower them to make the necessary, long term lifestyle changes. According to an Australian qualitative study on the experiences of women with GDM [51], in addition to partner support, support from health providers is also critical for women with GDM to make lifestyle changes. Key informants also mentioned that they detected a resistance to long-term dietary change among some women with GDM and imagined that interventions in the post-partum period might be challenging - a view borne out in a systematic review of lifestyle interventions for women with GDM [19]. Sustained diet modification is difficult for women with prior GDM due to factors such as the unaffordability of healthy food, the absence of the pregnancy as a source of motivation and the lack of social support, especially from the family for dietary change once the pregnancy was over [10, 52, 53, 54]. Despite this, the initial diabetes prevention trials, which showed benefit in using intensive behaviour change interventions for people with pre-diabetes or impaired glucose tolerance [55], were also found to be just as effective among women with and without self-reported prior history of GDM [7,49]. However, these challenges indicate the importance of conducting formative research to understand the context in which lifestyle modification is to be made. Our proposed lifestyle intervention for women with prior GDM would need to consider the

particular barriers and facilitators for lifestyle change relevant to our target audience and offer recommendations for changes that are realistic and feasible [10].

Our study also highlights challenges with postpartum follow-up care for women with GDM which can be categorised as health systems barriers and patient-related barriers. The health systems barriers were similar to those cited by healthcare workers in other settings and included fragmentation of care and poor communication between health care workers delivering care at different levels [52,56,57]. Our respondents also discussed patient characteristics which appear to be common barriers to postpartum follow-up, such as lack of perceived future risk for developing type 2 diabetes and non-attendance for postpartum OGTT [10,52]. The low perception of future risk for type 2 diabetes by women with GDM reported by our key informants may relate to the health system barriers which result in inadequate counselling and education during pregnancy. This is evident in clinicians not having the time during antenatal visits and the absence of a dietician to provide and reinforce lifestyle change counselling and education on GDM and the fact that physical activity is not adequately discussed with women despite its potential benefits [10]. Moreover, there is little emphasis during antenatal care on GDM being an opportunity to make long-term lifestyle changes which extend beyond the duration of the pregnancy. This may be attributed to health providers' lack of appropriate training on lifestyle change counselling compounded by the shortage of dieticians in the public sector. Regardless, the unintended consequence of the foetal-centric approach versus a life-course approach to counselling is that women with GDM view the health of the unborn child as the main, if not only, incentive for lifestyle modification which does not extend beyond birth [58]. On the other hand, studies have found that where women perceive their risk of developing type 2 diabetes as immediate, they too may decide

not to attend the 6-week postpartum screening out of fear of a diagnosis of diabetes and inadequate awareness that this risk can be modified [17,56].

Non-attendance for postpartum follow up, is complex in that whilst it is a patient-related barrier, it is closely linked to (1) the quality of counselling and education women with GDM receive during pregnancy and (2) the implementation of health policy at primary care level once discharged. Several studies have found that even when women do attend for healthcare post-partum, many of them do not complete an OGTT [12,52,59,60] either because it is not offered, or they do not request it. These findings emphasize the importance of training health providers and non-clinicians to offer high quality lifestyle change counselling and education to women with GDM, both to improve women's understanding of the need for sustained lifestyle changes, as well as to facilitate long-term follow-up and [52,54,61].

Our findings confirmed that long term follow up in the postpartum period is problematic. Management of GDM in the postpartum period is unsatisfactory in comparison to during pregnancy where women receive intensive medical care from a specialised multidisciplinary medical team. This finding is not unique to South Africa; similar patterns have been reported elsewhere [8,52,62]. In this particular context, the absence of a standardized postnatal care approach for women with GDM and the organization of primary health services may be creating an additional obstacle to women with GDM accessing health services in the postpartum period – representing a missed opportunity for long term diabetes prevention care. Firstly, there is no system in place for the health providers at the delivery unit – i.e., the tertiary hospital to verify whether a woman with prior GDM has attended a follow-up visit and been offered an OGTT at her local community clinic. Discharge summaries which indicate

the woman's diagnosis and need for follow-up, seldom make it to the community clinics where women should attend for their postpartum screening for diabetes. In addition to improving communication between clinicians at the different levels of care, perhaps reminder systems for both patients and health providers could be utilized to improve rates postpartum follow-up and screening as suggested and demonstrated in previous studies [8,52,63,64]. Results from a retrospective cohort study in the US suggest that women with GDM are more likely to attend postpartum visits at a hospital-based clinic than at a hospital affiliated community clinic and this may be attributed to non-adherence to guidelines for postpartum follow-up care by health care providers at the community clinics [62].

Secondly, our respondents confirmed that maternal and child health services are currently two distinct services which the mother and baby have to navigate to access care. This set-up may be inconvenient and therefore contributing to women not seeking post-partum follow-up care for themselves after a GDM pregnancy yet still attending child health services for their baby. Compartmentalisation of care in the postpartum period is a known barrier to postpartum follow-up for women with GDM [52]. It was a positive finding in our study that the policy makers and health service managers are cognisant of the inconsistencies between provision of antenatal and postpartum care for this group of women and are beginning address this through gradual policy change towards integrated postnatal care. It is imperative that health systems improve their responsiveness and capacity to prevent and manage chronic diseases affecting reproductive-aged women. Fortunately, there is support among both decision makers and clinicians in SA for the idea of integrating a postpartum type 2 diabetes prevention intervention into our public health system. Our key informants viewed the concept of integrated care for the mother and baby as an opportunity to improve

postpartum care for women after GDM. Although they supported the proposed intervention in principle, a few expressed concerns regarding the feasibility of integrated health services given the resource constraints in our setting. However, given the high burden of type 2 diabetes in LMICs [65,66], such health system interventions to support women with a history of GDM in making positive lifestyle changes that are sustainable in the long term are needed if high rates of progression to type 2 diabetes are to be avoided [67].

4.5 Limitations

Due to the qualitative study design, generalisability of the findings may be limited. Our study results reflect the views of health stakeholders in the context of urban public health sector hospitals which may not be applicable to rural hospitals. However, the document review provided some triangulation of the interview findings in relation to policy guidelines for GDM management in SA. Further research on the perspectives of women with a history of GDM is necessary to ensure that the proposed intervention will be feasible and acceptable to its target population.

4.6 Conclusions

The intensive antenatal care for women with GDM in the study settings ensures high rates of positive delivery outcomes. However, there is currently a significant gap between the high standard of antenatal care for women with GDM and services for women with GDM in the postpartum period. This formative qualitative study (1) provides a general overview of the

management of GDM in South Africa; (2) highlights some of the main facilitators and challenges with lifestyle modification during pregnancy and (3) identifies important barriers and opportunities for postpartum intervention for women with a history of GDM. Finally, this study provides some useful formative research findings for the development of a complex intervention trial on type 2 diabetes prevention in women with a history of GDM and will assist in determining the most effective means of delivering a feasible and sustainable intervention for this high-risk group in the South African setting.

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CHAPTER 5:

Study 2: Experiences of lifestyle change among women with gestational diabetes mellitus: A behavioural diagnosis using the COM-B model in a low-income setting

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Contributions of the candidate:

Lorrein Shamiso Muhwava conceptualised this sub-study and developed the protocol for the study. She developed the data collection instruments, collected the data and conducted data analysis with guidance from A/Professor Katherine Murphy (main supervisor). Lorrein Muhwava wrote the first draft of the manuscript. The supervisors: A/Professor Katherine Murphy, Professor Christina Zarowsky and Professor Naomi Levitt provided critical input in reviewing drafts of the manuscript. All authors read and approved the final manuscript for publication.

Abstract

Lifestyle change can reduce the risk of developing type 2 diabetes among women with prior gestational diabetes mellitus (GDM). While understanding women's lived experiences and views around GDM is critical to the development of behaviour change interventions to reduce this risk, few studies have addressed this issue in low- and middle- income countries. The aim of the study was to explore women's lived experiences of GDM and the feasibility of sustained lifestyle modification after GDM in a low-income setting. This was a descriptive qualitative study on the lived experiences of women with prior GDM, who received antenatal care at a public sector tertiary hospital in Cape Town, South Africa. Nine focus groups and five in-depth interviews were conducted with a total of thirty-five women. Data were analysed using content analysis and the COM-B (Capabilities, Opportunities, Motivations and Behaviour) model to identify factors influencing lifestyle change during and beyond the GDM pregnancy. The results suggest that the COM-B model's concepts of capability (knowledge and skills for behaviour change), opportunity (resources for dietary change and physical activity) and motivation (perception of future diabetes risk) are relevant to lifestyle change among women with GDM in South Africa. The results will contribute to the design of a postpartum health system intervention for women with recent GDM. Our findings highlight the need for health services to improve counselling and education for women with GDM in South Africa. Support from family and health professionals is essential for women to achieve lifestyle change. The experience of GDM imposed a significant psychological burden on women, which affected motivation for lifestyle change. To achieve long-term lifestyle change, behaviour interventions for women with prior GDM need to address their capability, opportunity and motivation for lifestyle change during and beyond pregnancy.

5.1. Background

Low- and middle-income countries (LMICs) have the highest mortality due to non-communicable diseases [1]. In 2016, diabetes was the second leading cause of mortality in South Africa, accounting for 5.5% deaths [2]. In addition, the country is among the top five in the African region with the highest prevalence of diabetes (9.3%) [3]. The prevalence of gestational diabetes mellitus (GDM) in South Africa, currently estimated to be 9.1% [4] is increasing along with the rise in obesity among women of reproductive age [4-6]. For the majority of women, GDM resolves after the affected pregnancy [7] but there is a 7-fold increased risk of developing type 2 diabetes in the 10 years thereafter [8]. According to a recent systematic review, the risk for progression to type 2 diabetes is highest within 3 to 6 years of the GDM pregnancy [9]. There is consistent evidence demonstrating that in at-risk populations lifestyle change mainly diet and physical activity, can reduce the risk of developing type 2 diabetes [10-13] and among women with GDM, continuation of lifestyle changes after a GDM pregnancy can prevent progression to type 2 diabetes [7, 14]. In addition, studies have shown that postpartum follow-up, continued monitoring and ongoing support for lifestyle change are critical in motivating women to sustain efforts to change their behaviour. GDM therefore provides a unique window of opportunity to educate women on their future risk of type 2 diabetes and to engage them on lifestyle change to prevent or delay progression to type 2 diabetes [15].

Several qualitative studies have explored women's perspectives on GDM, and lifestyle related behaviour change in North America and Europe [16-21]. However, studies on women's lived experiences of GDM in LMICs are still lacking [22, 23]. Lifestyle change among low-income populations should be viewed in the broader socioeconomic context of high rates of poverty

and unemployment, where food choices are limited by affordability [24] and physical inactivity is increasingly prevalent [3]. Although women with GDM achieve lifestyle change during pregnancy, sustaining these lifestyle changes is particularly challenging in the postpartum period [7, 25]. Common barriers to continued lifestyle change postpartum include poor understanding of health information, financial constraints, low perception of risk of developing type 2 diabetes, lack of motivation, emotional stress, personal and family adjustment to the baby [25-28]. Such primary research is recommended by the Medical Research Council framework as an important first step in the development of evidence-based interventions [29]. An in-depth understanding of contextual factors is also critical if such interventions are to be not only well informed, but realistic and feasible [29, 30].

The present study is a component of the formative research phase for the development and evaluation of an integrated health system intervention for women with GDM in the South African public health system. The main study, (IINDIAGO) [31] is a complex intervention trial aimed at reducing the subsequent risk of progression to type 2 diabetes among women with GDM. The planned intervention starts in pregnancy and continues post-partum. It leverages the scheduled 6-week immunisation visit for the baby to conduct an Oral Glucose Tolerance Test (OGTT) for the mother after a GDM pregnancy and provide ongoing social and professional support to facilitate long-term lifestyle changes. The aim of this study was to explore women's lived experiences of GDM and their views around the feasibility of sustained lifestyle modification after GDM, with a view to inform the development of a tailored behaviour change intervention. The specific objectives were to gain insight into women's knowledge, understanding and interpretation of GDM, as well as their perceptions and lived experiences regarding lifestyle modification and health behaviour change (past achievements

and difficulties; perceived barriers; factors that influence their health-related behaviour during pregnancy and in the postpartum period).

5.2. Methods

Study design

The study was a descriptive qualitative study to understand the lived experiences of women who had GDM, how they interpreted or made meaning of the experience and their perspectives on the potential for lifestyle change in their context. Focus group discussions were used to explore women's knowledge and experiences of GDM and reveal their understanding and evaluation of their capacity for behaviour change. The group setting encouraged conversation among participants revealing different views whilst also enabling collection of data on shared perspectives. Challenges with recruitment necessitated in-depth interviews instead of focus groups with five participants, which therefore still allowed us to explore their lived experiences.

Theoretical framework

The chosen theoretical framework for the development of the IINDIAGO intervention was the COM-B model of behaviour change outlined in the Behaviour Change Wheel [32]. The COM-B (Capabilities, Opportunities, Motivations and Behaviour) model incorporates context in understanding behaviour and developing behaviour change interventions, while providing a systematic method for analysing the target behaviour and then characterizing interventions based on the behavioural diagnosis [32]. Behaviour is a result of the reciprocal interaction between the three fundamental components: Capability, Opportunity and Motivation [32].

The COM-B model can be used to structure an analysis into the barriers to and enablers for behaviour change in a given context, thereby ensuring that intervention developers set realistic behaviour change targets [33, 34]. This model has been used in the context of GDM to develop effective health communication content for the STAR MAMA program for low-income Latina women in the US with a history of GDM [35]. In the present study, the COM-B model was used to guide the analysis of the focus group data and provide a theoretical framework for understanding women's capacity for lifestyle change and the available opportunities and barriers in their environments.

Setting

In South Africa, government funded public sector health services cater to more than 80% of the population, who cannot afford the high costs of medical insurance and private health services [31]. The study was conducted at a public sector, tertiary referral hospital, which provides health services to patients residing in Cape Town and other surrounding areas of the Western Cape province. Once diagnosed with GDM, women are referred from their primary health care facility or a district hospital to the tertiary hospital, where they attend a dedicated antenatal diabetes clinic until delivery. The majority of women are referred from Midwife Obstetric Units in Cape Town's low-income, peri-urban townships. The women seen at this hospital are predominantly 'coloured' (mixed ancestry) and black African who speak mainly Afrikaans and isiXhosa, as well as English. Antenatal care for women with GDM is provided by a team of health care providers including obstetricians, endocrinologists and nurses.

Participant selection

A folder audit was conducted to identify women with GDM who had delivered at the tertiary hospital in Cape Town between 2014 and 2015. Information regarding the GDM diagnosis and general medical history was used to purposively select potential participants that met the inclusion criteria. The following were eligible: women who had been diagnosed with GDM between 2014 and 2015; had received antenatal care at the tertiary hospital; delivered a live baby and who did not need treatment for diabetes at discharge. Eligible participants were contacted telephonically and invited to participate in focus group discussions at a private seminar room on the hospital premises. Reasons for refusal were recorded in a communication log. Depending on their preference, women could select a suitable day to attend a focus group discussion from provided options.

Focus groups were scheduled with between five to ten women per focus group. Reminders were sent by telephone and text message a day before and on the morning of the scheduled focus group to confirm attendance. To improve recruitment, we scheduled focus groups on weekends to accommodate women who were working during the week, organised focused groups at local community venues for those women who could not travel to the hospital and allowed women to bring their infant along to the focus group. When fewer than three women turned up for a scheduled focus group, the researchers took the opportunity to conduct individual in-depth interviews.

Data Collection

A focus group guide was used in the discussions and consisted of open-ended questions and probes. The main topics for discussion were knowledge and attitudes regarding GDM, experience of health care during GDM pregnancy, experience of health care in post-partum period, lifestyle modification during and after pregnancy and finally, attitudes to the proposed

postpartum intervention for women with GDM. Participants were encouraged to raise other issues of interest to them that related to the broad topic of the discussion. The focus groups and in-depth interviews allowed for discussions with women until saturation was reached. Two female researchers (LSM and KM) trained in qualitative research techniques conducted the focus groups in English. A third co-facilitator (BMD); a diabetes nurse who was conversant in the two local vernacular languages, isiXhosa and Afrikaans, was present to assist participants who preferred to express themselves in their native language. However, most women spoke English and occasionally used common Afrikaans phrases, which others in the group were able to interpret for the benefit of the larger group. Wherever a participant spoke a language other than English, the co-facilitator would translate this for the recording, and this made it easier during transcription. Their responses were then interpreted into English for the benefit of the wider group. The co-facilitator was also responsible for taking notes, observing group dynamics and monitoring the audio recorder to increase dependability of the data collected.

Each focus group lasted between one and two hours or until data saturation was reached. Verbal consent to participate in the focus group was obtained telephonically. At the start of each focus group and interview, the researchers introduced themselves and explained the purpose of the study. Written informed consent was then obtained from each participant and all participants were given the opportunity to ask questions. Participants were reimbursed for their transport costs and given a supermarket grocery voucher for their time as well as a locally developed recipe book for preparing affordable healthy meals. Healthy snacks and refreshments were served during intervals to encourage informal social interaction among

participants. Focus groups and interviews were audio recorded and transcribed verbatim. Transcripts were stored in a locked cabinet with restricted access.

Data Analysis

Data analysis followed the methods of qualitative content analysis as described by Elo & Kyngä¨s [36]. The analysis process was both inductive in that some categories were derived from the data to understand women's lived experiences of GDM and how they interpreted it and deductive in that it was driven by the broad conceptual categories theorised to be the precursors of behaviour change in the COM-B model [32]. The pre-existing, conceptual categories of the COM-B model provided a lens through which to view and interpret the data. Using this model served to answer the key research questions of a) What was the potential for change, given the barriers and opportunities perceived and experienced by this population of women with GDM? and b) What kind of intervention was needed to meet their needs and enhance their potential for change?

The first author (LSM) is a public health researcher and is familiar with the SA maternal health context. The second author (KM) is a qualitative researcher whose research work focuses on the development and evaluation of behaviour change interventions for NCDs. The third author (CZ) is a medical doctor and medical anthropologist, with substantial clinical and health systems research experience in the SA setting. The last author (NL) is a clinical endocrinologist in the public health sector with strong interests in NCDs in the African context. All four authors are female. For triangulation and to facilitate a robust analysis, LSM and another researcher, worked independently in coding the transcripts. As a first step, all transcripts were read for overall familiarization with the data. The transcripts were then re-

read and annotated to understand meaning from the participant's perspective. The data was then systematically organised and abstracted through a process of open coding and generating conceptual categories. LSM and the second coder met frequently to discuss and compare their analyses, resolve discrepancies and came to an agreement on a common coding framework to apply across all the data. KM was present in the discussions between the data coders to ensure credibility of the findings. This coding framework was further developed and refined through continued collaboration between the researchers as the analysis proceeded. For the purposes of this manuscript, the data was analysed according to the categories of the COM-B model; *Capability, Opportunity* and *Motivation.* We found that some dominant themes (e.g. mental health and women's experience of health services) were important issues to women and warranted further exploration. These themes are to be the focus of other papers.

Ethical approval

Written informed consent was obtained from each participant in the focus groups and interviews. Ethics approval for the study was obtained from the University of Cape Town (HREC: 946/2014) and Université de Montréal (CR CHUM: 2018-7091, 17.128-ID). Permission to conduct the folder audit was obtained from the relevant hospital authorities.

