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An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the case of Soweto, South Africa

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A THESIS

Submitted to the School of Clinical Medicine, Faculty of Health Sciences, University of the Witwatersrand, in fulfilment of the requirements for the degree of

Doctor of Philosophy

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Declaration

I, Edna Nyanchama Bosire (student no: 1828411), hereby declare that the work submitted for examination for the above degree is my own unaided work except where explicitly indicated otherwise and acknowledged. This work has not been submitted before for any other degree or examination at this or any other University. I have followed the required conventions in referencing the thoughts and ideas of others. I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong. I also understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

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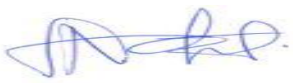
Signature: 

Dedication

To the LORD who is my strength and my shield;
my heart trusts in him, and he helps me.
My heart leaps for joy,
and with my song I praise him.

Psalms 28:7

And to you my son, Myles Austin Abuodha, I want you to say, "My mom was a strong woman, and I am who I am because of her strength and dedication."

Original Papers for this Thesis

1) **Edna N Bosire** (2020). Comorbid Experiences with HIV/AIDS and Diabetes in Soweto, South Africa: From Hospital to Home. *Qualitative Health Research* (Status: Manuscript has been revised and resubmitted. It is currently being considered for publication)

   Student's contribution to the paper: Study design and conceptualisation, data collection, data management and analysis, drafting the manuscript, responding to reviewers' comments.

2) **Edna N Bosire,** Emily Mendenhall, Shane A Norris, Jane Goudge (2020). Patient-Centred Care for Patients with Diabetes and HIV at a Public Tertiary Hospital in South Africa: An Ethnographic Study. *International Journal of Health Management and Policy* (Status: Published).

   Student's contribution to the paper: Study design and conceptualisation, data collection and management (cleaning and data analysis), drafting manuscript and responding to the reviewers' comments.

3) **Edna N Bosire,** Shane A Norris, Jane Goudge, Emily Mendenhall (2020). Pathways to care for patients with Type 2 Diabetes and HIV/AIDS comorbidities in Soweto: A Health Systems Perspective. *Global Health: Science and Practice* (Status: Under review).

   Student's contribution to the paper: Study design and conceptualisation, data collection and management (data cleaning, analysis, interpretation of findings), writing of the manuscript, responding to the reviewers' comments.

Preface

"My HIV/AIDs care is provided free of charge but other diseases such as diabetes I pay for."
[Sarah (pseudonym), Kibera informal settlements, Nairobi].

What does it mean to prioritise one disease in your life and marginalise another? How might the healthcare system influence how you think about, care for, and treat multiple diseases at once? My PhD research originally stemmed from part of a research study that I was involved in Kenya six years earlier that examined how people experience living with and caring for multiple morbidities. We investigated social experiences and mental health among primary care patients with and without diabetes in Nairobi, Kenya's capital. Most participants I interviewed at Mbagathi District Hospital (50 of the 100 involved in the study) resided in Kibera, one of the largest slums in Africa. Among the 50 women I interviewed, half had previously been diagnosed with diabetes (recruited from the speciality clinic) and half did not (recruited from primary care). Most had other comorbidities, including HIV, which further complicated their illness experiences. I was particularly interested in understanding patients' experience seeking care and managing comorbid diabetes and HIV because of the unique social, political, and medical experiences surrounding diagnosis, perception of illness, and structures of care that influenced what was attended to or not. We found that HIV care was free of charge and easily accessible (as a result of donor funding), and patients were required to pay-out-of-pocket for other non-communicable chronic diseases, including diabetes. This finding had a profound impact on how patients perceived each illness; citing diabetes as "worse" than HIV, prioritised care (taking insulin only when they "feel bad"), and routinely sought medical care (always for HIV, rarely for diabetes). I was involved in the in

depth analysis of this research as well as data collection and published several papers[1]; however, the paper I led focused on the complexities of care seeking related to "biological sub-citizenship"—or the legitimisation of care based on diagnosis (Bosire et al., 2018).

This background shaped my interest in how patients with comorbid diabetes and HIV navigated care at public hospitals in resource constrained settings. This opportunity came in August 2017 when my long-term mentor and current main supervisor, Prof Emily Mendenhall (Medical Anthropologist), invited me to work with her in Soweto, South Africa. She connected me with the Wits Developmental Pathways for Health Research Unit (DPHRU), under leadership of Prof Shane Norris (Clinical Medicine), in which my PhD scholarship was borne and where my PhD study is nested. At the same time, the two supervisors introduced me to Prof Jane Goudge, Director at the Centre for Health Policy (CHP), Wits School of Public Health (SPH), who has done extensive research on health systems in South Africa, who became an essential mentor. This interdisciplinary team of three supervisors helped me conceptualise and design an ethnographic study to investigate health and healthcare for patients with comorbid diabetes and HIV in Soweto, South Africa. In truth, this study exemplifies my interdisciplinary supervisory team, borrowing from anthropological and public health theory and methods to inform chronic care in South Africa.