5.3. Results

Nine focus groups (N=30) and five in-depth interviews were conducted between March and June 2016. Eight focus group discussions were held at the hospital study site and one at a

community venue. Twenty-three women declined participation and fourteen accepted participation in the focus groups but could not attend due challenges with transportation, time and availability of childcare. Participants' demographic information is summarised in Table 4. Our sample consisted of black African and 'coloured' (mixed ancestry) women. The majority of participants were married (60%) and unemployed (77%).

Table 4: Summary of participants' demographic characteristics (N = 35)

Variable	Frequency	%
Age (years)		
25-29	7	20
30-34	15	43
35+	13	37
Marital Status		
Single	13	37
Married	21	60
Divorced	1	3
Employment status		
Employed	6	17
Unemployed	27	77
Student	2	6
Home Language		
English	11	31
Xhosa	10	29
Afrikaans	10	29
Shona	1	3
French	3	9

The results are organised according to the constructs of the COM-B model namely; Capability, Opportunity and Motivation, which are necessary pre-conditions for desired behaviour to

occur. Figure 7, adapted from Howlett et al [37], represents the focus group findings in relation to the Theoretical Domains Framework (TDF) of the COM-B model [38].

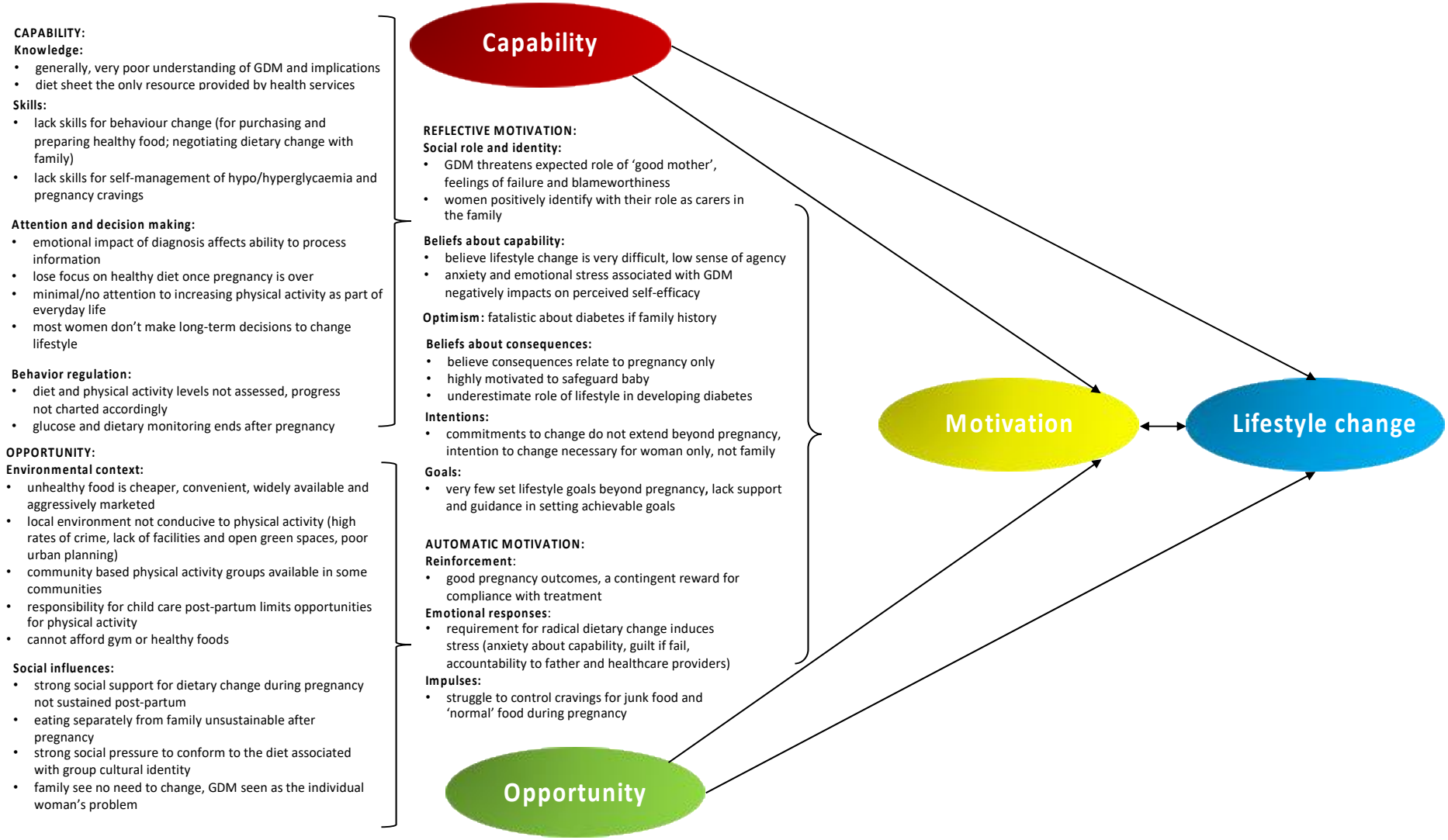

Figure 7: Findings from focus group discussions mapped according to the Theoretical Domains Framework (TDF) of the COM-B model framework for understanding behaviour [38]

i. Capability

Capability can be described as the individual's 'physical and psychological capacity to engage in the activity concerned' [32]. Physical capability refers to the physical skills required to achieve a desired behaviour whereas psychological capability is the capacity to engage in the thought processes necessary for behaviour change [30]. Both physical and psychological capability can be improved through intervention or training [32].

Psychological capability:

(i) Limited knowledge and understanding of GDM

Generally, the women demonstrated limited knowledge and understanding of GDM. They expressed a strong desire for the GDM clinic to provide more education and counselling as part of their routine clinical care. They felt that this was especially important during their first visit at the hospital following their referral, because this was a time of heightened anxiety and confusion. There was a general sense that due to high patient numbers, health care providers did not have the time to explain the GDM diagnosis to them. Although women spoke of the high standard of clinical care they received, they were dissatisfied with the lack of counselling and education and were left feeling frustrated by the lack of opportunity to ask questions to help them clear up their confusion.

> *There's no proper interaction between you and the person you're sitting with, to tell you, 'this is the reason why you've got this.' There's no explanation, so you can imagine my confusion. (Focus Group 4, Participant 14)*

> *I didn't understand why I can't have normal food, because no one said to me, 'You have Diabetes' (Focus Group 4, Participant 16)*

One woman explained how she had to strongly assert herself in order to get the answers she needed:

> *I started snooping through my file and searching the internet to understand what the terms meant, which caused frustration and that pent-up feeling in me. You're just left in the dark there until you throw a tantrum. You've got to raise the roof in order for them to actually give you a decent sit-down conversation. (Focus Group 6, Participant 20)*

Whilst most women relied on health care providers as a primary source of information, a couple with access to resources such as the internet and dieticians in private health services took the initiative to seek out more information in order to gain a better understanding of their condition.

> *I told myself, it's the first-time pregnancy with Gestational Diabetes, and I'm going to try to get as much information as I can. I also did a lot of research on how it is caused and how I'm actually going to deliver the baby (Focus Group 9, Participant 35)*

Other participants were more knowledgeable regarding GDM due to their experience of having a family member or partner with diabetes. These women felt less anxious on receiving the diagnosis as diabetes was familiar to them;

> *I understand Diabetes because my mother has Diabetes. I understand what you have to eat and that sometimes there are days where you don't feel well because your sugar levels are not okay. (Focus Group 4, Participant15)*

Women described being so emotionally overwhelmed by the GDM diagnosis that they were unable to process and understand the limited information they did receive during the initial consultation. They suggested that during the diagnosis consultation, providers be sensitive to the emotions that women may experience and instead, leave the provision of information and advice on how to manage GDM for a subsequent consultation. As one participant recalled:

> *There wasn't room for me to ask questions. I was shown how to prick myself [insulin injections] but I was still in so much emotion; I couldn't even recall how often she said I had to do it. (Focus Group 1, Participant 4)*

The education materials provided by the hospital did not help fill the gap in knowledge. Typically, women received a one-page diet sheet. This information was limited in scope: prescribing what dietary changes needed to be made but offering no detailed guidance about *how* to change behaviour. When directly questioned about physical activity, the majority of women reported that physical activity was not mentioned or emphasized by health care providers as part of recommended lifestyle changes.

> *They didn't explain that [physical activity]. They just said lifestyle change, but they didn't explain, like, exercises and things like that, no (Interview 1, Participant 5)*

Only a few women recalled being advised to do some light to moderate physical activity by the dietician.

> *They did say something about exercise, just to take a brisk walk, maybe thirty minutes, but not too much, but just so that you can exercise (Focus Group 9, Participant 35)*

This lack of understanding of GDM sometimes resulted in denial in accepting the GDM diagnosis and resistance to treatment;

> *They said they have to put me on Insulin, and I was very upset, I was very cross. I even told myself, I'm not going to use the Insulin. (Focus Group 3, Participant 12)*

In contrast to this respondent's evident anger about the lack of counselling and information, it was clear that some women made adjustments to their lifestyle (in particular by making dietary changes) regardless of their lack of understanding of GDM and its implications.

> *My health would have been in bad condition, and it would also have affected my son, so whatever they used to tell me, I used to follow. If they tell me, do this at this time, you have to eat this, I used to follow. (Focus Group 8, Participant 32)*

Physical capability:

(ii) Physical discomfort during pregnancy

A few women reported that they had engaged in some leisurely physical activity such as walking in the neighbourhood or parks, yoga and attending a private or community gym, but that this became more difficult towards the end of the pregnancy, due to physical discomfort.

> *In the last trimester, I was huge, and I looked uncomfortable, because I'm short. People thought I was carrying twins, because of my size and my belly. It was very uncomfortable (Focus Group 1, Participant 4)*

Another woman said that she felt too anxious to do her usual walking once she was full term as she was afraid of the onset of labour:

We had a nice path, so I could just walk down there, just a bit, because I didn't want to stretch myself too far, and anything could happen (Focus Group 1, Participant 4)

ii. Opportunity

Opportunity refers to 'all the factors that lie outside the individual that make the behaviour possible or prompt it' [32]. These are factors in the environment that encourage or discourage achieving behaviour change, which can be physical (related to time, access to resources, affordability of resources, actual physical environmental barriers, existence of cues) or relating to the social context (including interpersonal influences that can cause individuals to change or not change their beliefs, attitudes, feelings, or social norms, culture, social pressure, expectations of others, group identity)[32].

Physical environment:

(i) Opportunities for physical activity

In general, the majority of women in this study did not engage in leisure time physical activity outside of their daily activities such as chores and travel to work because of concern for personal safety, due to high levels of crime and violence.

I stopped going to the gym is because I had to walk alone at night when I'm finished, we're mostly just girls there I'm too scared to walk around there; the shooting and stuff. (Focus Group 5, Participant 17)

Some women mentioned that there were available opportunities in their communities, which they had utilised.

We have a community exercise programme in a local hall, so, I started exercising. It's aerobics, running, it's everything. It was hardcore. I felt like I was the odd one out with all this weight, (Focus Group 1, Participant 2)

There's a centre, where they give gym to the ladies that stay at home, every Thursday morning. There is a qualified instructor who comes to Mitchells Plain, and the City Council pays her. (Focus Group 2, Participant 6)

Post-partum, it was difficult for these women to continue with physical activity as certain facilities did not accommodate children.

We moved houses and I had to change the gym. At that gym you can't take your children so that was difficult for me. My husband is at work, so where must I leave my children, and then I just stopped. (Focus Group 4, Participant 16)

Women also suggested that the health services could increase opportunities for physical activity:

Activities need to be provided, like how about a walkabout in the hospital for the patients. I mean, for the guys who have just had a Caesar, they need to get mobilised as soon as possible (Focus Group 6, Participant 19)

(ii) Influence of prevailing food environment

Two participants who worked in catering, described how continual exposure to unhealthy food in their work environments made sticking to the healthy eating recommendations particularly difficult:

The thing is that where I used to work, I was in charge of the kitchen. I didn't know what to eat. I was eating junk, any food which I see. I didn't know how to control myself; you know (Focus Group 8, Participant 32)

The one participant described how support from the head chef helped her to overcome this barrier:

It was stressful because I had cravings and I was hungry all the time. My head chef said 'No, I'm going to set up a diet for you. You're not going to eat that food; you must think of your baby.' (Focus Group 8, Participant 27)

(iii) Affordability of healthy food

There was a general perception among respondents that healthy foods were more expensive than "ordinary foods". While pregnant, the woman and her family were prepared to incur the extra expense of adhering to dietary recommendations to safeguard the pregnancy, but once the baby was born, it was understood that this extra cost could not be sustained. As most women were unemployed and financially dependent on their partners, they had limited decision-making power in relation to household expenditure.

For me it's expensive, because I don't work. Before we had the baby, it was okay, because it was just the two of us, but now we've got more expenses for everything. It's either I get his things or buy stuff for myself. I can't do both of them (Focus Group 4, Participant 14)

Continuing with a healthy diet was also considered difficult post-partum because women believed that it required eating separately from the rest of the family. This was a more

expensive way of eating, as well as being impractical when having to also cater for the rest of the family.

> *When one goes shopping, you would normally buy what you need to make the normal pot of food [for the entire family]. But now you have to cater for yourself and the things aren't cheap if you want to eat healthy and fresh. The sugary things are much cheaper than the healthier things. (Interview 1, Participant 5)*

Social environment:

(iv) Prevalent social norms

A high carbohydrate diet, the consumption of sugary beverages and fatty meat were perceived as part of a 'normal' diet and an aspect of cultural or community identity. As a result, dietary change during pregnancy was a major adjustment for some women, as it required shifting from the social norm.

> *I was used to my cool drinks and things, it's the type of home that you come out of. I was used to having cool drink or juice at supper and so it was a big lifestyle change that I had to do. (Interview 1, Participant 5)*

> *I would eat the food like any normal African eats. I would put a lot of sugar in my tea. Now I'm eating more healthy food, when I make chicken, I remove the skin. I boil the chicken and my milk is low fat. When I want to put sugar, I put very little brown sugar. (Focus Group 2, Participant 8)*

(v) Importance of social support

All women emphasized the importance of having a supportive social environment to make lifestyle changes and indicated that support from partners, family, peers and health professionals was essential. Participants described how receiving encouragement and motivation from their partners and family in particular, aided them in making the necessary changes. Some family members changed their diet to support the expectant mother and others supported her by ensuring that she adhered to a healthy diet.

My mom was my best supporter. If I bought chicken with my veggies, she will eat with me. (Focus Group 8, Participant 30)

My family was very supportive, and my husband was very strict. He'll watch me at restaurants and functions. They will always remind me. (Focus Group 3, Participant 11)

Women also recalled sharing experiences and tips with other pregnant women during their antenatal clinic visits or when hospitalized and how these relationships provided a sense of mutual support. Some women also expressed sincere appreciation for the compassion and support they received from healthcare providers during their pregnancy. Such social support and feelings of connection positively impacted on their perceptions of the quality of care they received and were clearly important in enabling them to adhere to treatment. For example:

The professor gave me inspiring encouragement; and I think that is what kept me going. (Focus Group 2, Participant 6)

They have a Sister; we called her the 'Breast Sister'. They would call her up just to help [with breastfeeding] and she's the loveliest person ever. She encouraged you and she would motivate you. (Focus Group 4, Participant 15)

This was not however the experience of all women: some recounted very negative experiences with healthcare providers:

> *The sisters were very rude. We even had to remind them about getting our medication and food. They don't have patience for us. I was always arguing with them, because they're not on time to give you medication (Focus Group 9, Participant 34)*

> *The [nursing] staff are so stressed out there; they really don't have the patience to deal with the patients. (Focus Group 6, Participant 19)*

iii. Motivation

Motivation refers to 'all the brain processes that energize and direct behaviour, not just goals and conscious decision-making' [32]. This consists of reflective processes (i.e., conscious intent, goal setting and planning) and automatic processes (i.e. habits, reflex behaviours, impulses determined by external factors) involved in evaluating the potential consequences and benefits of carrying out or achieving the desired behaviour [32].

Reflective motivation:

(i) Concern for the health of the baby

During pregnancy, concern for the health of the baby was reported as a strong motivating factor for adherence to prescribed medication. Although some participants reported anxiety and side effects associated with metformin and insulin, these were outweighed by the perceived benefits for their health and that of the unborn baby. Thus, they continued to take the medication for the sake of the baby;

I remember the first time I took Metformin, I started shivering. It was like a cold shiver that I'd never experienced before. It was so bad, and I wanted to stop taking it, but I couldn't because of the baby, you know, I had to consider the baby. (Focus Group 4, Participant 15)

So right through the pregnancy I was on Insulin and Metformin, and it's not an easy thing for us. It's really not easy to inject yourself every time. (Focus Group 8, Participant 29)

For the majority of the women, adherence to treatment and the recommended lifestyle change during pregnancy were non-negotiable and a necessary sacrifice, even if they did not fully understand their condition.

You don't know how this [GDM] is affecting your pregnancy and what it's going to do to the baby, you don't know, you're just going to do what you need to do for the safety of yourself and your baby. (Focus Group 4, Participant 14)

(ii) Fear of failure as a 'good' mother

One respondent expressed resentment towards some health care providers because of their judgemental and blaming attitudes:

They make you feel like your body is failing. They say, 'listen, you ate wrong and it's your fault if something happens to your baby.' (Focus Group 1, Participant 2)

Women discussed the challenges of caring for a new baby and how these impacted their sense of identity as mothers. One respondent described how struggling to breastfeed added to her feelings of failure as a 'good' mother:

> *He couldn't latch on and I felt so guilty. I waited till my husband went to bed every night and then I'd cry when he was sleeping. (Focus Group 4, Participant 16)*

(iii) Prioritising own health after the pregnancy

Women described their intentions to focus on their own health after delivery and expressed a desire to continue the healthy lifestyle habits they had developed during pregnancy in order to reduce their risk of type 2 diabetes;

> *During pregnancy your focus is your baby because you want everything to be okay with baby. So, after baby is born, you take more time also into your own life again, and then you realise, okay, I have to focus on me now. (Interview 1, Participant 5)*

(iv) Desire to lose weight

Some women were unhappy with the fact that they had not returned to their pre-pregnancy weight and expressed a strong desire to continue with physical activity and a healthy diet for weight loss. Being overweight or obese was described as uncomfortable and an emotional burden;

> *With weight also comes a lot of stress. I'm getting older and changing. I don't do family functions a lot anymore, because where am I going to get an outfit? I'm always tired, because I'm overweight and I'm not enjoying myself the way I used to (Focus Group 1, Participant 2)*

(v) Considering the next pregnancy

The desire for another baby motivated some women to continue with the lifestyle changes after the GDM pregnancy. They were also more prepared and equipped with the knowledge gained during pregnancy to sustain the behaviour changes postpartum.

> *I'm really more health wise, because it's very important. I do want another baby. That's why I'm looking after myself. I go to gym every Thursday. (Focus Group 2, Participant 6)*

Automatic motivation:

(vi) Psychological vulnerability

Women's feelings of motivation to make lifestyle changes were affected by their emotional responses to the GDM diagnosis. Having GDM led to feelings of fear, worry, anxiety and stress during pregnancy.

> *It was very traumatising, and I cried for several days. It was my first baby, and I waited so long for this baby. I was scared (Focus Group 8, Participant 30)*

Some women continued to experience psychological distress even after delivery, which affected their ability to cope with motherhood and continue lifestyle changes. When asked about postpartum follow-up care and diabetes screening, one woman reported being unable to attend the clinic for postpartum follow-up due to postpartum depression (PPD):

> *I was in post-natal depression. I just didn't feel like me. My husband couldn't understand why I was so moody and edgy. I just couldn't cope. (Focus Group 5, Participant 15)*

Table 5 provides a summary of facilitating factors identified for developing capability, opportunity and motivation for lifestyle change during and after a GDM pregnancy.

Table 5: Summary of facilitating factors for developing capability, opportunity and motivation for lifestyle change during and after a GDM pregnancy

Capability	*Opportunity*	*Motivation*
Psychological capability *Knowledge and understanding of GDM* · Provision of counselling and education on GDM by health care providers · Detailed educational materials teaching skills for lifestyle change · Ability to engage with health care providers and ask questions · Access to additional resources for further information · Experience of caring for a family member or partner with diabetes **Physical capability** · Tolerating physical discomfort and fatigue during pregnancy	**Physical opportunity** · Access to affordable healthy food options · Access to safe outdoor spaces for physical activity within their community · Availability of personal time for physical activity after delivery **Social opportunity** *Professional support* · Expert advice, encouragement, compassion and empathy from health care providers during pregnancy *Family support* · Emotional and practical support from family and friends in making lifestyle changes · Support from family in caring for the baby *Autonomy* · Having negotiating power regarding family diet *Cultural influences* · Healthy food incorporated into individual and group cultural identity · Able to resist social pressure to eat unhealthy food at family gatherings and other social events · Supportive social norms regarding physical activity	**Reflective motivation** *Concern for the health of unborn baby* · Fear of stillbirth, deformities · Adherence to treatment despite side effects for the sake of the baby · Fear of delivery by Caesarean section · Fear of failure as a mother *Concern for own health* · Fear of developing type 2 diabetes post-partum · Prioritising and valuing own health after pregnancy · Desire for weight loss after pregnancy · Intention to have another baby and fear of another GDM pregnancy **Automatic motivation** · Ability to exercise self-control and resist unhealthy food during pregnancy · Receiving support to address emotional responses to GDM diagnosis and for mental health issues (e.g.; anxiety & stress during pregnancy; postnatal depression)

5.4. Discussion

To our knowledge, this is the first qualitative study in sub-Saharan Africa to explore the lived experiences of women with GDM as well as the feasibility of sustained lifestyle changes beyond pregnancy. Several key factors that influence women's ability to implement lifestyle change were identified (Figure 7) and are discussed in relation to the COM-B model constructs and in the context of existing literature. These findings will contribute to the development of an appropriate and feasible behaviour change intervention for women with prior GDM to reduce the risk of developing type 2 diabetes among this population.

Capability

A common finding was that lack of information from their health care providers impacted negatively on women's capability to respond adequately to the GDM diagnosis and affected their adherence to treatment. Women with GDM in China [22] and Vietnam [39] also reported that the health information they received from health care providers was unclear, lacking detail and that they desired more information about GDM. Women's poor knowledge of GDM is associated with poor understanding and therefore poor interpretation of health information [25]. For example, some respondents interpreted the fact that GDM resolves after pregnancy to mean that once the pregnancy was over, they could revert to their 'normal' unhealthy lifestyles. Poverty, poor maternal education and low health literacy all contribute to women's poor comprehension of health information on GDM management [40]. In order to improve women's psychological capability to respond to GDM, health services must prioritise the provision of sufficiently detailed health information at diagnosis, a view supported by systematic review findings on postpartum health care seeking behaviour among women with a history of GDM [26].

All women in this study were interested in understanding their GDM diagnosis and desired an opportunity to engage with health care providers to improve their knowledge and develop skills for self-management (e.g.; glucose monitoring and insulin administration) and behaviour change (e.g.; purchasing and preparing health meals). Given the very limited time available for counselling in our setting due to high patient numbers and resource limitations, women with GDM should be provided with additional, comprehensive and culturally appropriate educational resources, that take varying literacy levels into consideration [26, 41]. It is noteworthy that the provision of such information alone would be insufficient to effect long term behaviour change [30] and is likely to be most helpful to women when delivered in the context of a supportive, personal interaction, which allows them to engage personally with the information and ask questions [7].

Opportunity

Our findings that women with GDM have to overcome several barriers to lifestyle change in their physical and social environment are in agreement with studies with women with GDM from high-income countries such as the United States and Ireland [12, 42, 43] and some LMICs [44]. During the GDM pregnancy, the woman and her family direct all financial resources towards her to ensure positive obstetric outcomes. However, financial responsibilities increase once the baby is born and opportunities for lifestyle change (i.e. finances, personal time) become more limited in the post-partum period with the added responsibilities of childcare [7].

Another important finding was that our respondents were generally unaware of the physical and mental health benefits of physical activity. This has previously been reported by pregnant women from similar communities of low socioeconomic status in Cape Town [45]. This could be readily overcome by consistent counselling or messaging, but the barriers of a lack of attractive, local open outdoor spaces and high levels of crime in in their communities require different strategies. These include creating safer spaces within communities, introduction of physical activity programs by the health services, partner, family and community involvement and the use of media to raise awareness [46, 47]. The GDM pregnancy is also an opportune time for women to establish physical activity routines that can realistically be sustained beyond the pregnancy, for example; incorporating simple physical activity into their daily routine and in the postpartum period, easing back into physical activity with safe and light exercises that can be done while holding the baby.

The majority of women experienced strong social support from their families during pregnancy for dietary change. However, some women reported having some difficulty in persuading their partners and families to change the overall family diet. In SA, as in other patriarchal societies, women have limited negotiating power to significantly change the family diet. Further, the consumption of certain high caloric foods has become incorporated into group cultural identity and dietary change despite its benefits, requires deviation from social norms. The same social influence of family and friends on women's diet has also been noted among non-pregnant women with type 2 diabetes in Soweto, South Africa [48]. Health behaviour change interventions should therefore target women's partners family members and social networks [34].

Expert advice and psychological support from health care providers during pregnancy were highlighted as critical. However, in the postpartum period, the absence of follow up left women feeling abandoned. It was interesting to note that women in this study found emotional release from sharing their experiences and valued the peer support derived from participating in the focus groups. The perceived withdrawal of support, which has also been found in studies conducted in the UK [18, 19] and Australia [49], resulted in some women reverting back to unhealthy lifestyle behaviours. Thus, ongoing support from health services during pregnancy and thereafter, that may be complemented by peer support groups [50, 51] should be considered.

Motivation

Women's initial emotional reactions to the GDM diagnosis of fear, worry, anxiety and stress [19, 51] illustrated their deep sense of responsibility for their baby. According to the literature, concern for the baby is the strongest motivating factor for behaviour change during pregnancy [18, 40] and in our study provided motivation to make major lifestyle adjustments at any cost, including resisting cravings for unhealthy food and enduring the side effects of medication. Some respondents described negative experiences with antidiabetic therapy in keeping with previous reports that women with GDM find insulin use overwhelming and burdensome [16, 41, 51]. Yet in comparison to dietary modification, others prefer insulin use to manage GDM [40].

The psychological impact of the GDM diagnosis may be currently underestimated by health services. As with some respondents in this study, women with GDM in previous studies have reported feeling unsupported by their health care providers to face the overwhelming

distress of the GDM pregnancy [22]. With a GDM pregnancy, women are often perceived as baby machines [19] closely scrutinised by their partners and health care providers, which adds to maternal anxiety. The diagnosis and experience of GDM in itself has been linked to postpartum depression (PPD) [52], which affects women's motivation to sustain lifestyle changes. Although a GDM pregnancy can be considered a 'prime teachable moment' [34], this needs to be tempered with 'caring GDM care', which Ge et al., have described as humanistic care [22]. Findings from previous research suggest incorporating a clinically valid psychological assessment into the care for women with GDM to assess the impact of GDM on quality of life [53, 54]. In addition, increasing health care providers awareness of the emotional impact of GDM supported by targeted psychological interventions and provision of adequate information could help alleviate the anxiety and psychological distress associated with GDM and thereby enhance women's psychological motivation for behaviour change [19].

In summary, women's capability to make lifestyle changes was significantly impacted by lack of knowledge and understanding of GDM. Health care providers should be trained in patient-centred counselling methods (e.g., motivational interviewing) and provide women with adequate health information and appropriate educational resources to facilitate their developing practical strategies to achieve lifestyle changes. The limited resources in LMICs make it particularly pertinent to tailor physical activity and dietary recommendations to women's social and environmental context. It is clear that social support plays a critical role in facilitating lifestyle change as lack of support in the postpartum period resulted in disruption of healthy behaviours made during pregnancy.

5.5. Strengths and Limitations

Our study has several strengths. The descriptive qualitative approach allowed for detailed insights into women's subjective experience of GDM and their perceived capacity for behaviour change, while the COM-B model provided a validated theoretical framework on which to map the facilitators for developing capability, opportunity and motivation for lifestyle change, as a first step towards the development of an appropriate behaviour change intervention for women with a history of GDM in this setting. The COM-B model may also be utilised by health care providers and those involved in health policy planning [30, 33, 34].

We acknowledge some limitations of this study. Generalisability of the findings is limited due to the qualitative study design. Our sample consisted of women who received antenatal care at a single tertiary hospital in the Western Cape, were reachable and agreed to participate. However, the study site is one of two large tertiary hospitals that receive specialist referrals for GDM from primary care clinics and district hospitals across the Western Cape province. Both hospitals adhere to provincial and national guidelines for the management of GDM. The intent of the study was not generalizability of findings but rather to explore women's perceived capacity for behaviour change within their context. Our study sample is representative, in terms of socioeconomic status, ethnicity and age, of women in this low-income urban setting. Lastly, the participants were at least one year postpartum, which may have introduced recall bias. On the other hand, it gave women sufficient time to reflect on their experiences of the GDM pregnancy. Despite these limitations, our findings are consistent with evidence in the literature and may be applicable in other low-income urban areas.

5.6. Conclusions

Using a combined descriptive qualitative and theoretical framework (i.e.; COM-B) approach, this study elicited important insights into the lived experiences of women with GDM and the feasibility of lifestyle change in a low-income setting. The findings highlight barriers to capability, opportunity and motivation for lifestyle change. Consistent counselling and provision of appropriate educational resources are necessary to overcome these barriers. In order to achieve long-term lifestyle change, continued support from the health services, partners, family members and peers is essential.

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CHAPTER 6:

Study 3: Perspectives on the psychological and emotional burden of having gestational diabetes amongst low-income women in Cape Town, South Africa

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Contributions of the candidate:

Lorrein Shamiso Muhwava conceptualised this sub-study and developed the protocol for the study. She developed the data collection instruments, collected the data and conducted data analysis with guidance from A/Professor Katherine Murphy (main supervisor). Lorrein Muhwava wrote the first draft of the manuscript. The supervisors; A/Professor Katherine Murphy, Professor Christina Zarowsky and Professor Naomi Levitt provided critical input in reviewing drafts of the manuscript. All authors read and approved the final manuscript for publication.

Abstract

The diagnosis of gestational diabetes mellitus (GDM) may affect women's mental wellbeing, functioning and quality of life, with potentially negative effects on treatment adherence. Identifying and addressing the psychological and emotional needs of women with GDM, could have benefits for sustainable long-term behavioural change following the affected pregnancy. This study explored the lived experiences of women with GDM and the impact of GDM on their experience of pregnancy and sense of well-being. Purposive sampling was used to recruit women who had been diagnosed with GDM in their previous pregnancy and received antenatal care at a tertiary hospital in Cape Town, South Africa. This was a descriptive qualitative study using a combination of focus groups and in-depth interviews for an in- depth exploration of women's lived experiences of GDM, their context and perceived needs. Data analysis followed an iterative thematic analysis approach. Thirty-five women participated in nine focus groups and five in-depth interviews. Women discussed the emotional and psychological burden of having GDM, highlighting (i) their initial emotional reactions to receiving a GDM diagnosis, (ii) their experience of adjusting to the constraints of living with GDM (iii) their feelings of apprehension about childbirth and their maternal role and (iv) their feelings of abandonment in the post-partum period once the intensive support from both health system and family ends. The current biomedical model used in the management of GDM, is highly foetal-centric and fails to acknowledge important psychological factors that contribute to women's overall wellbeing and experience of pregnancy. These results demonstrate the importance of incorporating mental health support in the management and care for women with GDM in public health services, along with facilitating emotional support from partners and family members. Based on our findings, we recommend routine mental

health and psychosocial vulnerability screening and monitoring for women diagnosed with GDM throughout pregnancy and postpartum to improve prognoses.

6.1. Background

Gestational diabetes mellitus (GDM), currently defined as 'diabetes diagnosed in the second or third trimester of pregnancy that is not clearly overt diabetes' is one of the most common obstetric complications, affecting 18.4 million live births globally [1-3]. Women with GDM face increased risk of maternal, foetal and perinatal complications and have a significantly increased risk of developing type 2 diabetes [4, 5]. GDM may also have a negative impact on women's mental wellbeing, functioning and quality of life [6-10]. The sparse literature on GDM and mental health suggests that the diagnosis of GDM is a risk factor for anxiety and stress during pregnancy [11-14], antenatal [15] and postpartum depression [16, 17], with potentially negative effects on treatment adherence [8, 9, 18]. The perceived stress of effectively managing GDM through lifestyle change coupled with the fear of failure to achieve glycaemic control may trigger depressive symptoms [19]. The management of GDM is centred on glycaemic control to prevent adverse obstetric outcomes [20-22], while the potential impact of the diagnosis on women's psychological and emotional well-being is seldom considered in managing the condition.

In recognition of the psychological and longer term health needs of women with medical complications in pregnancy, who remain at risk after the pregnancy, the World Health Organisation (WHO) has called for the global health community to adopt a more comprehensive, woman-centred life course approach to maternal health that extends beyond pregnancy and childbirth [23, 24]. Understanding pregnant women's lived experiences of

morbidity as well as their psychological needs and concerns is important in itself. In low and middle-income countries (LMIC) settings such as South Africa, women may be exposed to high levels of stress due to numerous contextual factors [25]. Furthermore, as GDM may contribute to potential emotional disequilibrium during pregnancy [26], identifying and addressing the psychological and emotional needs of women with GDM, could also have benefits for sustainable long-term behavioural change following the affected pregnancy.

This study forms part of the formative research for an exploratory intervention trial with low-income women with GDM in South Africa, which aims to reduce their risk of progression to type 2 diabetes by providing continued support and care through the 12-month post-partum period. The purpose of this sub-study was to explore the lived experiences of women with GDM, including their experiences of antenatal and post-partum care and the impact of GDM on their lives, experience of pregnancy and sense of well-being.

6.2. Methods

Study design

This was a descriptive qualitative study [27], using a combination of focus groups and in-depth interviews to explore women's lived experiences of GDM, their context and perceived needs. Focus groups enabled the collection of data on shared experiences and group norms around GDM in the context of a social group while individual in-depth interviews allowed exploration of the personal narratives of women in greater detail. The Consolidated criteria for Reporting Qualitative Research (COREQ) were followed in reporting the findings [28].

Setting

The study site was a large tertiary academic teaching hospital in Cape Town, South Africa, which provides free health services in a context where the majority of the population cannot afford the cost of private health care. The hospital has a specialised antenatal clinic for women with diabetes in pregnancy (i.e.: Type I Diabetes, Type 2 Diabetes and GDM). Pregnant women are referred from various primary health care facilities around the Cape Town metropolitan district to receive antenatal care at this hospital. Antenatal care for women with GDM at this hospital is intensive, highly structured and follows local and international (i.e.; WHO and NICE) policy guidelines [21].

Recruitment and Data collection

Purposive sampling was used to recruit women who had been diagnosed with GDM in their previous pregnancy, according to the WHO 2013 criteria [29]. Women were eligible if they had received antenatal care including delivery at the hospital study site between 2014 and 2015 and were at least one year postpartum. Women with pre-existing diabetes or who had a stillbirth were excluded. Potential participants were identified from the medical records at the antenatal diabetes clinic in the hospital. Eligible participants were then contacted telephonically and invited to participate in the study.

Two female researchers (LSM & KM) with formal training in qualitative research methods conducted the focus groups and individual in-depth interviews in English, in a private venue on the hospital premises, away from the clinic. LSM has experience in public health research among low-income communities in South Africa. KM has extensive experience in qualitative research and has facilitated focus group discussions around sensitive topics. A diabetes nurse

educator and counsellor, who was fluent in the local languages isiXhosa and Afrikaans, was present to assist participants who wanted to express themselves in their home language and to respond to specific questions around GDM management. A topic guide (Supplementary File 1) was used to structure the discussions to ensure that specific topics were covered consistently across focus groups. The discussions aimed to elicit women's experiences of receiving a GDM diagnosis; antenatal care, including referral to the tertiary hospital; lifestyle modification; medication; delivery of the baby and postpartum health, as well as their opinions about how a potential intervention could meet the needs of women with GDM. Women were also encouraged to raise issues of importance to them and discuss these among themselves. This enabled certain topics to emerge which may otherwise not have been covered. Data collection continued until data saturation was reached after nine focus groups and five in-depth interviews, and no new information was emerging from the discussions. The focus groups were digitally recorded and transcribed verbatim.

Data analysis

Data analysis followed an iterative thematic analysis approach [30, 31] summarised in Figure 8 to explore the GDM journey through the lens of these women. Initial coding of the transcripts was done independently by two trained researchers as a measure to reduce the potential for researcher bias and increase rigour. The two researchers (LSM, KM) met regularly during the initial coding process to discuss their developing analysis, define codes and identify and resolve differences until consensus was reached on a common coding framework. This was then applied across the remaining transcripts. Codes were both inductively and deductively derived in that some codes were related to pre-determined concepts drawn from the literature and were present in the interview guide, whereas others

emerged directly from issues raised by women as they spoke about their experiences. Feminist insights around maternal responsibility and mother-blaming (i.e. feeling blamed and maternal self-blame) provided some guidance for interpretation of the findings [32, 33].

Ethics Approval

Ethics approvals for the study were obtained from the University of Cape Town (HREC: 946/2014). All participants were provided with an information sheet and gave written consent to participate. They were informed of their right to withdraw from the study at any time, or to refuse to answer any questions without fear of consequences. The researchers also had the ethical responsibility to refer women to additional support services, where necessary. No names or other identifying information were used in data analysis and dissemination of findings. Participants were informed of the importance of confidentiality and urged to refrain from divulging information shared in the discussions with anyone outside of the focus group.