My PhD study aligned with the National Department of Health's initiative in South Africa to implement integrated chronic disease management (ICDM) in 2011. Since 2011, most PHC

[1] Mendenhall E, Musau A, Bosire E, Mutiso V, Ndetei D, Rock M. What drives distress? Rethinking the roles of emotion and diagnosis among people with diabetes in Nairobi, Kenya. Anthropol Med. 2020;27(3):252-267. doi:10.1080/13648470.2019.1650243

Bosire E, Mendenhall E, Omondi GB, Ndetei D. When Diabetes Confronts HIV: Biological Sub-citizenship at a Public Hospital in Nairobi, Kenya. Med Anthropol Q. 2018;32(4):574-592. doi:10.1111/maq.12476

Mendenhall E, Omondi GB, Bosire E, Isaiah G, Musau A, Ndetei D, & Mutiso V. Stress, diabetes, and infection: Syndemic suffering at an urban Kenyan hospital. Soc Sci Med. 2015;146:11-20. doi:10.1016/j.socscimed.2015.10.015

clinics in South Africa aimed to decentralise and integrate chronic care at PHC clinics. This was important to me because I knew chronic care integration was a priority in the South African health system, and I knew my work may provide useful insights on existing opportunities and gaps to inform policy and practice. I hope that this focused research on South Africa's attempt to integrate chronic care within the health system may provide some insight for other countries in sub-Saharan Africa hoping to achieve the same, despite the variations within and between contexts.

"The major challenge of the health system is increasing burden of disease and the twin epidemics of communicable and non-communicable diseases."

(SA Minister of Health, Dr Zweli Mkhize, Budget speech 12 July 2019)

Abstract

Background and rationale: South Africa has the largest and most high-profile HIV epidemic in the world, with an estimated 7.7 million people living with HIV in 2018. The country also has the largest antiretroviral treatment (ART) programme and this has increased life expectancy, reducing the mortality of the affected and consequently led to most people developing comorbidities associated with prolonged survival and aging. Concurrently, South Africa has seen a significant rise in the consumption of processed and ultra-processed foods, including sugary beverages and this has been linked with a corresponding increase in non-communicable (NCD) disease risk such as obesity and Type II Diabetes (hereafter, diabetes). As a result, clustering of HIV and other NCDs such as diabetes and hypertension is becoming common, especially in low income settings. In response to the dual burden of disease, the National Department of Health (NDoH) has implemented the integrated chronic disease management (ICDM) aimed at strengthening primary health care (PHC) facilities to manage chronic conditions. However, chronic care is still fragmented in public health facilities with the HIV programme being 'siloed' within the health system. There is limited literature examining the experience of comorbid patients accessing care, or of the providers in responding to the needs of patients with two or more chronic conditions.

The aim of this thesis was to investigate health and healthcare challenges and opportunities among patients with comorbid diabetes and HIV as well as healthcare workers providing care for them at a tertiary hospital in Soweto, South Africa. The thesis endeavoured to address the following specific objectives: (1) To understand patients' perceptions and experiences in care seeking for comorbid diabetes and HIV at a tertiary hospital in Soweto, and self-management at home; (2) To understand healthcare providers' experience in administering care to patients with comorbid

diabetes and HIV at a tertiary hospital in Soweto, and to investigate their perceptions on integrated and patient-centred care; (3) To understand the factors that facilitate or impede patients' ability to achieve good health and healthcare providers' ability to provide good health care in Soweto.

Study design: This research used ethnographic methods encompassing participant observations at the clinic and in patients' homes, and multiple qualitative interviews with patients and healthcare providers at a tertiary hospital in Soweto. The first study (which answered objective 1) draws from participant observations at the diabetes/endocrine clinic and in patients' homes, and in-depth life narrative interviews with fifteen patients (n=15), who were recruited from the diabetes/endocrine clinic using purposive sampling. The second and third studies (which answered objectives 2 & 3) used observations at the diabetes/endocrine clinic and medical outpatient department (MOPD), and qualitative interviews with healthcare providers. Thirty (n=30) healthcare providers were recruited using purposive sampling from the diabetes/endocrine clinic and the medical outpatient department (MOPD). In addition, the researcher wrote intensive field notes during observations at the clinics and in patient's homes.