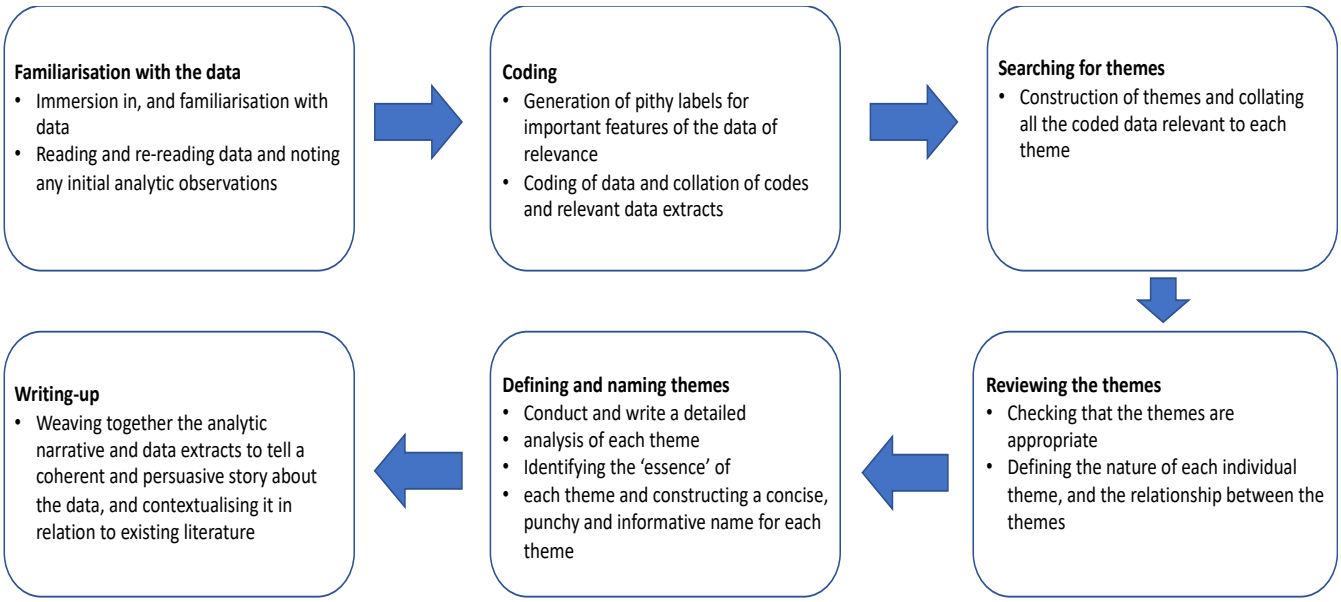

Figure 8: Flow chat of the six phases of thematic analysis. A summary of the six phases of the thematic analysis process as outlined in Braun et al [31].

6.3. Results

The focus group discussions and individual in-depth interviews were completed over 3 months. Recruitment ceased after nine focus groups and five individual in-depth interviews with a total sample of 35 women, as data saturation had been reached. The participants' ages ranged from 25 to 43 years old. Most of the women were married (60%) and unemployed (77%). The participants were of black African and 'coloured' (mixed ancestry) ethnicity and spoke mainly isiXhosa, Afrikaans and English. Our sample also included four foreign nationals who were conversant in English.

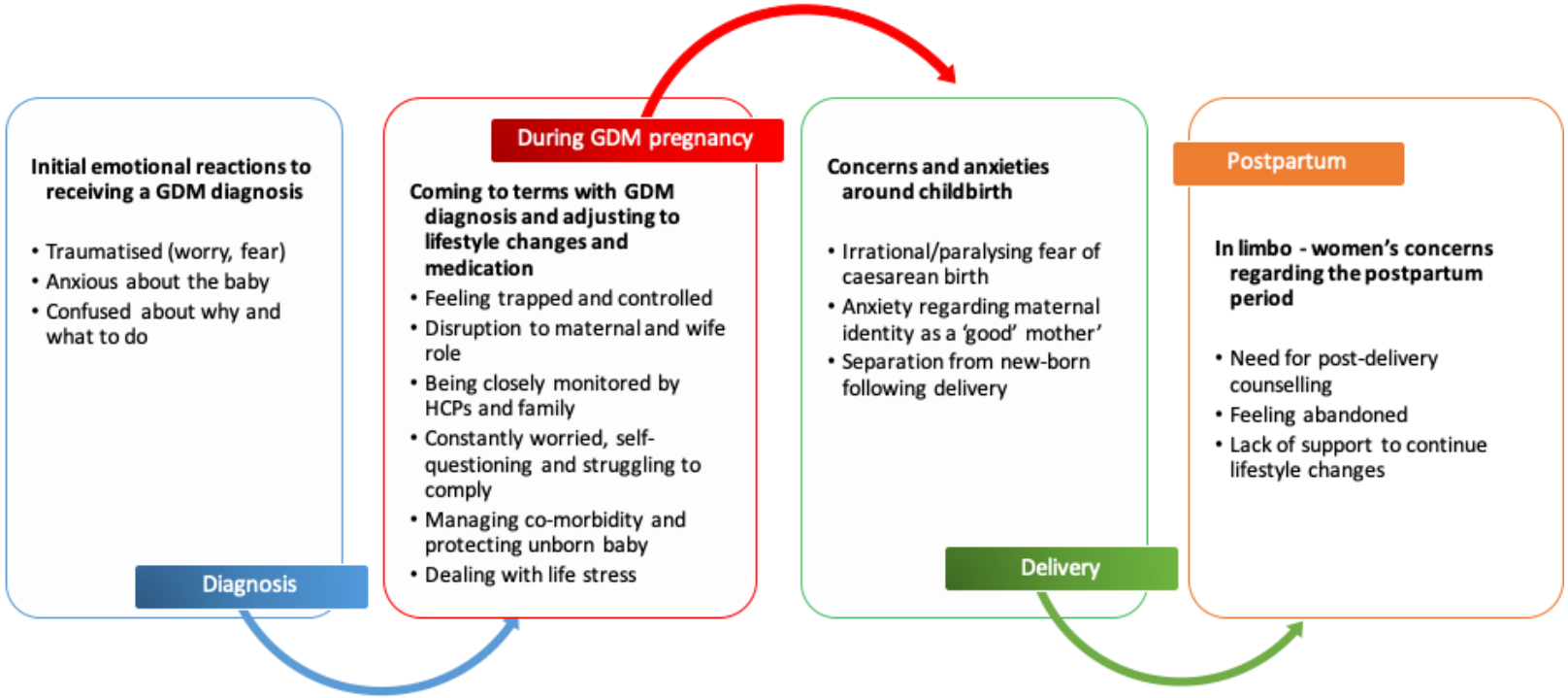

Figure 9: The different emotional burdens associated with the different phases of a GDM pregnancy. An overview of the sub-themes that relate to four different phases in the pregnancy affected by GDM

The interviews explored a range of issues related to GDM and several themes emerging from the data are reported elsewhere [34]. This paper focuses on the emotional and psychological aspects of women's experience of GDM, which emerged as one of the most dominant topics. The findings are discussed under four sub-themes that relate to the four different stages in the pregnancy affected by GDM (see Figure 9): (i) their initial emotional reactions to receiving a GDM diagnosis, (ii) their experience of adjusting to the constraints of living with GDM (iii) their feelings of apprehension about childbirth and their maternal role and (iv) their feelings of abandonment in the postpartum period once the intensive support from both the health system and family ends.

i. "Why me?": Shock and confusion at diagnosis

For virtually every woman interviewed, the diagnosis of GDM came as an unexpected shock. Reflecting back to the diagnosis during their second trimester, women described how at the time, they were unsure of the purpose of the blood tests and confused as to how or why they would have suddenly developed GDM.

> *When I got here for my first visit, they said to me 'You need to go to this floor, and they'll see to you there.' I didn't understand why. I didn't know what was happening. I just took the doctor's instructions and went. They would take my blood, but I was never explained anything. (Focus Group 4, Participant 16)*

> *I was unhappy because I was thinking I can't be diabetic because in my family there's no-one [with diabetes]. I was the first one. I was shocked. I didn't know anything (Focus Group 8, Participant 28)*

One woman explained how she was so shocked to be told that her glucose was high that she refused to accept the diagnosis.

> *They said, 'Your sugar is high'. I said, 'My sugar is high?!!I am not a diabetic, how can you say that my sugar is high?!!' (Focus Group 2, Participant 8)*

Women felt disempowered by their lack of knowledge and this was a cause of much of their anxiety. They voiced their frustration with the lack of information from health care providers and the limited opportunity to discuss their GDM in detail. Some participants felt that health care providers did very little to calm their fears at diagnosis or to address their immediate concerns about it.

> *You're here because you need to undergo all these tests and things. They are just like; 'We'll review your case tomorrow'. They're doing the best they can, but they're not communicating it to you, and that's what's frustrating. (Focus Group 6, Participant 19)*

For some women, learning that there was something 'wrong' with the pregnancy, made them feel that they were failing to meet social expectations in their roles as women and mothers. This appeared particularly acute among women who were pregnant for the first time and more susceptible to feelings of failure:

> *I was thinking what's going to happen. I don't want to lose my baby. It was my first baby, I didn't know I could fall pregnant, so it was like a huge thing for me to just get it right the first time. (Focus Group 3, Participant 11)*

ii. "Feeling like a prisoner": adjusting to the constraints of living with GDM

Most women gradually accepted their GDM diagnosis and began to implement health behaviour changes. However, they highlighted the burden placed on them by having to attend frequent antenatal care visits; the challenges of adhering to the strict, new healthier diet regimen; their fear of the results of the frequent blood glucose tests and the reaction this would elicit from the healthcare providers.

Women who had been hospitalised for close monitoring at some point during their pregnancy felt the loss of autonomy particularly acutely, describing how they felt oppressed by the hospital routine, the boredom, surveillance of the nurses and having to eat the bland 'tasteless' food. One woman analogized her experience of having GDM to being a prisoner, describing that she felt a loss of control over her own life and resented the constant monitoring and overbearing scrutiny by healthcare providers, a sentiment echoed by many other women.

> *I would say I felt like a prisoner. I was never explained anything. I didn't understand, even when I was here in hospital, they would say, 'Come, you shouldn't eat that' that's why I'm saying that I felt like a prisoner, because I didn't know what was happening. No one was speaking to me (Focus Group 4, Participant 16)*

Women who were required to self-administer insulin as part of their management of GDM also felt particularly burdened by the experience.

> *I didn't know how to do the pricking at first, and they assumed that I did. There wasn't room for me to ask questions, it was very quick, fast-paced. I was still in so much emotion; I couldn't even recall how often she said I had to do it. (Focus Group 1, Participant 4)*

A few women reportedly rebelled against this loss of control by 'cheating' and secretly eating whatever they wanted to.

> *I phoned my boyfriend to bring for me what I ask him to bring for me. I was always hiding food. The doctor and the nurse didn't know that I was eating fish and chips and cool drinks[2]. (Focus Group 3, Participant 12)*

Struggling to comply

Adjustment to having GDM was clearly an ongoing intricate process that required self-motivation, as well as social and professional support. All the women in our study reported being highly conscious of how their behaviour could affect their unborn baby, yet many admitted to struggling to balance adherence to healthier diet recommendations while managing comorbidities, maintaining relationships with family and health care providers as well as coping with other life stressors.

Each antenatal visit evoked fear and concern that by not always adhering to behaviour change recommendations, particularly regarding their diet, they may have caused harm to their unborn baby. One woman with a history of miscarriage described the fear she felt every time she was referred for an ultrasound that the doctor would find something wrong with the baby;

> *I was going for ultrasound every time. For me it was like, just now they could tell me something negative, as was my experience with my previous baby where they told me*

[2] A term used to describe sweetened carbonated beverages

something was wrong with baby. And now I was scared that I was going to hear something like that again. (Focus Group 5, Participant 17)

Managing co-morbidity

A few women in the study had pre-existing medical conditions such as hypertension and HIV, in addition to the GDM, which compounded their fears regarding their health and that of the baby. They also described the pressure they felt having to take a combination of medications, in addition to changing their health behaviour;

I was just worried because I had high blood pressure with the diabetes, I was just worried like, is there going to be enough space for the baby to grow? Do I need to keep the sugar down, what am I going to do? How do I do it? It felt like a constant battle. (Focus Group 6, Participant 20)

Disruption to maternal and wife role

Being hospitalised and away from home disrupted families' routines, as well as women's maternal role and personal identity as the family's caregiver. Even with sufficient social support from spouses and family members to assist with childcare at home, women were still often stressed and worried about the wellbeing of their children and expressed a sense of guilt for burdening their spouses with additional responsibilities.

Now I think of the time when I was in hospital, the children were alone at home and my husband had to look for something for them to eat. Who was going to cook for them? (Focus Group 2, Participant 8)

Dealing with other life stressors

One woman, an immigrant from the Democratic Republic of Congo, described the stress of having to renew her documents at the immigration offices while she was hospitalised for poorly controlled GDM:

> *I had to go to Home Affairs to renew my papers. I was already booked in the hospital because my sugar was high. The doctor wrote a letter to give to people at Home Affairs, because sometimes you can go, and they're don't see you. There are a lot of people and you can be there until late. (Focus Group 2, Participant 8)*

Relationship with healthcare providers

Whilst several women reported positive experiences of being supported and encouraged by health care providers, a few women described how the nurses scolded and chastised them if their glucose was high. They believed that nurses had little sympathy for their difficulties in complying with the prescribed diet and resented being shamed for not meeting glucose targets and being treated like irresponsible children. Women also felt that nurses blamed them for having GDM because they were overweight:

> *They make you feel like your body is failing. They say, 'listen, you ate wrong and it's because of you and, and it's your fault if something happens to your baby.' They need to educate the people, like, 'listen, it's a sickness, anybody can get it, but you can manage it' (Focus Group 1, Participants 2)*

iii. Apprehension about birth and maternal role

Several women, particularly women in their first pregnancy, expressed a strong desire to have a "natural" birth and were frustrated and disappointed upon learning that they would deliver by caesarean section.

I was in denial about having the caesarean, I was really fixed on having natural birth. It was my first child. I wanted the experience. (Focus Group 1, Participant 4)

Others were afraid to undergo major surgery and initially protested when requested to consent to a caesarean birth;

One of them [doctors] said 'This is a big baby; you must deliver by C-section'. I have never had a Caesar in my life. I was shocked. I said' I can't sign this paper' to say that they must take out the baby via Caesar. No! (Focus Group 2, Participant 8)

Women also found the common practice of being separated from their babies immediately after the birth very stressful. Apparently, this was a necessary process in order to the baby to undergo blood glucose tests. However, women reported that this was not adequately explained to them, which left them feeling worried about what was happening to their baby and upset about being deprived of the opportunity to establish a bond with their new-born.

The nurses went with the baby the whole day. I just saw the baby, and they took the baby to check the baby, maybe she also has sugar. So, you are not with the baby, the baby is in another place, do you know how that feels [gestures]? I started to stress; now where is my baby? (Focus Group 2, Participant 8)

iv. Feeling abandoned: The lack of post-partum follow-up and support

Following their discharge from hospital, the majority of women reported feeling a sense of great relief that they no longer had to worry about harming their baby, attend the hospital or follow the 'diabetic diet' and they looked forward to settling back into their "old lives". Some

women described how they felt a sense of abandonment when care abruptly ceased after delivery and there was no follow up contact.

> *I had to figure it all out on my own afterwards, because there was no counselling or no doctor's appointment that I could go to. I had to find my own way, basically…I lost all faith in public hospitals because of my experience and I was just discharged with no return letter to come for a check-up, or anything like that. (Interview 1, Participant 5)*

This state of being "in limbo" as a result of not having support from the health system once they were discharged from hospital was worsened by the diminished social support from partners and family members postpartum. One woman explained that while she made the financial sacrifices during pregnancy to eat healthy food, she could not afford to incur the extra expense postpartum:

> *I know what I'm supposed to eat, but there are times I don't have the food that I'm supposed to eat, then I have to eat whatever because I'm hungry; but I know what is good for me, but there are times I don't have food. During pregnancy, I tried. I was motivated because I was scared for my unborn child, so I had to sacrifice for her. I didn't want complications (Focus Group 7, Participant 22)*

In the aftermath of the GDM pregnancy, only a few women felt empowered to continue with the lifestyle changes made during pregnancy.

> *During pregnancy your focus is your baby, because you want everything to be okay with baby. So, after baby is born, you take more time also into your own life again, and then you realise, okay, I have to focus on me now. If there's someone also counselling*

you, and telling you look, this is what you need to do, that would be even better. (Interview 1, Participant 5)

In a few cases, women felt that the experience of a GDM pregnancy had been a 'wake-up call' for them to adopt long-term lifestyle changes to prevent having GDM in subsequent pregnancies and avoid type 2 diabetes. They described having a renewed commitment to taking care of their health and concluded that the experience of GDM helped had helped to equip them to do this.

I'm really more health wise, looking after myself, because it's actually very important; because like I tell everybody, I do want another baby. That's why I'm looking after myself (Focus Group 2, Participant 6)

It is worth noting that several participants mistakenly interpreted their invitation to attend the focus group at the hospital as a form of follow up and an expression of care for their well-being, which they regarded in a very positive light. There was broad consensus that participation in the group discussion was both therapeutic and informative. Table 1 provides a summary of the results from the thematic analysis of women's emotional and psychological experiences associated with a GDM pregnancy.

6.4. Discussion

Our findings highlight the psychological distress experienced by women with GDM at different stages of the pregnancy. The GDM diagnosis triggered anxiety and stress for most women, echoing findings among women with GDM from high-income countries such as Australia, Canada and the United Kingdom[9, 15, 18, 19] and few LMIC countries such as Vietnam and

China [13, 35]. However, there is a lack of studies on GDM and mental health from LMIC such as South Africa where maternal mental health remains a neglected area despite high prevalence of maternal depression and anxiety [25, 36]. Other reactions to the diagnosis of GDM by our participants such as denial or skepticism and a resistance to initiate the recommended lifestyle changes were as a result of women feeling ill-informed and disempowered about GDM. Lack of adequate information has also been highlighted as a major source of confusion, frustration and helplessness for women with GDM in other studies [13, 37, 38].

On a positive note, the majority of women in our study were able to overcome the initial shock and anxiety following the GDM diagnosis and gradually made the necessary adjustment to living with GDM. Their perceived anxiety did not increase as the pregnancy progressed suggesting that it could be reactive anxiety triggered by the unexpected diagnosis of GDM as opposed to intrinsic anxiety [18]. These findings are consistent with most of the literature which suggests that women are psychologically most vulnerable around the time of diagnosis [15, 22, 37]. However, our research also showed that the focus of women's anxiety shifted as the pregnancy progressed to issues around compliance and the impending birth. Similarly, maternal distress relating to potential harm to the baby and obstetric complications continued up 37 weeks in more than half of a Canadian study population [19]. Understanding women's emotional response to the GDM diagnosis is therefore important for designing appropriate interventions and improving their care during the remainder of their pregnancy [20].

A lack of capacity to adhere to recommendations and effectively control their glucose levels also contributed to heightened maternal distress in our study population. As we have reported previously [34], women experience several barriers to implementing lifestyle changes related to socio-economic status including food insecurity and inadequate social support. Psychosocial deprivation associated with low socio-economic status, affects women's capacity for self- management and has been linked to poor prognosis among women with GDM in the UK and France [39, 40]. A US study among low-income mothers found that women who had diabetes in pregnancy (known diabetes and GDM) had nearly twice the risk of being diagnosed with depression during pregnancy or in the first year postpartum [41]. In our study, insulin administration, managing comorbidities and coping with other life stressors in addition to GDM were common sources of maternal distress associated with GDM, which have also been cited in other studies [37, 38, 42]. Having GDM was particularly burdensome for primigravidae women who felt 'robbed' of the joy of pregnancy. Interestingly, women with GDM in an Italian study reportedly experienced a better quality of life, compared to pregnant women without GDM [7] as a result of the improved health behaviours. Considering that among low-income women in South Africa, the experience of at least one stressful event can impact on maternal mental health [25], risk surveillance for mental health disorders, close monitoring and tailored programmes to reduce perceived emotional distress may have benefits for the overall well-being of women with GDM [10, 11, 16, 19].

An important finding in this study was the additional stress women felt having to manage the expectations of health care providers, partners, and family members. With a GDM pregnancy, maternal behaviour is heavily scrutinised, and women feel a sense of losing control over their

bodies. There is an expectation of women diagnosed with GDM to make considerable adjustments to their health behaviour with little recognition of or sensitivity from the medical and social environment to the multiple barriers they face in changing these behaviours. For low-income women like those represented in our sample, the nature of the physical and social environment, availability and access to healthy affordable food and the extent of social support from partners and family all profoundly influence women's capacity for lifestyle change and adherence to clinical recommendations [10, 22, 32, 33, 43]. Yet, women in our study and others report feeling that they are held primarily accountable for the health of their unborn child and that any pregnancy complications or adverse outcomes are perceived both by themselves and others as reproductive or maternal failure [22, 33, 44]. In South African society, as in many others, women's identity is rooted in pregnancy and motherhood [45]. Self- blame is therefore common in women who experience a complicated pregnancy. This contributes significantly to heightened anxiety and an overwhelming sense of guilt, especially when maternal behaviour such as diet or smoking is implicated in the problem - a phenomenon described in feminist literature as mother- blaming [33].

Women in other studies have also reported feeling unsupported and isolated as a result of health care providers' shaming and blaming attitudes [35, 37]. However, our study also shows that positive patient-provider relationships can create a platform for women with GDM to openly discuss their fears and concerns regarding their health with their health care providers. There is a need to re-frame messaging around developmental origins of health and disease to emphasise the role societal factors and not focus solely on the mothers [32]. Educating and engaging with partners and family members of women with GDM could afford

them a clearer understanding of women's needs and enable them to provide the woman with GDM with appropriate social support [38].

Women with GDM are more likely to deliver by caesarean section compared to women without GDM [11]. The fear of delivery by caesarean section described by women in our study is consistent with the literature and has been reported as a major cause of anxiety during pregnancy among women in some high- and low-income countries [19, 46]. As reported in a recent systematic review, the increased risk of antepartum depression among women with GDM could partially be attributed to fear of obstetric complications and adverse outcomes for their health and that of their unborn baby [47]. The desire to experience a 'normal' vaginal birth and the perception of delivery by caesarean section as an indication of reproductive failure have also been cited as reasons for caesarean section refusal among women in Nigeria [46]. These fears and misconceptions could be addressed with proper counselling by health care providers to allay women's fears.

The majority of our participants reported that they neither attended follow-up for diabetes screening nor sustained lifestyle change in the postpartum period. Pregnancy is an opportune time to promote long-term lifestyle changes to mitigate the risk of GDM in future pregnancies and the subsequent risk of developing type 2 diabetes [37]. Yet, based on their experiences during the GDM pregnancy, the postpartum period signified relief and freedom to resume unhealthy behaviours. According to a recent systematic review, women's postpartum behavior is influenced by their perception of risk for diabetes as well as other factors such as affordability and fragmented health systems [48]. The low perception of future risk for type 2 diabetes evident in our study could be attributed to the highly foetal-centric approach to

managing GDM in our context. Behaviour change recommendations are framed around foetal health and focused on blood glucose monitoring to prevent adverse pregnancy outcomes. As a result, without continued psychosocial support from health services and family in the postpartum period, women feel abandoned and *in limbo*, which hinders their ability to maintain health behaviour changes. Finnish and American studies have found a significant association between GDM and postnatal depression using the validated Edinburgh Postnatal Depression Scale [11, 49]. Only one woman in our study reported having postnatal depression following the GDM pregnancy and similar studies from LMIC are still lacking. Postnatal depression may interfere with women's capability and motivation to engage in health behaviour changes [34], further affirming the importance of postnatal follow up, screening and counselling for women with GDM [37, 49].

6.5. Strengths and Limitations

Our findings add to the much-needed body of literature on maternal mental health in resource constrained settings facing complex burdens of disease such as South Africa and provide a basis for future studies. To the best of our knowledge, this is the first study in Africa to explore the impact of GDM on women's experience of pregnancy and sense of well-being. Assessment of maternal distress (including anxiety and stress) was based on women's self-reported experiences rather than a validated screening tool, given that this study aimed to gain an in-depth understanding of women's lived experiences and the psychological impact of GDM on their lives. Future research should assess extent of maternal distress among women diagnosed with GDM using validated instruments such as the Edinburgh Postnatal Depression Scale. Generalizability of the findings to all women with GDM is limited due to the qualitative study design. Women's perspectives may have been influenced by recall bias as

they were at least one year postpartum at recruitment. However, the time elapsed between the pregnancy and inclusion in the study may have been sufficient for women to reflect on their experiences. Lastly, our participants were identified from women with GDM who had attended antenatal care at one of two large tertiary referral hospitals in the province. Based on the diversity of the sample, our participants are somewhat demographically representative of women who utilize these health services.

6.6. Conclusions

South Africa has made steady progress over the last decade to improve maternal health services and reduce maternal mortality through public health programmes and initiatives (e.g.; Prevention of Mother to Child Transmissions (PMTCT)). Yet attention to psychological distress and the provision of maternal mental health services for women with complicated pregnancies such as GDM remains a neglected area. The current biomedical model used in the management of GDM, is highly foetal-centric and fails to acknowledge important psychological factors that contribute to women's overall wellbeing and experience of pregnancy [21, 50]. Our findings echo prevalent views around the 'burden' of maternal responsibility and the culture of mother-blaming. Acknowledgement of other contributing factors such as the prevailing physical and social environment [34] is a crucial step towards shared accountability and provision of appropriate support for women with GDM. The study findings have several implications for the management of GDM in South Africa. Health policy makers and health care providers should recognize the impact of a GDM- disrupted pregnancy [51] on women's mental health, emotional wellbeing and quality of life and how the added psychological stress may affect adherence with treatment and recommended lifestyle changes [18]. Based on these findings, we recommend routine mental health and

psychosocial vulnerability screening and monitoring for women diagnosed with GDM throughout pregnancy and postpartum [9, 41] to improve prognoses. Furthermore, these results demonstrate the importance of incorporating mental health support in health policies and clinical practice for the management and care for women with GDM in public health services, along with facilitating emotional support from partners and family members.

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CHAPTER 7

Study 4: Women's perceptions and experiences of GDM health services in Cape Town, South Africa: A qualitative study

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Authors:

Lorrein Shamiso Muhwava BSc (Hons) MPH[1,2]*, Katherine Murphy B.A, PG Dipl., Ph.D[1,2], Christina Zarowsky M.D., M.P.H., Ph.D[2,3,4], Naomi Levitt M.B.Ch., M.D., F.C.P [1,2]

[1]Department of Medicine, Faculty of Health Sciences, University of Cape Town, Cape Town, South Africa

[2]Chronic Diseases Initiative for Africa, Cape Town, South Africa

[3]Département de médecine sociale et préventive, École de Santé Publique, Université de Montréal, Montréal, Canada

[4]Centre de recherche en santé publique (CReSP), Université de Montréal et CIUSSS du Centre-Sud-de-l'Île-de-Montréal, Montréal, Canada

Contributions of the candidate:

Lorrein Shamiso Muhwava conceptualised this sub-study and developed the protocol for the study. She developed the data collection instruments, collected the data and conducted data analysis with guidance from A/Professor Katherine Murphy (main supervisor). Lorrein Muhwava wrote the first draft of the manuscript. The supervisors; A/Professor Katherine

Murphy, Professor Christina Zarowsky and Professor Naomi Levitt provided critical input in reviewing drafts of the manuscript. All authors read and approved the final manuscript for publication.

Abstract

Despite high rates of gestational diabetes (GDM) in South Africa, women's experiences of GDM care in this setting remain understudied. Insights from women's experiences of the healthcare system for GDM care are important for informing health policy and intervention to improve the quality of care. We conducted 9 focus groups and 5 in-depth interviews to understand women's perspectives of and satisfaction with GDM care in the public health sector. Participants were women diagnosed with GDM in their previous pregnancy. Data analysis followed a thematic analysis approach and was informed by Donabedian's quality of care framework. Key sub-themes relating to the structure of care were; the organisation of GDM health services, efficiency of the referral, efficiency of management practices, quality of hospital facilities and services and the availability of adequate healthcare resources. We identified technical and interpersonal 'processes' linked to quality of GDM care. Overall satisfaction with GDM care processes was qualified by women's unmet need for appropriate and adequate education and behaviour change counselling, the extent to which they received interpersonal support from health care providers (HCPs) and peers as well as the health services' capacity to enable women to actively participate in the care process. This qualitative study provides insights into women's perceptions of the quality of care they received during their GDM – affected pregnancy and highlights important areas of unmet need within the health system. Health services should incorporate patient-centred approaches in the management of GDM to improve women's overall experiences of care. Health policies that directly support continuity of care are urgently needed to prevent type 2 diabetes in this population.

7.1. Background

The increasing prevalence of gestational diabetes mellitus (GDM) is a public health concern globally. The International Diabetes Federation estimates that GDM accounts for 86.4% of all hyperglycaemia in pregnancy [1]. In South Africa, the high prevalence of GDM estimated to be up to 25.8%, is driven by the high rates of obesity [2, 3]. Untreated GDM is associated with foetal macrosomia and shoulder dystocia and women with a history of GDM remain at high risk of developing GDM in subsequent pregnancies and a seven-fold increased risk for type 2 diabetes post-pregnancy [4, 5]. Prioritising GDM as a public health issue is therefore critical for improving maternal and child health outcomes and NCD prevention efforts [6].

Health systems have an important role in responding to the emerging GDM epidemic through comprehensive maternal health care services [7]. Early detection and referral are essential for identifying women at high risk for GDM and linking them to healthcare services where they can receive timely and appropriate intervention [7-10]. Moreover, continuity of care is crucial for women with prior GDM to access postpartum diabetes screening, support for sustained lifestyle modification, breastfeeding, contraception as well as preventive care [11]. Despite the evidence, advocacy for policy action to improve health services for women with GDM is currently lacking [6]. Furthermore, continuity of care remains a major challenge [5] due to a lack in research ([6] and effective health systems interventions to specifically target risk factors for type 2 diabetes in the postpartum period [9, 11, 12].

Despite high rates of GDM in South Africa, women's experiences of GDM care in this setting remain understudied. Insights from women's experiences of GDM health services are important for understanding factors that influence adherence behaviours and identifying

opportunities to improve the quality of care [13-15]. The Donabedian quality of care model [15] provides a conceptual framework from which inferences on the quality of care can be drawn. This model has been widely used to assess quality of health care globally and applied in assessing quality of integrated chronic disease management in South Africa [16].

The IINDIAGO project - an acronym for Integrated Intervention for DIAbetes risk after GestatiOnal diabetes, is an ongoing implementation research project that aims to develop and evaluate an integrated health system intervention to reduce the risk of type 2 diabetes among women with GDM in South Africa. The aim of the present study, which is a component of the IINDIAGO project, was to explore women's perceptions and experiences of utilising health services for the treatment and management of GDM in Cape Town, South Africa, in order to inform the development of an appropriate integrated health system intervention for women with GDM.

7.2. Methods

Study setting

Primary healthcare clinics (e.g.; Midwife Obstetric Units within community health centres and private antenatal care clinics), day hospitals as well as district and regional hospitals within the Cape Town metropolitan area refer pregnant women diagnosed with GDM to tertiary level hospitals for antenatal care. The study site was one of the large academic tertiary hospitals that offers a range of health services including management of complicated pregnancies and delivery. The hospital has a dedicated antenatal diabetes service and specialist medical teams of obstetricians, endocrinologists and nursing staff trained in

diabetes care. The majority of patients utilising these public health services are from low-socioeconomic communities and services are free.

Study design and participant selection

This was a descriptive and analytic qualitative study using focus groups and in-depth interviews to understand women's perspectives of and satisfaction with GDM care in the public health sector as well as their views on the feasibility and acceptability of the proposed intervention. The findings are reported in accordance with the COREQ guidelines for qualitative research [17]. Participants were women diagnosed with GDM (according to WHO 2013 criteria) [18] in their previous pregnancy who received antenatal care at the study site. In addition, the women had to have delivered a singleton baby and not required diabetic medication at discharge.

Data Collection

Participants were purposively sampled from hospital folders to identify women from specific geographic areas targeted for the IINDIAGO project. Participants were recruited by telephone and invited to take part in a focus group discussion. In the event that less than three participants showed up for a scheduled focus group discission, we conducted in-depth interviews. The topics for discussion were informed by the literature as well as the results of key informant interviews conducted as part of the formative research for the larger IINDIAGO project. A discussion guide (Supplementary File 1) was developed and refined through consultations with the wider project team. The discussion guide was semi-structured and included some probing questions to facilitate discussion. Two female researchers trained in qualitative research methods, facilitated the discussions, while an experienced multilingual

diabetes nurse educator was present as a co-facilitator. The focus groups and in-depth interviews were conducted in English although a few participants preferred to express themselves in their native language (i.e. isiXhosa or Afrikaans). Their responses were translated into English for the benefit of the wider group. All focus groups and in-depth interviews were digitally recorded with consent from the participants and professionally transcribed verbatim. Data collection ceased when data saturation was achieved after completion of nine focus groups and five in-depth interviews, and no new issues were identified. Data were de-identified prior to analysis to protect participants' anonymity.

Ethics Approval

Ethics approvals for the study was granted by the authors institute. Oral and written consent were obtained from all participants and confidentiality of their data was assured. Participants were informed about the purpose of the study and their right to withdraw from the study at any point without consequences.

Data Analysis

Data analyses followed thematic analysis procedures [19]. Firstly, all transcripts were read for familiarisation and to understand the content of the data. Transcripts were then re-read in detail, highlighting text segments and identifying abstract codes that related to the broad research questions. To reduce potential of researcher bias and increase trustworthiness of the analysis, two researchers conducted data analysis independently and met regularly to resolve any variations or discrepancies in their findings. The researchers agreed on a final coding framework for the analyses. The coding process was iterative; involving discussions and revisiting the data to reach a consensus. Finally, the codes were organized into broad

categories according to the three elements of the Donabedian quality of care model; namely Structure (relating to material and human resources as well as organisational structure) , Process (relating to both patient and provider activities in receiving and providing health care respectively) and Outcome (relating to the effects of care on health status and patients' satisfaction with care) [15].

7.3. Results

A total of thirty-five women participated in nine focus groups and five in-depth interviews. Participants were predominantly black African and 'coloured' (mixed ancestry) women between the ages of 25 – 43 years old residing in low-income peri-urban townships.

Figure 10 provides a summary of the sub-themes emerging from the data analysis and illustrates the relationship between the constructs of the Donabedian quality of care framework i.e. *Structure*, *Process* and *Outcome*. In addition, the findings highlight perceived health system facilitators, barriers in the provision of health services for women with GDM. Women highlighted their need for specialised clinical care, adequate education and counselling, sufficient health care resources (e.g., trained and competent HCPs), opportunities to engage with HCPs about GDM and their care and improved postpartum health services. The mediating factors considered by women in their assessment of quality of care are presented in Table 6.

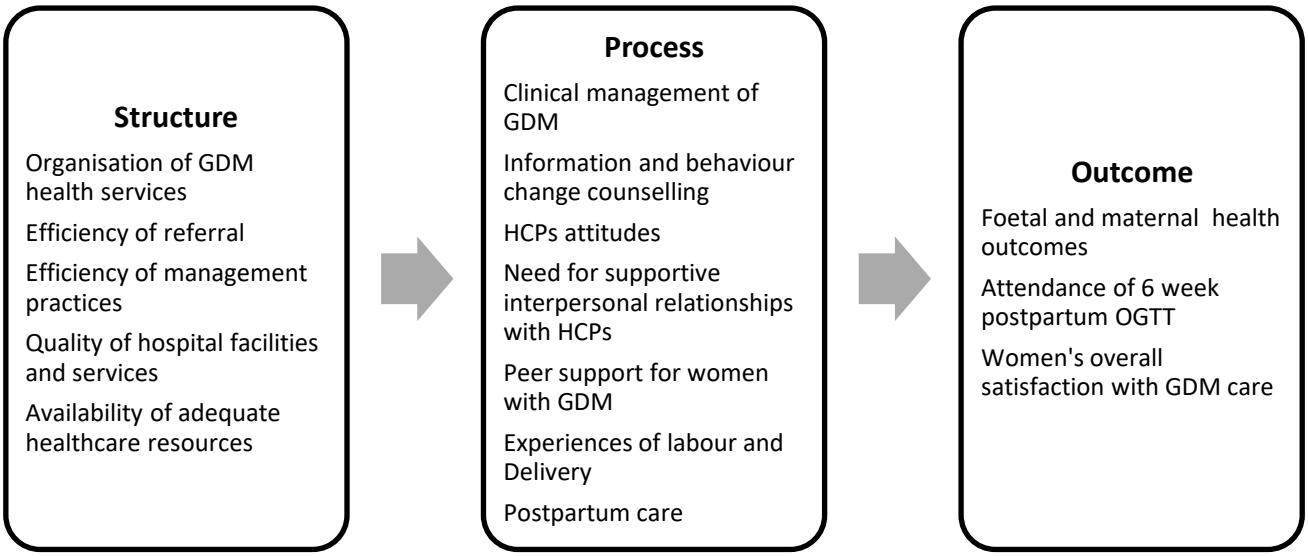

Figure 10: Sub-themes relating to quality of GDM care according to the domains of the Donabedian Quality of Care framework, which suggests that good structure ideally leads to good processes, which in turn result in good outcomes

i. Structure

Key sub-themes relating to structure of care were the organisation of GDM health services, efficiency of the referral, efficiency of management practices, quality of hospital facilities and services and the availability of adequate healthcare resources (i.e. health personnel).

1.1 Organization of GDM health services

In general, women demonstrated understanding of the organization of GDM health services and the referral systems. They were aware that women with complicated or high-risk pregnancies would be referred from the antenatal clinic to receive specialized antenatal care at the tertiary hospital. However, most participants reported uneven access to GDM health services and that this was attributed by participants to miscommunication between HCPs regarding proper referral protocols or other organisational structure-related factors.

> *First, I went to the clinic to book my pregnancy, and they sent me to the day hospital. From there, they sent me to the regional hospital, then they said I must come for GTT test. When I went back for the results, they told me; Your sugar is very out. You have to go to the tertiary hospital, then I came here. (Focus Group 8, Participant 28)*

1.2 Efficiency of referral

Most women had been diagnosed with GDM in the second trimester of the pregnancy, following risk-factor based screening. There were mixed views regarding referral systems for women with GDM. Some women reported being promptly and efficiently referred to the tertiary hospital for further treatment and management;

> *It was the start of my third trimester. I did tests and they picked up the gestational diabetes and called me in for another test, just to be sure. My baby also had a big growth spurt, and for those two reasons, they made the call to transfer me to the tertiary hospital (Focus Group 1, Participant 4)*

Some women were immediately referred on diagnosis of an underlying health condition such as hypertension, asthma or HIV subsequently diagnosed with GDM at the tertiary hospital.

I booked at the day hospital. With my second or third appointment, they found out that my blood pressure was high, so they sent me to the tertiary hospital. I had a previous stillborn with my third child and so I was high risk. (Focus Group 8, Participant 29)

For others the referral process was less efficient (see Figure 11). Two women described how they had been sent from pillar to post before being booked into the GDM clinic at the tertiary hospital.