Data management and analysis:

Data collection and analysis were conducted concurrently. Data were analysed at two levels. ***Level 1: Analysing data from healthcare providers -*** In this phase, data analysis adopted both deductive and inductive approaches. The deductive codes were informed by literature and questions used in the interview guide while inductive codes emerged from the data. These codes were refined by the constant comparative method. Making comparisons facilitated challenging already grouped data with new categories and this helped in validity and precise interpretation of the data. These categories were then reviewed by other researchers involved in the study, and any identified

discrepancies were solved at this level. The researcher then developed a codebook which she uploaded in QSR Nvivo 12 software where coding was done, and emerging codes were added throughout analysis. Key identified themes in relation to study objectives were used in reporting the findings. ***Level 2: Analysing data from patients:*** The researcher took an inductive approach to analysing data. Initially, the researcher categorised data (coding) from interviews and field notes, based on phrases or patterned meanings that related to the study aims. More categories were added as new ideas emerged from the data. She cross-checked these categories, compared with new data and refined to identify similarities and differences. After developing key categories, the researcher involved other researchers who took part in the study, who collaboratively reviewed the data for further analysis and classifications. Based on collaborative agreement on data analysis, the researcher came up with key emerging themes identified in this study. She summarised these themes and developed case stories which she used in reporting the findings.

Findings:

Objective 1: This study revealed that patients' ability to manage their multiple chronic conditions could not be dissociated from intertwined factors related to social and economic life, access to health facilities, and other family challenges, and household members managing chronic conditions. First, poverty, lack of transport to hospital, food insecurity and living environment (which constrained physical activities) hindered proper self-management. Second, many interlocutors spent a great deal of time caring for others, while neglecting their own health. Third, patients received fragmented services for their chronic comorbidities. Ultimately, this study demonstrates that both physical and mental health are reinforced by social or contextual factors, which render individuals vulnerable to other bodily or affective conditions, which underscores the

tenet of syndemic theory – that structural factors impede individuals lives within the home, community, and clinic, which influence how diseases emerge, cluster, and interact, which produces health outcomes worse than any one single factor might cause alone.

Objective 2: Providers described how they conceptualised and practiced patient-centred care (PCC). Mostly, those who practiced PCC used the Sotho-Tswana idiom ***'Batho-pele'*** principles, which means people come first. Others understood PCC to mean placing the patient at the centre of care; empathising with the patients or treating the patient as a person. Practice of PCC was hampered by both structural barriers within the realms of the health system (e.g. lack of equipment and guidelines for multimorbidity, staff shortages and fragmented care) and patient (e.g. language barrier, poverty, lack of transport to the hospital, and missed clinic appointments). These factors triggered provider frustrations, inabilities, and burnout and constrained their abilities to deliver PCC.

Objective 3: This study found that challenges within the health system, including insufficient medical staff and medication within the PHC clinics necessitated patient referrals to a tertiary hospital. At a tertiary hospital, patients with diabetes were managed first at the MOPD before they were referred to a specialty clinic. Those with comorbidities attended different clinics at the tertiary hospital partly due to the structure of the tertiary hospital that offers specialised care. In addition, there was little to no collaboration amongst healthcare providers due to poor communication, non-centralised patient information, staff shortage, and professional differences amongst providers at a tertiary hospital. As a result, some providers were not aware that patients had other comorbidities

beyond the immediate disease they were treating; patients experienced disjointed care and drug duplications.

Conclusion:

Implementation of the ICDM is underdeveloped in public facilities in Soweto. Patients with diabetes continue to be referred to the tertiary hospital in Soweto when they could easily be managed at PHC clinics. There is need to strengthen PHC clinics in Soweto to manage patients with diabetes, and other comorbidities. This will entail addressing health system challenges such as lack of medical supplies, staff shortages, and non-centralised patient information system in the public healthcare system. There is also a need to ensure appropriate guidelines for comorbidities or multimorbidity exist, are known and available. In addition, healthcare providers (especially at PHC clinics) must be trained to manage diabetes and other chronic conditions, offer integrated and patient-centred care, and utilise cultural humility and structural competence when engaging with patients who struggle financially or prioritise other cultural beliefs to improve patients' routine medical care attendance and adherence to clinical recommendations for long term self-care.

Integrated care must be designed in a way that takes stock of the social embeddedness of diseases, and therefore must be considered as a social practice (as opposed to a medical practice, which is how it is traditionally understood). I argue that integrated care must address both medical (in the clinic) and social (in the home/family) challenges and bring together opportunities for fostering good health in both domains. Thus, integrated care must involve families, households, and social or economic conditions that shape the course of illness.

Finally, this scholarship around living with, caring for, and managing multiple chronic diseases at once sheds light on comorbidity or multimorbidity in SSA, and offers insights into how the healthcare system in SSA could better organise to care for patients with comorbidity or multimorbidity.

Key words: Diabetes; HIV/AIDS; Integrated Chronic Care Management (ICDM); Patient-Centred Care (PCC), Self-management, Health Systems, Primary Health Care (PHC); Structural Vulnerability; Syndemics; Soweto, South Africa.

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Prof Jane Goudge, you were an amazing supervisor to me. Thank you for securing me an office space, a stone's throw away from your office at Centre for Health Policy (CHP). Indeed, sitting

close to your office made it easy for me to access you often. Thank you for introducing me to the CHP Unit, which became my family. CHP seminars and research meetings were an eye opener to my research work. Thank you for facilitating my field work especially during patients' home visits.