I went to book at the antenatal clinic. They transferred me to the district hospital but there they said their beds are very small, and I'm big, so they transferred me to the tertiary hospital. [Translated from isiXhosa] - Focus Group 6, Participant 21)

My husband called the hospital to make an appointment for my first booking and they told him that I can't book here, I must go to any other hospital to book. I then went to go book at the district hospital. The doctor looked at my file and told me; You don't belong here because of your previous incident [i.e. miscarriage], you must go back to the tertiary hospital. (Focus Group 2, Participant 6)

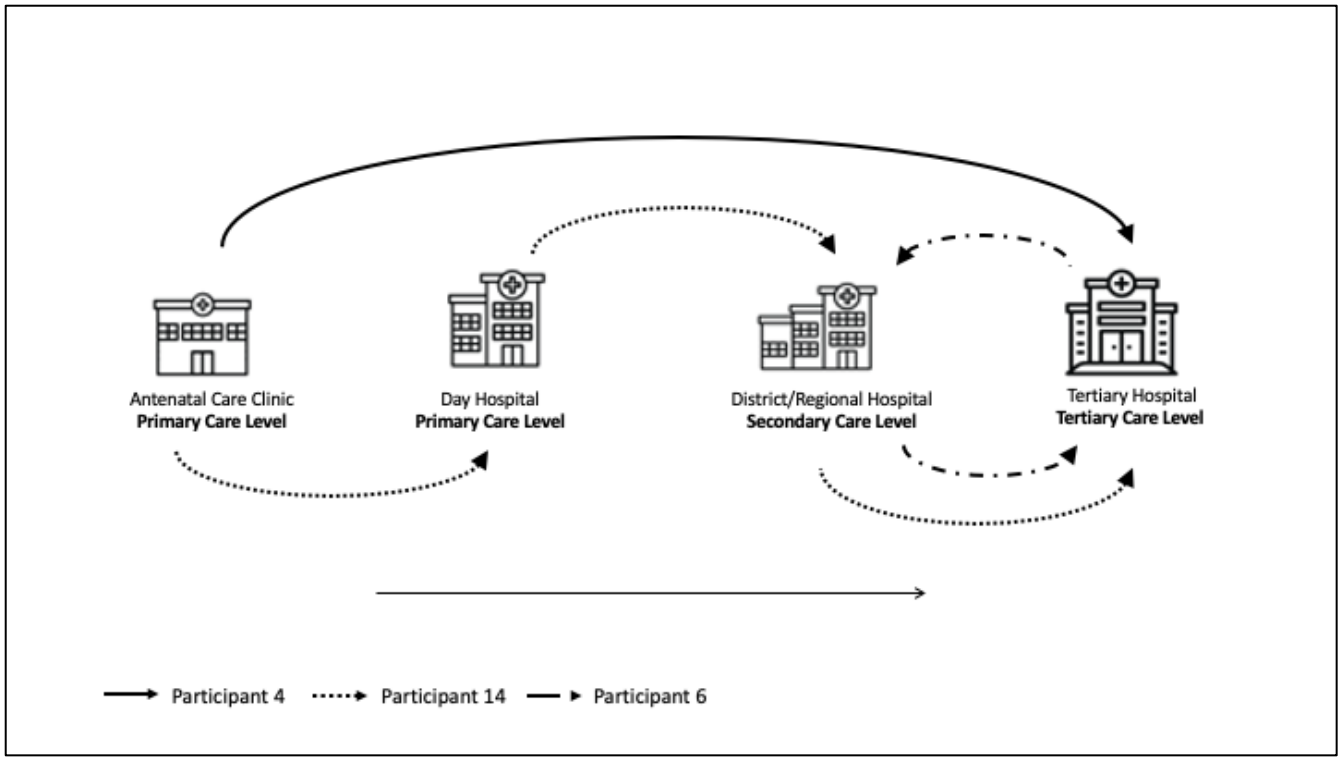

Figure 11: A representation of women's journey through the GDM referral pathway and across different levels of care during pregnancy up to delivery, but not extending to postnatal care

1.3 Efficiency of management practices

Participants noted that some antenatal clinics were poorly managed by the nurses, and the administrative decisions implemented at the clinic affected women's experiences of care. For example, one participant, frustrated with the long waiting times during antenatal visits, had managed to convince the nurses that she met the criteria to be transferred to the tertiary hospital for antenatal care, where she was subsequently diagnosed with GDM;

I got quite fed up with the staff because my appointment was on a Monday morning and they always had a meeting and so we had to wait. They told us be there at half past six, and then only around about ten o'clock they would start helping us. I decided

I'm telling these people that I have a heart condition, because I do. They said to me, then you shouldn't be here, you should be at the tertiary hospital; and they phoned the hospital. I gave them my folder immediately I was so relieved. (Focus Group 4, Participant 16)

1.4 Quality of hospital facilities and services

A few women expressed disappointment with the lack of cleanliness of the maternity ward facilities at the tertiary hospital. At least three participants reported that the bathrooms in particular were poorly maintained;

The bathrooms need a definite upgrade, because the showers have been there, probably when the first doctors were here! They are broken and dirty and the dirt can't come off. (Focus Group 6, Participant 19)

According to our participants, the special 'diabetic' meals served to patients with GDM in the hospital ward were generally unpalatable and at times even unhealthy, contradicting the recommendations by HCPs.

Sometimes the food that they gave you had a lot of oil, like that mince, it was full of oil. Then they come and test your sugar and then they skel [scold] you, but you only eat the hospital food (Focus Group 6, Participant 19)

1.5 Availability of adequate health care resources

The majority of women shared the general view that there was a shortage of trained health personnel to provide women with appropriate counselling and education on GDM. Several women reported that the nurses at primary care clinics had not explained the GDM diagnosis

or the reasons for referral to them. They had simply provided them with a referral letter and instructions to go to the tertiary hospital;

> *It's like you're not sitting with someone and they're explaining to you what's happening; This is the reason you're going there [tertiary hospital]. You're just told, here's a letter, you need to go there, and it's because of your sugar. (Focus Group 4, Participant 14)*

Women also expressed their frustration with the lack of guidance or assistance to navigate the different points of care upon arriving at the tertiary hospital, as well as the vague information from HCPs regarding the testing processes.

> *When I got here, I didn't know where to go, the security told me, You must sit in that room. You would go sit there, then you will go wee, measure your weight and after that you will see the doctor then you go home. (Focus Group 4, Participant 14)*

Some participants felt that the quality of the care they received had been compromised due to high patient numbers and a shortage of nursing staff;

> *I feel they're overbooking at the diabetes clinic, because there are so many people and they don't have that one on one. By number 22, they're now tired, then it comes up that you ate wrong; then that frustration is building up. Maybe there isn't an extra person that's coming in, or they're short of staff, and now the patients are getting it. (Focus Group 1, Participant 2)*

ii. Process

The technical aspects of GDM care (e.g. screening, and testing for GDM, glucose monitoring, clinical examinations) were perceived to be of a high standard. However, women's overall satisfaction with GDM care processes was affected by their unmet need for education and behaviour change counselling; interpersonal support from HCPs and peers; and the health services' capacity to enable them to actively participate in the care process.

2.1 Appreciation for the high standard of clinical management of GDM

At the tertiary hospital, the GDM diagnosis was confirmed by conducting an Oral Glucose Tolerance Test (OGTT) prior to initiating treatment. The majority of participants had spent at least one night in hospital for observation and monitoring, while awaiting test results. They commended the high quality of medical care they received at the tertiary hospital and contrasted it to their previous experiences of antenatal care at other hospitals. Several women highlighted how the HCPs; particularly the doctors whom they perceived as highly competent, had treated them with dignity and made them feel valued.

> *The doctors are very good and give you the right advice. I even liked it when we had to go for all the ultrasounds because you felt important. Even though it's a government hospital, the service that I got was perfect. (Focus Group 3, Participant 11)*

In contrast, women who had not been hospitalized during their pregnancy felt that despite HCPs' technical competence, they had failed to engage with women during consultations and involve them as active participants in their care.

You come in, you wait your chance, you give your name in your file and then eventually you go do your urines. From there, you will sit and wait all day until they call your name. They don't have, like, how we are having a discussion here now. (Focus Group 5, Participant 17)

2.2 Information and behaviour change counselling – an unmet need

The majority of participants emphasized that the information they received on GDM and behaviour change was insufficient. The women in our study who had either never been hospitalized or had only been admitted for overnight observation, had not attended a dietary counselling session during their GDM pregnancy. The few women who did encounter the dietician recalled being advised on dietary modification and receiving educational material in the form of a very basic diet sheet;

When you're in the ward, they'll normally have a certain day that they'll have people coming [dieticians]. They'll come, and explain everything to you, the different types of foods and give you the pamphlets you can take home. (Focus Group 3, Participant 11)

The experience of the majority of women in our study was that the HCPs lacked sufficient time and patience to communicate with them and instead rushed through consultations using technical language that they could not understand.

They should give people more information. That's the worst thing, they don't have time. They don't have patience for us. It's like, when you ask, they're always in a hurry (Focus Group 9, Participant 35)

If there's one thing, I would ask them to change their way of communicating. Speak to the layman. Speak to the person that doesn't understand. Come down. We know that you work very hard, respect goes to the doctors, but take one second and let us know that it's okay. (Focus Group 6, Participant 20)

Only a few participants could recall having a doctor explain the GDM diagnosis to them, although they too reported that the information provided to them was incomplete;

This one doctor sat me down, and said, Because you have gestational diabetes, you have to change your diet, your whole way of life now, otherwise it can carry on after pregnancy if we don't treat it now, and it's harmful to baby as well. But then he didn't go into detail. I had to make up my own conclusion later on. (Interview 1, Participant 5)

An interesting observation was that women who had reportedly been assertive towards HCPs, demanding more information and better care, reportedly felt more knowledgeable and empowered during the GDM pregnancy. These participants were also generally more vocal and confident in expressing their views during the focus group discussions.

I think sometimes if we shy away and don't ask about the illness that we have, you don't really get some information. I told myself, it's the first pregnancy with gestational diabetes, I'm going to try to get as much information as I can. (Focus Group 9, Participant 35)

2.3 Reliance on peer support

The experiences described by women in our study emphasize the importance of peer support for women with GDM, in addition to clinical care. Women reported having to rely on each other for the support they needed and there was unanimous agreement across the focus groups that an organized peer support group for GDM with a facilitator would be helpful;

> *There was no other specific support for us . So, we would just chat to each other and kind of, counsel and support each other, but there can be better intervention of one on one counselling when you're at the hospital, and group counselling as well, to support and inform you; like now, we're hearing different stories from each other. That's very useful for us. (Focus Group 1, Participant 4)*

> *My biggest thing being here was it's so lonely, and that's because we don't know what is going on. We all stand in a corner and try to figure out; so, what is your story? At the end of the day, it's simply not being educated on our own story, so we try to figure out, maybe there's a similarity or something and that is so, so wrong. (Focus Group 6, Participant 19)*

2.4 Rendered invisible: the attitudes of healthcare providers

Participants bemoaned the lack of communication and engagement from specialist doctors. According to some respondents, this was not only due to the pressures of time, but also because doctors' viewed patients as subjects of clinical interest and passive recipients of treatment;

> *When the professors come, they will just stand there with the students and say; This is the patient. They don't say, OK this is what's happening and explain to you, They don't*

do that, It's just, you have to lay there and watch. You're listening to what they say, but you don't understand and then when they're finished, they go out. (Focus Group 6, Participant 19)

Although women encountered different doctors at the tertiary hospital during the GDM pregnancy, they interacted more frequently and consistently with nursing staff. Perceived lack of empathy and emotional support from nurses were a common finding and contributed substantially to women's overall experience of the GDM pregnancy and their perceptions of the quality of GDM care. Women reported that some of the nurses were rude and uncaring;

The doctors don't have time. They do care, but they don't have time, We spend most of the time with the nurses, and they don't care. Especially when the doctors are not there, in front of the doctors they care. They are rude to the patients. [Translated from isiXhosa]- (Focus Group 6, Participant 21)

2.5 The value of supportive interpersonal relationships with HCPs

In contrast, some participants described how the frequent, specialized antenatal visits and occasional hospitalisation provided an opportunity for them to establish meaningful interpersonal relationships with HCPs. They regarded those HCPs, who showed genuine concern for their health as an important source of practical and emotional support, which was essential for them to successfully implement the recommended behaviour changes.

There's one sister who was always watching me. She would scratch in my cupboard, because she knew if my boyfriend had visited, I would have something unhealthy. I would see those things sitting on top the cupboard and she would tell me that she is

throwing them in the bin, before the doctor comes in the morning. I felt like I was at home. You get to know the nurses and the doctors, so you have that relationship with them (Focus Group 3, Participant 12)

Several women spoke highly of their experiences with one particular nurse who had played a critical role in encouraging and assisting women to successfully breastfeed their new-born;

They have a nurse; we called her the Breast Sister. They would call her up just to help you and she's the loveliest person ever. She encouraged you and she would motivate you; Are you succeeding? Is everything okay? You could not go home if your child doesn't breastfeed or latch on, because formula is not encouraged. (Focus Group 4, Participant 15)

Only two women in our study reported not receiving any assistance to initiate breastfeeding while in hospital;

I had a good experience here, but they did not show me how a baby must latch. I had a big struggle; because I didn't know how. I didn't know that I'm not doing it properly, because they never showed me here how to breastfeed. (Focus Group 8, Participant 25)

2.6 Varied experiences of labour and delivery

The majority of women were informed that they would require a caesarean section because their babies were too large. However, many women attached significant value to a natural childbirth experience and had initially refused to consent to the C-section, despite doctors' recommendations.

One of them [doctors] said 'This is a big baby; you must deliver by C-section'. I have never had a caesar in my life. I was shocked. I said, I can't sign this paper to say that they must take out the baby via caesar. No! (Focus Group 2, Participant 8)

Although some women had difficult delivery experiences, they reported appreciation for the HCPs involved in their care who treated them with dignity and compassion. On the other hand, other participants reported that some nurses were at times insensitive and unsympathetic towards women in labour;

It was traumatic. You're in labour, and the next minute they're telling you to sit up…I mean you're in pain and this person is telling you 'I need you to sit like this now' and I'm like, you can be a bit more sympathetic (Focus Group 4, Participant 14)

Women understood that the intensive and specialized antenatal and immediate post-natal care they received at the tertiary hospital ensured positive health outcomes for themselves and their babies. One woman contrasted her experience of delivery at the primary care level with that of the tertiary level hospital;

I gave birth at the Day Hospital [primary level] with my first son, I was in labour seven hours. No one ever came to check if am I okay, to check my blood or whatever. I gave birth and two hours later, you go home. But here [tertiary hospital], they're constantly monitoring you. Even after birth they were constantly monitoring you. (Focus Group 3, Participant 12)

2.7 Barriers to post-partum diabetes screening

Women should receive a referral letter at discharge recommending that they undergo a 6-week postpartum OGTT at their primary care clinic. However, more than half of the women in our study did not recall receiving any discharge information and even among the few women who did receive a referral letter, the majority did not attend diabetes screening in the postpartum period;

> *They gave me the referral letter to the day hospital, but I never went for myself, only for the baby; the important things, I never had time for, to go for myself. (Focus Group 3, Participant 11)*

Two participants detailed how they had made the effort to schedule an appointment at the hospital only to be turned away by health services;

> *I phoned here, because my appointment was for here. They said they couldn't give me another date; I should go to my clinic and they will assist me there. And I was sent from one Sister to the other Sister, to the other room, and nobody would assist me. (Focus Group 4, Participant 15)*

> *The time I gave birth, they said you have to go to the day hospital, so that they can check your sugar. The day I went for the check-up, they said, the doctor is not here. I went back home. I said I'm not going back there (Focus Group 8, Participant 28)*

Long waiting times to see HCPs at the day hospital (primary care level) was the most common barrier to women attending the 6-week postpartum OGTT;

> *You know, at the day hospital, there are people that sleep outside the day hospital just to be early, then they still sit there the whole day. You will hear people in the taxi*

saying, I've been here since four o'clock this morning, I'm so hungry. And it's four o'clock the evening already. I mean that's bad. (Focus Group 4, Participant 16)

There was a significant difference between the highly intensive and structured antenatal care and sub-optimal postpartum follow-up care. When asked about the support they required from health services following the GDM pregnancy, one woman responded;

A check-up. Somebody phoning you and asking How are you coping? Is the Diabetes okay, because you had your six week check-up? or an SMS. I know the nurses don't do home visits, like in the old days. I was really surprised when I got this phone call for this research. Why now, do you understand? (Focus Group 1, Participant 4)

The researchers described the proposed health systems intervention for women with GDM that would potentially incorporate education and behaviour change counselling during pregnancy and offer a combined mother-baby postpartum visit at the Well Baby Clinic, inclusive of the recommended 6-week OGTT as well as postpartum counselling to promote long-term behaviour change. There was consensus that leveraging the 6 week immunisation visit at the baby clinic to conduct the recommended diabetes screening, would be more convenient for women as they would not need to make separate appointments for themselves and their baby;

When you have a baby, your time is consumed, You don't know the mother's schedule with work and things like that. So, when baby gets seen to and you see to yourself as well, it's one day. If there's a separate nurse to see to you, even better, because then, you know, everything can get done in one day. There's no excuse that you can't keep your appointment, because you are there for baby, so you might as well be there for yourself, and it's convenient. (Interview 1, Participant 5)

Table 6: Mediating factors in perceived quality of GDM care

Factors considered by women in their assessment of quality of care	Quotes
High standard of specialised clinical care for women with GDM	*The care was very good. I was happy with the care. I was shocked at how good it was, compared to the stories I've heard from people. They [HCPs] were friendly. There was maybe the one odd one, that brought food and wasn't nice but that was not really the nurses or the staff, it was more the kitchen staff. Everyone else was nice and they check up on you.(Focus Group 1, Participant 4)*
	The doctors here, they are the best. They taught me how to eat well, and after that, I changed my diet. They really helped me, because if I was ignorant, I would have been in bad condition and it would also have affected my son. (Focus Group 8, Participant 32)
Lack of adequate education and counselling for women diagnosed with GDM	*I feel that they could give you more information. I was given just the basics, right, and that is concerns for the baby, concerns for you, diet. I feel there's much more to this Diabetes than just that. (Focus Group 1, Participant 1)*
	When I got here for my first visit, they said to me, You need to go to this certain floor, and they'll see to you there'. I didn't understand why. I didn't know what was happening, I just went. When I got there, they said I should wait on a bed. Eventually, probably after three hours or so, they said to me, 'There's a bed available, you need to spend the night'.(Focus Group 4, Participant 16)
Insufficient healthcare resources (e.g.; shortage of trained health personnel)	*When you come there, it's like, thousands of people will be next, so maybe there's too little time. (Focus Group 4, Participant 14)*
	They do a whole lot of testing, a whole lot, and the thing that really is not okay, is the fact that they keep you in the dark, because they have so many things to do. They don't take time out to talk to you.(Focus Group 6, Participant 20)
Perceived incompetence and neglect by nurses	*I was always arguing with the night shift Sisters because they're not on time with the Insulin, to give you Insulin, they take time to give you your tablets. (Focus Group 9, Participant 35)*

	The nurses must check your sugar but sometimes they would delay. I don't know whether there's no staff or what? I would always go to the nurses' station. I feel sorry for the others; they end up with their sugar uncontrolled, because they're hungry, they then eat. They can't wait [that long]. It's not right. (Interview 2, Participant 9)
Lack of opportunities to engage with HCPs	*They would come and stand around your bed and check your folder, you know, and all those things but there was no communication, and then they go to the next one, and then you can go to the next room. (Focus Group 4, Participant 16)*
	I saw different doctors all the time. They came, took your folder, went through it, asked you how you're feeling, whoosh, gone. And then for most of the time you don't know who your doctor is, because you have so many coming around all the time. (Focus Group 4, Participant 14)
Fragmented postpartum health services	*When you go to the clinic, the other side it's for the babies and the other one is for the adults. So, you have to wake up early, you go to the kids' part. When you go to the adult side once you are finished with the child, they tell you, no, time is up, you have to come tomorrow morning. (Focus Group 8, Participant 28)*

7.4. Discussion

To the best of our knowledge, this qualitative study is among very few in Africa to explore women's experiences of utilising public sector health services for the treatment and management of GDM. Our findings provide insights into women's perceptions of the quality of care they received during their GDM – affected pregnancy and highlight important areas of unmet need within the health system.