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To my Almighty God, you proved to me that everything works for those who trusts in you. Thus far, you led me. May your name be glorified!

Thesis Overview and Structure

This thesis is written 'by publication' and is structured around six chapters as presented below:

Chapter 1: Background and Literature review: In this chapter, I describe the background of the thesis, outline the problem statement, research questions, objectives and the conceptual framework. I then present literature review – including epidemiologic transitions that underpins the dual burden of HIV and NCDs in sub-Saharan Africa (SSA) with a keen focus in South Africa; Health systems and building blocks; South Africa health system and challenges to health care delivery; Key health system reforms in South Africa; Strengthening the health systems to manage chronic comorbidities and theoretical frameworks. I conclude the chapter by summarising the gaps identified in literature, methodology used to fill these gaps and contribution of the current study.

Chapter 2: Research Methods: This chapter covers the methodology used in this study. I begin by describing the study setting and its characteristics, study design (with detailed description of ethnographic methods used for data collection), data management and analysis as well as ethical considerations for the study. I end this chapter with a presentation on reflexivity and positionality which is key in ethnographic studies.

Chapters 3, 4 & 5: Research Findings: I present these chapters as outputs in form of the three PhD papers that make up this thesis. The first paper in chapter 3 forms the foundation of key findings in the thesis, touching on an interplay between structural vulnerabilities and health system challenges, and how they impede patients' access to care and self-management at home. The second paper in chapter 4 explores healthcare providers' experience managing patients with comorbid diabetes and HIV at a tertiary hospital in Soweto, South Africa. It looks at conceptualisations and practices of integrated and patient-centred care, existing challenges and

opportunities. The last paper in Chapter 5 cuts across the three specific objectives for this thesis. It describes care pathways and how the health system functions to care for patients with comorbidities or multimorbidities in Soweto.

Chapter 6: Integrated Discussion and Conclusion: This is the last chapter for this thesis. I provide an integrated discussion that merges the 3 papers that make up this thesis. First, I remind the reader of the specific study objectives and the key research findings that answers these objectives (in a table). I then provide an integrated discussion of the key themes that emerged from the whole research. I do not repeat specific findings from the three papers but provide an integrated discussion that cuts across the three papers and any other theme that emerged in the study that may not have been adequately described in specific papers. I end this chapter by discussing research limitations, recommendations, future direction and overall conclusion to the thesis.

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List of Abbreviations

ART	Antiretroviral Treatment
CCM	Chronic Care Model
CHBAH	Chris Hani Baragwanath Academic Hospital
CHP	Centre for Health Policy
DPHRU	Developmental Pathways for Health Research Unit
HIV	Human Immunodeficiency Virus
HRH	Human Resources for Health
ICCC	Innovative Care for Chronic Conditions
ICD	Infectious Chronic Disease
ICDM	Integrated Chronic Disease Management
IDF	International Diabetes Federation
LMIC	Low- and Middle-Income Countries
MOPD	Medical Outpatient Department
NCD	Non-Communicable Disease
NDoH	National Department of Health
NHI	National Health Insurance
PCC	Patient-Centred Care
PHC	Primary Health Care
PLWHIV	People Living With HIV
QSR	Qualitative Solutions for Research
SAMRC	South Africa Medical Research Council
SSA	sub-Saharan Africa
T2DM	Type II Diabetes Mellitus
TB	Tuberculosis
WHO	World Health Organization

CHAPTER 1: BACKGROUND AND LITERATURE REVIEW

"We need a comprehensive, integrated approach to service delivery. We need to fight fragmentation."

(Margaret Chan, Director General of the World Health Organization, 2007).

1.0 Introduction

This thesis focused on the health and healthcare experiences among patients diagnosed with Type II Diabetes (hereafter diabetes) and HIV comorbidity in Soweto, South Africa. I was interested in this project because I conducted research in Nairobi, Kenya, in 2014 with people who were diagnosed with both HIV and diabetes; I spent hours listening to life history narratives from women living with both conditions, and learning from them what complex challenges they faced associated with caring for multiple conditions. We found differential care was provided to patients with both HIV and diabetes at the public hospital in Nairobi; although HIV care was free of charge and easily accessible (as a result of donor funding), patients were required to pay-out-of-pocket for other conditions like diabetes (see Bosire et al., 2018). This drove my curiosity to investigate health and healthcare for patients with comorbid HIV and diabetes in Soweto, South Africa, given that more people with HIV live in South Africa than anywhere else in the world (UNAIDS, 2019), and many have other co-occurring conditions. Yet, in South Africa there is a stronger primary health care system in the public sector compared to Kenya, and I wanted to understand if the system itself would influence how people perceived and experienced chronic care for multiple conditions at once. Thus, understanding the opportunities and challenges that exist in chronic care may offer insights on how integrated chronic care can meet the growing demand of people living with chronic comorbidities or multimorbidities in sub-Saharan Africa.

This thesis used mixed ethnographic methods to look across the health system in Soweto to unpack what social and medical challenges shape risk for medical challenges associated with the two concurrent diseases, from the perspective of both patients and those working within the healthcare system, who provide routine medical care. Thus, instead of focusing on patients exclusively, as is traditional in anthropology, I did what Laura Nader (1972, p. 284) calls "studying

up", in order to learn not only from patients' experiences but also from healthcare providers and those working in the hospital management, to describe how health and healthcare are defined, mediated, and enabled through the health system.

This chapter will be presented in two sections. Section 1 presents the background to the study – with an outline on the problem statement, research questions, objectives and the theoretical framework. Section 2 presents the literature review and gaps that underpin this research.

1.1 Background to the study

Globally, one of the greatest challenges that health systems in the twenty-first century face is the increasing burden of chronic diseases (WHO, 2002). Greater longevity, 'modernization' of lifestyles, with increasing exposure to many chronic disease risk factors, and the growing ability to intervene to keep people alive, who previously would have died have combined to change the burden of diseases confronting health systems. Low- and middle-income countries (LMICs) are most affected by changes in patterns of population age distributions, fertility, life expectancy, morbidity and mortality, known as the 'epidemiological transition' (McKeown, 2009).

Chronic conditions are defined by the World Health Organization (WHO) as requiring "ongoing management over a period of years or decades" and cover a wide range of health problems that go beyond the conventional definition of chronic illness, such as heart disease, diabetes and asthma (WHO, 2002). They include some infectious chronic diseases, such as the human immunodeficiency virus and the acquired immunodeficiency syndrome (HIV/AIDS), that have been transformed by advances in medications from rapidly progressive deadly conditions into manageable health problems and allowing those affected to live with them for many years (WHO, 2002).

As a result, the increasing incidence of non-communicable diseases (NCDs) such as diabetes are now occurring against a background of continuing infectious disease epidemics (i.e. HIV and tuberculosis), gradually becoming a coinfection epidemic. Persons with chronic diseases require sustained engagement with the healthcare delivery system over the course of their lives (Howard, 2010). Sustained engagement is reflected by the ability of the health system to retain people in care and by the patients' ability to see a clinician familiar with their medical history. This then demands an integrated patient-centred approach to care (Entwistle et al., 2018), whereby health services are delivered in a complementary and coherent manner. These two dimensions are important for the management of chronic diseases that require continuous patient support after diagnosis and a comprehensive treatment approach (Kruk et al., 2018). Yet, the present response of health systems, both in high and in low income countries, is highly inadequate. For example, healthcare in LMICs is still largely built around an acute, episodic model of care that is ill-equipped to meet the requirements of those with chronic health problems (Clarke et al., 2017). As a result, chronic conditions frequently go untreated or are poorly controlled until more serious and acute complications arise, resulting in a heavy burden on health systems, populations and individuals (Gaziano et al., 2017; Jardim et al., 2018).

Comorbidity is not a new term; in the early 1970's, this term was increasingly used to describe the confounding nature of multiple chronic diseases. Clinician Alvan Feinstein first defined the word comorbidity as: "Any distinct additional entity that has existed or may occur during the clinical course of a patient who has the index disease under study" (Feinstein, 1970, p. 456). In other words, comorbidity is the presence of additional disease in relation to an index disease in one individual. Today, multimorbidity – commonly defined as persons with more than one medical conditions (WHO, 2016), is also gaining popularity as the number of individuals

living with more than one conditions is increasing. Changing disease patterns, growing public expectations and health needs are raising the demand for health systems to produce better health outcomes and greater social value. Thus, strengthening health systems to provide optimal healthcare, consistently deliver care that improves or maintains health and responding to changing population needs is paramount (Kruk et al., 2018).

South Africa has the highest number of people with HIV/AIDs globally with 7.7 million people living with HIV in 2018 (UNAIDS, 2019). Since the introduction of ART as a treatment for HIV, life expectancy has been prolonged, reducing the mortality of the affected (Antiretroviral Therapy Cohort Collaboration, 2008; Samji et al., 2013) consequently leading to most people developing comorbidities associated with prolonged survival and aging (Rasmussen et al., 2015; Schouten et al., 2014). As a result, people living with HIV (PLWHIV) are predisposed to similar risk factors to non-communicable diseases (NCDs) such as diabetes or hypertension just like the general population (Bloomfield et al., 2011). In addition, clustering of HIV and diabetes is escalating among low-income populations in South Africa, due to changes in what people eat, activity patterns, and stresses that become part of people's lives (Mendenhall et al., 2017). However, little is known about the complexities that drives the clustering of these diseases, including access to and provision of care in Soweto, South Africa.