Similar to other studies [20, 21], our participants attributed successful behaviour change and management of GDM to supportive interpersonal relationships with HCPs and peers, alongside family support. Women reported satisfaction with care when HCPs were respectful and empathetic; showing genuine concern and sensitivity to their needs. Positive patient-provider relationships characterised by mutual respect and trust have the potential to be leveraged for adherence with GDM treatment and lifestyle change recommendations. However, such relationships are often shaped by power dynamics [22] where HCPs may misuse their professional credibility and experience to enact pressure on women to adhere to lifestyle change recommendations. Therefore, training in patient-centred care and behaviour change counselling methodologies is necessary for HCPs involved in GDM care to build strong communication and interpersonal skills. Furthermore, involving women in decision-making processes; as active participants in their healthcare can lead to the development of sustainable behaviour change plans [23, 24]. Based on women's positive experience of the focus groups in this study, such peer interaction and support groups could be incorporated into the care for women with GDM to provide social and emotional support.

The current management of GDM in our setting appears to be foetal - centric and over-medicalised, focusing on clinical care processes to achieve glycaemic control and safeguard foetal health. Although GDM presents a 'prime teachable moment' to enable women to build intrinsic motivation and a sense of agency and self-determination [21, 25], the health system relies on imposing extrinsic motivation for women to implement lifestyle changes primarily for the sake of the baby. The provision of comprehensive information and access to appropriate behaviour change counselling and educational resources are essential for women to understand their GDM diagnosis in order take a participatory role in their care [20, 21]. However, in resource limited settings such as ours with high patient load and staff shortages [24] [20, 26], consultations with HCPs are often too brief and impersonal for women to adequately discuss the GDM diagnosis, treatment plans or provide them with the necessary support for self-management. Only one dietician, was available to provide diet-related information sessions to women diagnosed with GDM in the hospital ward, highlighting a critical shortage of adequately trained HCPs and an overburdened health system. As a result, women with GDM may have decreased self-autonomy to make informed decisions to manage their diabetes-risk in the postpartum period. These barriers suggest that there is a need for the development and use of comprehensive, language and culturally appropriate educational resources coupled with training of a cadre of HCPs such as lay counsellors [20, 21], to support existing practices.

A key finding was that health service delivery of antenatal care and postnatal care for women with GDM is disjointed and continuity of care is lacking. Our findings confirmed that postpartum screening for diabetes after a GDM pregnancy, which is generally offered at primary care level in our setting is poorly attended [9, 10, 27]. Health systems may be

contributing to this significant problem through fragmentation of postnatal health services (i.e.; separate mother and baby health services) and the lack of reliable, shared health information systems. Prior studies conducted in other low- and middle- income countries have shown that disorganisation of health services and systems can negatively impact treatment and health-related outcomes [26]. Communication between HCPs at tertiary and primary care level is essential to facilitate women accessing health services in the postpartum period [28]. Yet, the inconsistencies in the GDM referral system are indicative of a poorly coordinated health system that women find challenging to navigate successfully. Referral letters which should serve as instruments for communication between HCPs across different levels of care [29] are not used consistently. In the absence of any standardised record-linkage and follow-up processes, women with GDM are lost to follow-up once discharged from the tertiary hospital.

Although the intensive and specialised antenatal care at the tertiary hospital is perceived by women to be of a high standard, the current model of GDM care limits health systems' intervention to the pregnancy period and does not support women's transition back to primary care services in the postpartum period. Given the overwhelming evidence for increased risk for type 2 diabetes among this population, it is paramount for health policy makers to make GDM a public health priority and recognise the need for a continuum of care approach to GDM care throughout the various stages of a woman's life cycle and across different levels of care [7, 11]. In addition, we recommend health systems interventions to be integrated into existing GDM health services to address the identified barriers to care. Furthermore, monitoring and regulation of clinical practices in the management of GDM could help to ensure a high quality of health service delivery for women [14].

7.5. Strengths and Limitations

In this study, we have highlighted women's perspectives and experiences of GDM health services and identified important factors linked to quality of care as well as opportunities for improvement in the provision of these health services in our setting. Generalisability of findings is limited due to the qualitative study design. It was not within the scope of this study to explore HCPs views and knowledge on GDM health services. However, this study complements our previous research on GDM policies and clinical practice guidelines in South Africa [9]. Research with HCPs directly involved in the treatment and management of women with GDM is ongoing, as part of the process evaluation of the IINDIAGO project and will provide a balanced assessment of the quality of GDM health services. The findings of this study will contribute to the development of a tailored type 2 diabetes prevention health system intervention for women diagnosed with GDM aimed at promoting long- term behaviour change.

7.6. Conclusions

Women's experiences highlight the importance of structure (i.e., efficient and timely referral systems, good management practices and allocation of health care resources) in the provision of GDM health services. While the medical management of GDM during pregnancy is perceived by women to be of high standard, the healthcare climate is not conducive to motivating self-management and empowering women to participate as equal partners in their care. Health services should incorporate patient-centred approaches in the management of GDM in order to improve women's overall experiences of care and support

them in making the recommended changes in their behaviour. Finally, fragmentation of health services may be contributing significantly to poor attendance of the postpartum 6 week OGTT. Health policies that directly support continuity of care (e.g.; providing an integrated mother-baby health service, behaviour change counselling and peer support groups) are urgently needed in order to prevent or delay onset of type 2 diabetes among women of reproductive age.

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CHAPTER 8: INTEGRATED DISCUSSION AND CONCLUSION

This final chapter provides an integrated discussion of the findings from Chapter 4 – Chapter 7 in relation to the study objectives. The findings provide novel evidence for the need to prioritise GDM as an important public health issue in South Africa and give rich insights on women's lived and narrated experiences of GDM. These findings also lay the groundwork for the development of a feasible and acceptable intervention for women diagnosed with GDM, to be integrated within existing health services. Table 7 reflects the contributions made by each study with reference to the original aims and objectives. The key themes of the thesis, which have implications for the South African health system, women diagnosed with GDM and the larger IINDIAGO project, are discussed in line with recommendations for health systems interventions outlined in the WHO Maternal Morbidity Measurement (MMM) Framework.

Table 7: Consolidated findings from empirical studies

Chapter	Aims and Objectives	Methods	Main Findings
4	To explore current policies and clinical practices relating to antenatal and post-natal care for women with GDM in South Africa To explore health sector stakeholders' perspectives on the barriers to -- and opportunities for -- delivering an integrated mother-baby health service that extends beyond the first week post-partum, to the infant's first year of life (12 months postpartum)	- A combination of document reviews of policy documents, clinical practice guidelines and protocols, educational material including diet sheets and 11 key informant interviews	1. Health services in our study, adhere to international guidelines (WHO and an adaptation of NICE guidelines) for screening, diagnosis and management of GDM 2. Antenatal care for women with GDM in Gauteng and the Western Cape provinces is specialised and in line with health policy 3. Postpartum care for women with GDM appears to be poorly structured and misaligned with existing national policy. 4. Health systems barriers include fragmentation of care and the absence of standardised postnatal care for women with a history of GDM. 5. Patient - related challenges for postpartum follow-up include lack of perceived future risk of developing type 2 diabetes and non-attendance for postpartum 6 week OGTT
5	To explore women's lived experiences of having GDM and the feasibility of sustained lifestyle modification after GDM using the COM-B model in a low-income setting.	- 9 focus group discussions and 5 in-depth interviews with a total of 35 women with a history of GDM - Data analysis followed content analysis procedures and the pre-	1. The COM-B model's concepts of **Capability** (knowledge and skills for behaviour change), **Opportunity** (resources for dietary change and physical activity), **Motivatio**n (perception of future diabetes risk) are relevant to lifestyle

		existing conceptual categories of the COM-B model provided a lens for data interpretation	change among women with GDM in South Africa. 2. Health services need to improve behaviour change counselling and education for women with GDM in South Africa. 3. Support from family and health professionals is essential for women to achieve lifestyle change. 4. The experience of GDM imposed a significant psychological burden on women, which affected their motivation for lifestyle change.
6	To explore the lived experiences of women with GDM and the impact of GDM on their lives, experience of pregnancy and sense of well-being.	- Nine focus group discussions and 5 in-depth interviews with a total of 35 women with a history of GDM - Data analysis followed an iterative thematic analysis approach and feminist insights around maternal responsibility and mother-blaming provided guidance for data interpretation	1. Women with GDM experience psychological distress at different stages of the pregnancy linked to the GDM diagnosis, adjusting to lifestyle modification, fears and anxieties regarding risks and delivery, and uncertainty and concerns about the postpartum period 2. The current biomedical model used in the management of GDM does not account for important psychological factors that contribute to women's overall wellbeing and experience of pregnancy. 3. Mental health support is important in the management and care for women with GDM in public health services, along with facilitating emotional support from partners and family members.

7	To explore women's perceptions and experiences of utilising health services for the treatment and management of GDM using Donabedian's Quality of Care Framework	Nine focus group discussions and 5 in-depth interviews with a total of 35 women with a history of GDM	1. The medical management of GDM during pregnancy is perceived by women to be of high quality and high standards. 2. The GDM healthcare climate is not conducive to motivating self-management and empowering women to participate as equal partners in their care. 3. Fragmentation of health services may be contributing significantly to poor attendance of the postpartum 6 week OGTT.

8.1. The WHO Maternal Morbidity Measurement Framework

The WHO Maternal Morbidity Working Group (MMMWG) classifies GDM as a maternal morbidity condition, which is "any health condition attributed to and/or complicating pregnancy and childbirth that has a negative impact on the woman's wellbeing and/or functioning" [1]. In 2018, this working group developed a conceptual framework for rethinking maternal health and better understanding and measuring maternal morbidity [2, 3]. The WHO Maternal Morbidity Measurement (MMM) Framework advocates for a life-course approach that is woman-centred (i.e., prioritises women's views and health needs); recognises the cyclic, long-term health risks for women; the influence of context (social, physical, political environments) and the need for continuity of care [2] (see Table 8). The WHO MMM framework has potential to inform health interventions as it provides researchers, policy makers and health care providers with a comprehensive approach to identifying and addressing gaps in existing knowledge in order to improve maternal health service delivery beyond the traditional 6 weeks postpartum period. Although this framework was developed while the research was underway, it provided a critical lens for reflecting on the findings of this thesis. The main findings of the thesis are discussed against the backdrop of the six principles reflected in the WHO MMM conceptual framework (Table 8) as well as current literature.

Table 8: A summary of the six principles reflected in the WHO Maternal Morbidity Measurement Framework

1. The importance of using a woman-centred approach. (i.e., women's perspectives on what is important to them regarding their health.	**2.** Maternal morbidity risks are cyclical since women can become pregnant more than once. In addition, sequelae of a maternal condition can occur in the next pregnancy.
3. The effects of maternal morbidity can last a long time, beyond the customary 6 weeks postpartum, and there may be consequences later in life, during the post-reproductive or postmenopausal periods.	**4.** Maternal health is a social and economic phenomenon, not just a clinical and biological issue.
5. Context and environment influence the lived experience of morbidity. Living in a supportive environment can lead to better outcomes.	**6.** The framework includes meaningful groupings of maternal morbidity and has strong linkages with other WHO guidance (e.g., Strategies Toward Ending Preventable Maternal Mortality (EPMM)

8.1.1. 'Beyond surviving to thriving': a woman centred approach to GDM care

The series of studies (Chapter 4 – 7) were useful in understanding the current practices in the management of GDM in South Africa and identifying important gaps in the delivery of maternal health services for women diagnosed with GDM. Our findings in Chapter 4 confirmed that healthcare stakeholders acknowledge that the current clinical management of GDM may be foetal centric, in that it focuses primarily on safeguarding the health of the unborn baby and preventing adverse obstetric outcomes. This finding was further confirmed by women's accounts of their lived experiences of having a GDM-affected pregnancy (Chapter 6 and 7). From women's perspectives, GDM health services prioritize clinical aspects of GDM care while inadvertently neglecting women's need for practical, emotional and psychological support to cope with GDM. This finding is not unique to low-income setting. Previous studies,

including a recent systematic review of women's experiences of GDM, where most included studies were from high-income countries have reported that some women perceived GDM care to be over-medicalised and focused on physiological aspects of care, without adequately engaging women in decision-making [4-6]. The WHO MMM framework's Principle 1 recommends a woman-centred approach that incorporates women's perspectives and involves them in decision-making processes concerning their health and Principle 2 emphasizes that GDM is more than just clinical and biological issue [2]. Our findings therefore demonstrate the need for health policies and clinical practice guidelines that are woman-centred and prioritise women's need for personalised care. Efforts to make GDM health services more woman-centred should include individual and group counselling to empower women to prioritise their health; mental health screening as part of routine antenatal care visits and targeted psychological interventions as well as involving partners and family members as sources of additional emotional and practical support for behaviour change and treatment adherence.

8.1.2. 'Context is key': the imperative of understanding the GDM context

The findings from the preceding empirical chapters (Chapter 4-7) demonstrate the influence of the context and environment in which women experience a GDM pregnancy and GDM health services and are in alignment with Principle 5 of the WHO MMM framework [2]. As mentioned previously, this study was conducted with women living in a broader socioeconomic context of high rates of unemployment and poverty [7]. Chapter 5 provided detailed insights into women's capacity for behaviour change within the constraints of their physical and social environment, highlighting the extent of their capability (knowledge and

skills for behaviour change); opportunity (affordability, safety and other resources for lifestyle change) and motivation (perception of future diabetes risk) as important factors. The importance of addressing the social and cultural environment in the designing of behaviour change interventions for women with GDM has been previously documented in studies among ethnic groups in Australia [8], Canada [9] and low-income black women with type 2 diabetes in South Africa [10]. Similar to our findings in Chapter 5, these studies [8-10] have also demonstrated that dietary and physical activity behaviours are influenced by social and cultural contexts and that changing these behaviours may require women to deviate from their social and cultural norms. Based on our findings, lifestyle change in this population is feasible provided that physical activity and dietary recommendations are sensitively tailored to women's socioeconomic, sociocultural and environmental context and reinforced through professional and social support, as recommended in the WHO MMM framework. This formative research with women with GDM was therefore critical for formulating the guiding principles for the design and planning of a behaviour change intervention, rooted in an understanding of their context [11].

Our findings revealed that GDM care in the public sector is provided in the context of high patient load and staff shortages. Similar to other low-income countries, South Africa's public health system is overburdened and under-resourced [7, 12]. There is a critical shortage of trained health care providers such as dieticians and diabetes nurses in the public health sector in South Africa. As a result, women do not receive the necessary health education, behaviour change counselling and support they require to facilitate self-management and long-term behaviour change. This finding points to a missed opportunity to empower women to make critical behaviour changes for their own health and become key change agents for healthier

lifestyle in the home [13]. This could be achieved through awareness and ongoing training in behaviour change counselling methodologies for HCPs involved in GDM care to build strong communication and interpersonal skills. In addition, there is evidence from studies in South Africa to support the use of community health care workers (CHW) and lay counsellors in providing behaviour change and psychological counselling in low-resource settings [14]. With relevant training and supervision, lay counsellors could work in conjunction with diabetes specialist teams to promote healthy behaviours among women diagnosed with GDM. Further, health education materials such as diet sheets should be co-constructed with women and tailored to be practical as well as culturally and language appropriate in order to increase uptake.

8.1.3. The missing link: continuity of care and the integration of postnatal care

This thesis has demonstrated that postpartum follow-up care for women with GDM in South Africa is poor and continuity of care is lacking. As identified in a study across eight LMICs including two sub-Saharan countries [15], referral processes are somewhat inconsistent and there are several structural and process-related barriers to woman navigating the different levels of care to access care. From a health systems' perspective (Chapter 4), we identified two key barriers to postpartum follow-up: (i) fragmentation of postnatal services and (ii) the absence of standardised postnatal care services for women with recent GDM. From patients' perspective (Chapter 5 - 7), barriers include women's low perception of future type 2 diabetes risk, resuming their maternal role as the family's primary caregiver, returning to work and notably; the inconvenience of having to navigate two separate health services for themselves and their baby in the postpartum period. Reliable, electronic health information

systems are needed for record linkage as part of efforts to improve attendance for the 6-week OGTT at primary care level. The referral letter while important, is insufficient without additional follow-up. The transition from specialised tertiary care to primary care as well as the separation of maternal and child health services at primary care level present a major challenge for continuity of care in the postpartum period. Compartmentalisation of antenatal and postnatal health services for women with pregnancy complications or high risk pregnancies, reinforces the foetal centric model of care and inhibits continuity of care in the postpartum period. From both the health systems and patients' perspectives, there is an urgent need to address the disconnect between antenatal and postnatal health services for women with GDM. The WHO MMM framework's Principles 2 and 3 can be applied in reframing messaging during antenatal care from GDM being a temporary maternal morbidity to an opportunity to make long-term lifestyle changes which extend beyond the duration of the pregnancy, in order to prevent sequalae (i.e., developing GDM in subsequent pregnancies) and long-term consequences later in life (i.e., developing type 2 diabetes after GDM) [2].

To prevent women from 'falling through the cracks', the WHO proposes merging the maternal health and NCDs agenda, facilitating seamless transition between antenatal and postnatal care and widening the scope of maternal health services beyond the traditional 6 weeks postpartum period [2, 16]. This proposal is timely and in alignment with the aims and objectives of the IINDIAGO project. The primary aim of the IINDIAGO integrated health system intervention is to create a 'one-stop-shop' by leveraging the 6-week immunisation visit for the baby to conduct the recommended postpartum OGTT for the mother following a GDM pregnancy, as well as to provide ongoing support thereafter to reinforce continued lifestyle

change. The WHO MMM framework (Principle 6) has linkages to other WHO guidance such as the 'Strategies Toward Ending Preventable Maternal Mortality' (EPMM), which recommend integration of maternal and newborn health services at primary care level [16, 17]. The potential for integrating maternal health services into existing services at primary care level has been explored in similar low-resource countries such as Kenya, to promote efficient utilisation of services and improve access to care [13]. In South Africa, the effectiveness of integrated postpartum health services has been demonstrated among HIV-infected women resulting in increased retention in care and improved maternal and child health outcomes [18]. The integration of GDM management specifically into existing maternal and child health services at primary care level has also been suggested as a cost-effective solution in developing countries with limited resources such as Pakistan where it has been implemented as a part of a GDM prevention and control collaborative project with World Diabetes Foundation [19]. However, these efforts would require the support and backing of health policy makers and health care providers if they are to succeed. Based on our findings, healthcare stakeholders are in support of integration of postnatal health services at primary care level for women with GDM but caution against overburdening the healthcare system.