1.1.1 Problem Statement and Justification

South Africa maintains the highest number of people living with HIV globally (UNAIDS, 2019; Chang et al., 2019), of which many are co-infected with TB and also, a massive rise in non-communicable diseases (NCDs), including diabetes (Baleta & Mitchell, 2014). A growing number of recent studies have detected diabetes among people living with HIV in South Africa (Clark et al., 2015). The increase in number of people with chronic comorbidities or multimorbidities in

South Africa demands better healthcare system that can provide integrated and patient-centred care through continuous patient support during diagnosis, treatment, and self-management at home. Yet, most healthcare systems in LMICs, including South Africa, are geared towards care for acute conditions with insufficient attention being paid to chronic disease prevention and management. Thus, examining health and healthcare for comorbid diabetes and HIV in Soweto, South Africa provides a robust understanding of the diabetes-HIV intersection, their unique social and medical challenges, as well as useful ways in which integrated care can reduce symptoms and improve health outcomes. This is also imperative as scientists project that the economic impact (productivity loses, absenteeism from work etc.) and death toll associated with diabetes will surpass that of HIV in the near future (Atun et al., 2017).

Management of patients with comorbidities or multimorbidities is proving to be burdensome not only to the patients themselves but also, on the overstretched health system in South Africa (Chang et al., 2019). The question is, are policies or approaches aimed at strengthening the health system feasible and sustainable in the context of a steadily increasing caseload of patients with chronic illnesses? Are they even logical from the perspective of patients with chronic comorbidities or multimorbidities who are grappling with structural vulnerabilities in places like Soweto? These questions make it crucial to better understand syndemic interactions that exist with emerging NCDs and disease precursors.

Chronic disease clustering with social-economic factors makes clinical management more complex, time-consuming, or resource demanding (Valderas et al., 2009). Measuring this complexity, however, remains a challenge. Using a case of patients with comorbid diabetes and HIV, this thesis used a mixed ethnographic design to explore access to and provision of care for

patients with comorbid diabetes and HIV, and provides insights on how care can be organised around patient's needs. Ethnographic design allowed the researcher to take advantage of immersion in clinical spaces – using intimate face-to-face interaction with different actors in the healthcare system and conducting observations at the clinic and in patients' homes. This contributed to a "thick description" of chronic care in Soweto. Specifically, this thesis looked at provider-patient interaction as a means to discover and describe socio-economic and cultural values and beliefs, internalised and materialised within and outside the clinic. Methodologically, the work reported in this thesis emphasises the non-biomedical aspects of medical care, thus, informs how integrated care can better be designed to manage patients with chronic comorbidities or multimorbidities.

1.1.2 Broad Aim of the Study

The main aim of this thesis was to investigate health and healthcare opportunities and challenges among patients with comorbid diabetes and HIV and healthcare providers[2] providing care for them in Soweto, South Africa. The research focused on those seeking care and providing care at Chris Hani Baragwanath Academic Hospital (CHBAH), the largest public tertiary hospital in Soweto, South Africa.

Research Questions

The overarching research questions that guided this thesis include:

[2] *Healthcare providers- included doctors, endocrinologists, dieticians, podiatrists, nurses, hospital administrators, data managers, and social workers who engaged directly or indirectly with patients with HIV, Diabetes or both at CHBAH.*

1. How do patients perceive and experience care seeking for comorbid diabetes and HIV at CHBAH in Soweto? How do they self-manage their chronic illnesses at home?
2. What are the healthcare providers' experience in administering care to patients with diabetes and HIV comorbidities at CHBAH in Soweto? How do healthcare providers perceive integrated and patient-centred care in Soweto?
3. What factors facilitate or impede patients' ability to achieve good health and healthcare providers' ability to provide good health care in Soweto?

Study Objectives

1. To understand patients' perceptions and experiences in care seeking for comorbid diabetes and HIV at CHBAH in Soweto and self-management practices.
2. To understand healthcare providers' experience in administering care to patients with comorbid diabetes-HIV at CHBAH in Soweto, and to investigate their perceptions on integrated chronic care and patient-centred care in Soweto.
3. To understand the factors that facilitate or impede patients' ability to achieve good health and healthcare providers' ability to provide good health care in Soweto.

Organisation of research objectives and PhD Papers

A summary of specific objectives and the answers to these objectives, in form of three PhD papers (with cross cutting findings) is shown in table 1 below:

Table 1: Organisation of research objectives and PhD papers

Research Objectives	Sources of information	Paper 1	Paper 2	Paper 3
Objective 1: To understand patients' perceptions and experiences in care seeking for comorbid diabetes and HIV at CHBAH in Soweto and self-management practices at home.	Narrative interviews with the patients; observations at the clinic; observations at patients' homes.	✓		✓
Objective 2: To understand healthcare providers' experience in administering care to patients with comorbid diabetes-HIV at CHBAH in Soweto, and to investigate their perceptions of integrated chronic care and patient-centred care in Soweto	In-depth interviews with healthcare providers; observations at the diabetes clinic and MOPD.	✓	✓	
Objective 3: To understand the factors that facilitate or impede patients' ability to achieve good health and healthcare providers' ability to provide good health care in Soweto	Interviews with healthcare providers; observations at the diabetes clinic and MOPD; observations at patients' homes.	✓	✓	✓

1.1.3 Conceptual Framework: Chronic Care Model and Collaborative Care Model

This thesis was guided by the Chronic Care Model (CCM) that was developed by Edward Wagner (Wagner et al., 1999) and Collaborative Care Model developed by Craven (2006). The CCM presents a structure for organising healthcare for chronic conditions; it describes how better patient outcome can be improved when there is partnership between patients and families, healthcare teams, and community supporters, with an underlying notion that each member needs

to be informed, motivated and prepared to manage chronic diseases (Wagner et al., 1999). This framework is behind a collaborative model for chronic care, which is a broad term that encompasses a number of primary healthcare interventions that are fundamentally patient-centred and designed to increase access and availability to appropriate care (Craven, 2006). Collaborative care model states that effective care for patients can be achieved though collaboration of care amongst healthcare providers; which will result to improved access to patients, consultations in timely manner and ease in communications between different practitioners on any changes made on the patient, appropriate patient referrals, realistic expectations, adequate patient evaluation and establish a reliable health information tracking system for patients receiving treatment for chronic conditions (Craven, 2006).

I adapted the above models to include aspects of structural vulnerabilities (such as poverty, unemployment, food insecurity, living in unsafe neighbourhoods), and how these factors influenced access to care, quality of care provided, and self-management practices.

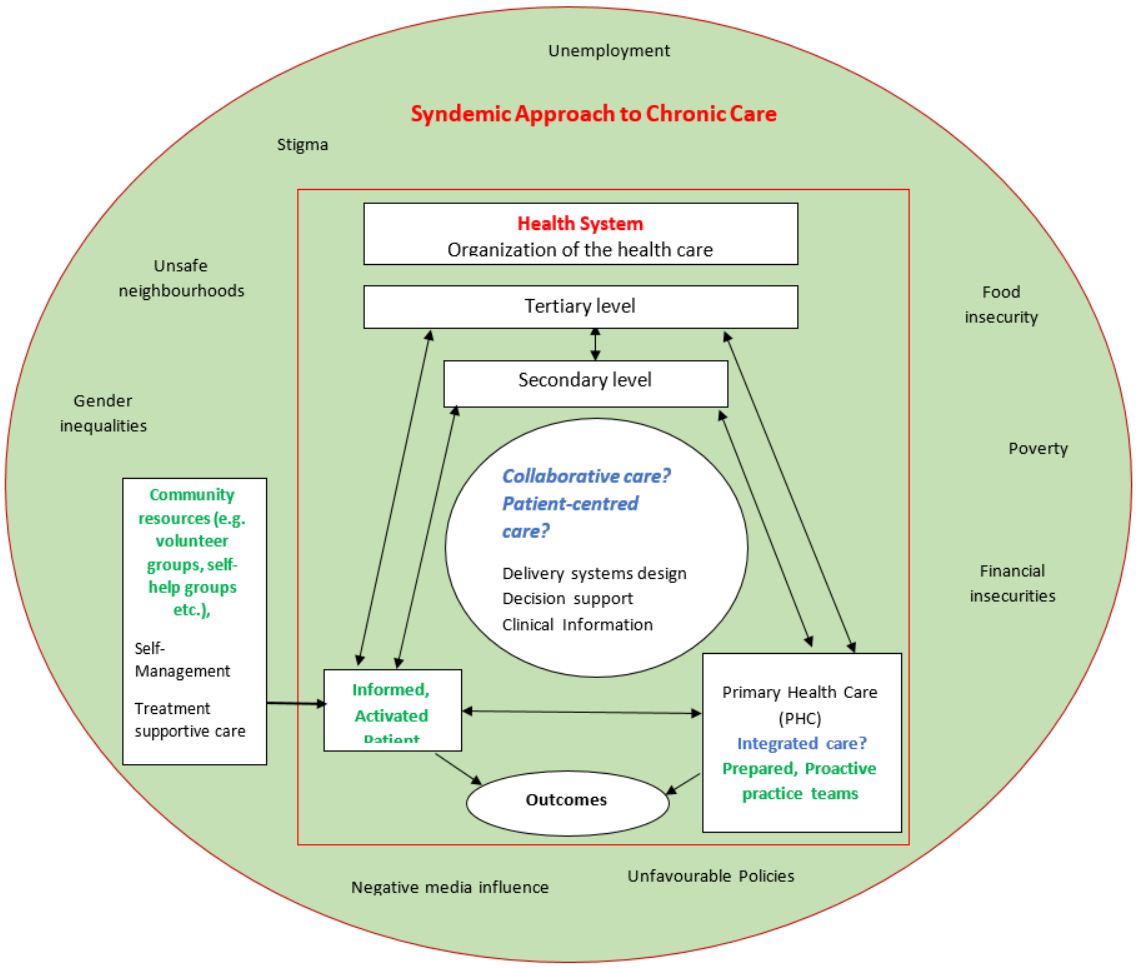

Figure 1: Conceptual framework: Chronic Care Model and Collaborative Care Model
Source: (Adapted from Wagner's Chronic Care model (1999) *and Craven's Collaborative Care Model* (2006)).