8.2. Implications for the IINDIAGO Project

Based on the findings and recommendations of this PhD thesis, the IINDIAGO randomized control trial will develop and assess a holistic intervention for women diagnosed with GDM in the public health sector, with the objective to promote healthy lifestyle behaviours and to delay or prevent development of type 2 diabetes in this population. The findings based on the COM-B model have been synthesized and mapped onto the Behaviour Change Wheel to

develop a theory and evidence-based intervention for women with gestational diabetes However, this consultative process with the broader IINDIAGO study team and the subsequent development of the holistic intervention are not within the scope of this PhD thesis and are therefore not reported here. A manuscript of which I am a co-author, has been drafted for publication and reports fully on how the data from this research was used in the development of the IINDIAGO intervention. Potential elements for consideration in the development of the intervention are summarized in Figure 12, in line with recommendations for health systems interventions outlined in the WHO MMM framework.

Figure 12: A holistic approach to a health system intervention for women with GDM, based on the six principles of the WHO MMM Framework

8.3. Implications for Future Research

The screening and diagnostic criteria for GDM have been a topic of intense global debate [20, 21]. In South Africa and other LMICs, selective screening on the basis of risk factors is common practice [22]. Recent studies in South Africa have compared various diagnosis criteria and the efficacy of universal versus selective screening and concluded that further research is needed in the South African context to establish an evidence-base for best practice in GDM screening and diagnosis [23, 24]. Future studies on cost-effectiveness of current GDM screening practices in our low-income setting could provide guidance towards best practices in our context. Efficient GDM screening at primary care level is important in ensuring early detection, referral and treatment to avoid adverse pregnancy outcomes. At present, GDM screening at primary care level is sporadic and the extent of implementation of the accepted WHO 2013 [25] and UK National Institute for Health and Care Excellence (NICE) criteria [26], is unclear [23]. Our research revealed some inconsistencies in the screening, diagnosis and referral processes for women with GDM. Further quantitative and qualitative studies are needed to (i) determine the extent of screening and efficiency of referral of women with GDM in South Africa and (ii) to understand the barriers and opportunities for these processes. The findings also confirmed that having GDM may negatively impact women's mental health and sense of wellbeing. A few quantitative studies have explored the correlation between GDM and mental health in high income and some LMICs [27, 28], although none have been conducted in the South African setting. Future research is therefore needed to measure the extent of this relationship using validated instruments for depression and anxiety among women with GDM in our context.

This body of work complements other quantitative studies linked to the larger IINDIAGO project which have explored the dietary intake and beliefs of pregnant women diagnosed with GDM [29]; progression to type 2 diabetes after GDM [30] and the potential for integration of maternal and child health services in the postpartum period [31]. The IINDIAGO randomised control trial, which will be informed by these findings, will provide novel insights on the effectiveness of an integrated health systems intervention for women with GDM and form the basis for further studies. Considering the resource limitations in our health system, studies to determine the cost-effectiveness of the intervention would be beneficial.

8.4. Strengths and Limitations

This thesis provides original evidence for the development of a complex health system intervention for low-income women with GDM in South Africa and contributes to the growing body of knowledge on the emerging GDM epidemic. **Manuscript 1 (Chapter 4)** adds novel insights to fill the knowledge gap on maternal mental health in low-resource settings, with complex burdens of diseases. **Manuscript 2 (Chapters 5)** based on the COM-B model and **Manuscript 4 (Chapter 7)** based on Donabedian's Quality of Care framework are the first in sub-Saharan Africa to assess women's lived experiences of GDM and their perspectives on the feasibility of behaviour change, within the context of their physical and social environment. Overall, this thesis highlights continuity of care for women with a history of GDM as a priority issue for the maternal health and NCDs policy agenda.

Qualitative research methods are typically used in formative research to understand factors that influence behaviour. The use of qualitative methods in this study enabled detailed

exploration of current policies and clinical practices for the management of GDM in South Africa and in-depth understanding of women's lived experiences of GDM, lifestyle change and their perceived needs. The FGDs allowed for collection of data within a group setting and observation of shared experiences, beliefs and social norms while in-depth interviews provided an opportunity to gather detailed personal experiences that women may not have shared in the context of a larger group.

The study, however, has some limitations. The study sample for the FGDs and in-depth interviews was selected from a single urban, tertiary level hospital in the Western Cape province and may not be entirely representative of the health care settings for women with GDM in other provinces and rural areas. However, the study site is one of two large tertiary hospitals servicing the Western Cape province and both hospitals adhere to provincial and national guidelines in the management of GDM. In addition, due to the perceived high standard of care in the Western Cape province, it is common for pregnant women from rural areas in the Eastern Cape province, to migrate to the Western Cape to access antenatal care services. We initially intended to recruit participants from a secondary level hospital that provides antenatal care to women diagnosed with GDM, but key informant interviews and early FGDs revealed that this secondary level hospital also referred women with GDM to the tertiary level hospital (i.e., study site) for further treatment and management. Hence, the study sample was demographically representative in terms of socioeconomic status, ethnicity and age, of women who utilise public sector health services for GDM care. Although some of the participants were isiXhosa and Afrikaans native speakers, the FGDs and interviews were conducted in English. Fortunately, the majority of participants were conversant in English and

the diabetes nurse-educator present in the discussions was fluent in both isiXhosa and Afrikaans, which helped to overcome any potential language barriers.

The first study reported on key informants' views on the management of GDM. The document review of policy and clinical practice guidelines therefore provided triangulation of the data. Women's reported experiences of GDM were also subjective and may have been influenced by recall bias as participants were at least one year postpartum. However, the time elapsed may have given women sufficient time to reflect on their experiences. Lastly, as with all qualitative studies, generalisability of the study findings is limited. A mixed-methods approach could have been useful for identifying priority areas for the proposed intervention and increasing generalisability of the findings.

8.5. Conclusion

Prioritising GDM as a public health issue is critical for improving maternal and child health outcomes and NCD prevention efforts . However, the current management of GDM in South Africa is foetal - centric and perhaps over-medicalised. Woman-centred approaches should be incorporated into the management of GDM in order to improve women's overall experiences of care. Behaviour change interventions for women with GDM should target factors within the physical and social environments, that influence women's capacity for lifestyle change. Finally, holistic interventions and health policies that directly support continuity of care are urgently needed if high rates of progression to type 2 diabetes in this population are to be avoided.

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APPENDICES

Appendix 1: Key Informants Interview Schedule (Chapter 4)

Chronic Disease Initiative for Africa

Formative research for the development of an appropriate, acceptable and feasible intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa

SECTION A: Standard of care for women with GDM

Policy & Clinical guidelines

1) What are the policies and clinical guidelines in place for the management of women with GDM and diabetes at this hospital?
    - When and how were they developed?
    - Who are the key implementers?
    - What is the oversight (Monitoring and Evaluation)?
    - How effective do you think they are?
    - How often do the women come to the hospital?
    - Who sees them?
    - What is the treatment regimen?

2) What are the policies and clinical guidelines relating to the care of the mother and baby after a GDM pregnancy?

3) What are the current in-hospital post-delivery guidelines for women with GDM and diabetes at this hospital?

4) To what extent are these policies and guidelines followed in clinical practice?

5) What are the problems (if any) in implementing these policies and guidelines?

6) What is currently happening at a policy level and within the health services regarding infant nutrition and vaccinations? How do you think this project can effectively align with these initiatives?

SECTION B: Current practice

7) Can you explain in detail the current practices relating to the care of women with GDM during pregnancy?
   - What lifestyle intervention do women receive during pregnancy?
   - What does it consist of? (Medication, educational materials etc.)
   - Who is involved in delivering the intervention?

8) What are the current practices/procedures relating to the care of women after a GDM pregnancy?

9) What is the current discharge plan for these women postpartum?
   - Is there a specific protocol in place?
   - Is there a referral system?
   - Where do women actually attend for postpartum follow-up for their diabetes or GDM?
   - Are women discharged on medication?
   - Is there a link between GDM management and labour/delivery procedures?

Prioritization of GDM in overall care

10) Do you regard postpartum follow-up of women with GDM as an issue needing to be addressed?

11) Is there anyone else who you think we would need to speak to as part of the formative phase of this study?

12) What do you think should be done for women with previous GDM during postpartum care?

13) What are your thoughts and feelings on integration of mother and baby care after a GDM pregnancy?

SECTION C: Views on proposed intervention

14) You have been given the draft protocol to read, do you have any critical comments/concerns you would like to raise about the proposed study? This could be

regarding the conceptualization and feasibility of the research aspects and/or the proposed intervention? Do you have any additions to the protocol?

15) How feasible is a maternal health intervention in the Well Baby Clinic? (OGTT + Lifestyle intervention) Is there enough space/personnel/time/equipment/material to implement it?

16) Do you know if there are any other initiatives like this (integrated mother-baby care) in SA or elsewhere? Do you know of any follow-up interventions for women with previous GDM?

Appendix 2: Key Informants Information Sheet and Consent Form (Chapter 4)

Chronic Disease
Initiative for Africa

Formative research for the development of an appropriate, acceptable and feasible intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa

STUDY INFORMATION AND CONSENT FORM

We, the Chronic Diseases Initiative for Africa (CDIA) are conducting research on developing an integrated health system intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa. At this stage, we want to assess the feasibility and acceptability of the proposed intervention among our key informants.

You are invited to participate in this study as we feel that your input will be extremely valuable in the development of the intervention given your positioning in the field. As part of the study, we will be asking you questions about the current policies, clinical guidelines and practices relating to the care of women with gestational diabetes during pregnancy and / or after delivery. We would also be interested in your views on our proposed intervention and whether its implementation is feasible in the Well Baby Clinics. The interview will last approximately 1 hour and will be audio-taped to ensure that we do not miss any important information.

Risks: As the study involves voluntary participation in the interviews, we do not anticipate any adverse events. However, at any point during the interview you are free to withdraw from the study with no penalty or consequences and you have the right to refuse to answer questions you are not comfortable with.

Benefits: This study offers you an opportunity to contribute to the development of the proposed intervention for reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa and therefore influence policy and clinical practice.

Confidentiality: No identifying information will be used in any of the publications resulting from this study. Any information you provide will be confidential and will not be discussed with anyone outside the research team. Please ensure that you have carefully read this information sheet and been given a copy to keep for yourself.

Contact details for researchers: For any questions or concerns, please feel free to contact the researchers whose details are listed below:

Ms Lorrein Muhwava +27832166123 Email: lorrein.muhwava@uct.ac.za

Dr Katherine Murphy +27826858927 Email: katherine.murphy@uct.ac.za

This study was granted ethical clearance from the Human Research Ethics Committee at UCT. Their contact details are:

The Human Research Ethics Committee
Old Main Building - Groote Schuur Hospital
Floor E52, Room 23
Observatory, 7925.
Tel: 021 406 6338
Email: lamees.emjedi@uct.ac.za

Chronic Disease Initiative for Africa

PARTICIPANT CONSENT FORM

Study Title: Formative research for the development of an appropriate, acceptable and feasible intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa

By signing this document:

I confirm that I have read the above information and understand it.

I confirm that I have had an opportunity to ask questions and I am satisfied with the answers and explanations that have been given to me.

I give my permission for the researchers to use the information I offer in the interview for the purposes of developing an intervention for women with previous GDM and for the purposes of academic publication.

I understand that my participation in this discussion is voluntary and I am free to withdraw at any time without having to give a reason.

Please tick one of the boxes below:

☐ YES, I would like to take part in this study

☐ NO, I do not wish to take part in this study

Name of Research Participant: _____

Signature: _____

Date: _____

Name of Researcher: _____

Signature: _____

Date: _____

Appendix 3: Focus Groups Discussion Guide (Chapter 5 - 7)

Chronic Disease Initiative for Africa

Formative research for the development of an appropriate, acceptable and feasible intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa

Focus Group Discussions (FGD) with women with a history GDM

Knowledge and attitudes regarding GDM:

1. Can you explain what you understand by gestational diabetes?

   Prompt: What is GDM? How is it diagnosed? How is GDM treated?
   Prompt: In your understanding, what are the consequences of untreated GDM to your health and that of your unborn baby?
2. What do you understand about being at greater risk of developing type 2 diabetes after GDM?

3. What health problems are associated with type 2 diabetes?

Experience of health care during GDM pregnancy:

4. During your pregnancy did you receive any information or advice from the health care provider on lifestyle changes; diet; physical activity; alcohol etc.? If so, please explain who advised you and what they said.

   Prompt: Did you receive any information to take home (pamphlets/booklets)?

   Prompt: Did you seek any other information about managing GDM? For example, from books or internet sites?

5. What concerns did you have during pregnancy about your health and your baby's health?

6. What support did you receive - personal/emotional/practical from your family or friends during pregnancy?

7. How did you feel about the medical care you received from the health care workers (doctor/nurse) during pregnancy?

Prompt: The manner in which you were treated, the way they explained information to you

Prompt: In your view, how well controlled was your diabetes during pregnancy?

8. After delivery, what counselling did you receive from the health care worker on the importance of follow-up care and screening for diabetes?

9. Were you referred to another health facility after discharge from the hospital (e.g., local clinic/CHC?) Please explain.

   Prompt: Were you provided with a referral letter when you were discharged from the hospital?

Experience of health care in post-partum period:

10. Did you go for a test for diabetes 6 weeks after you delivered your baby? If yes, Where did you go for the test?
    If NO: Did you go for a test for diabetes any time after that?
    If NO: What were your reasons for not going for follow-up?

11. Where did your baby receive their immunizations?
    Prompt: Private or public health facility? Which one? Who took the baby for the immunizations? (If not the mother: Why were you unable to go with your baby for immunizations?)

12. How did you feel about the care your baby received from the health care workers at the Well Baby Clinic?

13. Did you breastfeed your baby? If YES: For how long did you breastfeed your baby exclusively?
    If NO: What were your reasons for not breastfeeding your baby exclusively/not breastfeeding?

Motivation for lifestyle modification

During pregnancy:

14. When you were diagnosed with GDM during pregnancy, what changes to your lifestyle did you make, if any?

    Prompt: Changes around diet, physical activity, alcohol intake, smoking etc
    Prompt: What motivated you to make those lifestyle changes?

15. What were the difficulties you experienced (barriers) to making these lifestyle changes?

16. What could have made it easier for you to make these changes (facilitators)?

After pregnancy:

17. How has being at greater risk of developing type 2 diabetes influenced your diet and physical activity behaviours after pregnancy?

    Prompt: Have you continued with the lifestyle changes in your diet and exercise since the baby was born? What has motivated you to continue with these lifestyle changes after pregnancy?

    Prompt: Which of the lifestyle changes have you tried but failed to continue with? What difficulties have you faced with trying to continue with the lifestyle changes after pregnancy?

    Prompt: What would help/make it easier?

18. What personal/emotional/practical support did you receive from your family/friends to continue with the lifestyle changes after pregnancy? Please describe.

19. What are your thoughts and feelings about your current lifestyle?

Attitudes to proposed post-partum intervention for women with GDM
First explain the proposed intervention: We want to develop health services and an education programme for women with previous gestational diabetes that will help to prevent them from getting diabetes later. Our programme would offer tests for T2D, education and counselling at Well Baby clinics.

20. What information or support would you have liked to have received to help you after your GDM pregnancy?

    Prompt: If it had been available would you have come for a test for T2D 6 weeks after delivery?

    Prompt: What do you think of having the programme at the Well Baby Clinic? How far is the nearest Well Baby Clinic from your home? (either distance in km/time travelled walking/car/public transport)

    Prompt: What information/advice would you have liked to get after pregnancy? Would you have liked individual counselling/group counselling/health education materials or all of the above? Would you have preferred counselling by the nurse or community health worker? In the clinic or a community venue?

21. **Final question:** Is there anything you know now about GDM after your experiences, that could help someone newly diagnosed with GDM? If yes, please explain.

Appendix 4: Focus Groups Discussion Information Sheet and Consent Forms (Chapter 5 - 7)

Chronic Disease
Initiative for Africa

Formative research for the development of an appropriate, acceptable and feasible intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa

STUDY INFORMATION AND CONSENT FORM

We are researchers from the Chronic Diseases Initiative for Africa (CDIA) doing research on women who have had gestational diabetes (diabetes during pregnancy). Many of these women recover from the diabetes after the birth of their babies, but they are at high risk of developing diabetes sometime later. However, with a healthy lifestyle, this can be avoided. We want to develop health services and an education programme for women with previous gestational diabetes that will help them prevent getting diabetes later. In order to do this, we need to understand what women think about diabetes and their experiences of GDM during pregnancy and after delivery. We would also like to ask women what they think of a possible programme which would offer tests, education and counselling at Well Baby clinics.

We are inviting all women who live in Cape Town who were diagnosed with GDM and received antenatal care at Groote Schuur Hospital and delivered a live baby.

We will ask you to be part of a group of about 8-10 women at Groote Schuur Hospital organised by the researchers who will take part in discussions about your experiences of GDM during pregnancy and after delivery. The discussion will last for approximately one and a half hours in a language that you understand and will be led by members of the research team. We will record the discussion so that we do not miss any important information.

Risks: As the study involves you voluntarily taking part in discussions with the researchers, we expect minimal risk to you. There is a possibility that you might share some personal information during the discussion or feel uncomfortable with some of the topics being discussed. You may refuse to answer questions you are not comfortable with and you may stop participating in the study at any point without giving reasons.

Benefits: By taking part in this study you will get to learn more about the issue and risks of GDM and you will also experience social support from taking part in discussions with the researchers and other women.

Reimbursement: You will not be provided any incentive to take part in the research. However, you will receive a R100 Shoprite voucher as a token of appreciation for your time and R50 for your transport costs

Confidentiality: Your name will not be used in any of the reports written up about this research. Although every effort will be made to keep study information private, there is chance that other participants may not keep their word to not to repeat what is said in the focus group outside the meeting.

Please ensure that you have carefully read and understood this information sheet and been given a copy to keep for yourself.

Contact details of researchers: For any questions or concerns, please feel free to contact the researchers whose details are listed below:

Ms Lorrein Muhwava	+27832166123	Email: lorrein.muhwava@uct.ac.za
Dr Katherine Murphy	+27826858927	Email: katherine.murphy@uct.ac.za

This study was granted ethical clearance from the Human Research Ethics Committee at UCT. Their contact details are:

The Human Research Ethics Committee
Old Main Building
Groote Schuur Hospital
Floor E52, Room 23
Observatory, 7925.
Tel: 021 406 6338
Email: lamees.emjedi@uct.ac.za

Chronic Disease Initiative for Africa

PARTICIPANT CONSENT FORM

Study Title: Formative research for the development of an appropriate, acceptable and feasible intervention aimed at reducing type 2 diabetes risk in disadvantaged women after gestational diabetes in South Africa

By signing this document:

I confirm that I have read the above information and understand it.

I confirm that I have had an opportunity to ask questions and I am satisfied with the answers and explanations that have been given to me.

I give my permission for the researchers to use the information I offer in the interview for the purposes of developing an intervention for women with previous GDM and for the purposes of academic publication.

I agree to maintain confidentiality of information shared in this focus group.

I understand that my participation in this discussion is voluntary and I am free to withdraw at any time without having to give a reason.

Please tick one of the boxes below:

☐ YES, I would like to take part in this study

☐ NO, I do not wish to take part in this study

Name of Research Participant: _____

Signature: _____

Date: _____

Name of Researcher: _____

Signature: _____

Date: _____