1.1.4 Key Concepts

Table 2: Key concepts used in this thesis

Ethnography	The study of social interactions, cultures, behaviours, and perceptions that occur within groups, teams, or communities.
Triangulation	Using more than one method to collect data on the same topic. In this thesis, I use triangulation not only to cross-validate data but rather, to capture different dimensions of the same phenomenon.
Structural vulnerability	A positionality that imposes physical/emotional suffering on specific population groups and individuals in patterned ways.
Syndemics	Clustering of two or more diseases that interact biologically and are driven by social and economic inequalities.
Comorbidities	Presence of additional disease in relation to an index disease in one individual.
Multimorbidities	Coexistence of two or more chronic conditions in the same individual.
Integrated care	The organisation, management and coordination of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money.
Collaborative care	Care that is team based, involving inter-professional cooperation, including a primary or tertiary care team working with specialists e.g. dieticians, mental health professionals etc. to improve patient outcomes.
Patient-centred care (PCC)	PCC aims at designing care based on patient's needs, including the patient as an active participant in his or her care, and to promote the physician-patient partnership in care.
Integrated Chronic Disease Management (ICDM)	This model was introduced in South Africa in 2011, to address several elements of managing comorbidities or multimorbidity. It uses a diagonal approach to health systems strengthening, which integrates the vertical HIV programme with the horizontal general health system.
Epidemiologic transition	This model focuses on the complex change in patterns of health and disease and on the interactions between these patterns and the demographic, economic, and sociological determinants and consequences.
Nutrition transition	This is a model used to describe the shifts in diets, physical activity and causes of disease that accompany changes in economic development, lifestyle, urbanisation, and demography.

1.2. Literature review

Globally, as life expectancy increases, the population incidence of non-communicable diseases is also increasing. In addition infectious diseases such as HIV/AIDS and TB continue to affect millions of people every year (WHO, 2016). Together, all these factors mean that comorbidity or multimorbidity has become, and will increasingly be, an international health challenge. This makes it paramount to understand chronic care opportunities and challenges in sub-Saharan Africa (SSA) (Chang et al., 2019). In addition, it is important to come up with a model or framework for defining or understanding issues around comorbidity or multimorbidity.

Research conducted by multidisciplinary teams or using multidisciplinary approaches could improve countries' efforts to fight diseases and maintain health for the public. However, current research is mostly clinically based – with a focus on prevention, diagnosis and treatment of diseases in isolation. Such gaps could lead to inadequacies in care delivery and management of chronic comorbidities or multimorbidity.

1.2.1 Sub-Saharan Africa

The burden of disease in sub-Saharan Africa (SSA) is largely attributable to infectious diseases (e.g. HIV/AIDS, TB, and Malaria). However, there is an increase in the prevalence of non-communicable diseases (NCDs) in low- and middle-income countries (LMICs) as they develop, known as the epidemiologic transitions. The theory of the epidemiologic transition was first formulated by Omran as a model for integrating epidemiology with demographic changes in human populations (Omran, 1971). Omran stated that this model "focuses on the complex change in patterns of health and disease and on the interactions between these patterns and the demographic, economic, and sociological determinants and consequences" (Omran 1971, p. 509).

The concepts of demographic, epidemiological, and health transitions have proved quite valuable in the study of population changes in SSA.

Epidemiological transitions are unfolding in SSA in a similar pattern as already witnessed in developed countries. The decline in mortality from infectious diseases such as HIV/AIDS has been one of the most significant changes in human history leading to unprecedented increases in life expectancy. This is partly due to improved medications such as anti-retroviral therapy (ART) for people living with HIV (PLWHIV), which has been associated with increased longevity and favourable treatment outcomes (Johnson et al., 2013; Nakagawa et al., 2013). Globally, by the end of 2017, 21 million people were receiving life-saving ART (WHO, 2018). A further 15.8 million are expected to start treatment in accordance with the WHO "treat all" recommendation, resulting in 36.7 million people who must be successfully maintained on lifelong treatment (WHO, 2018). As a result, new HIV infections have been reduced by 40% since the peak in 1997; in 2018, around 1.7 million were newly infected with HIV, compared to 2.9 million in 1997 (UNAIDS, 2019). In SSA, particularly eastern and southern Africa, which is home to 53% of the world's people living with HIV, AIDS-related mortality declined by 42% from 2010 to 2017, reflecting the rapid pace of treatment scale-up in the region (UNAIDS, 2018).

Despite decreases in overall new infections and mortalities, HIV remains a major threat among vulnerable groups in SSA; nearly half of new HIV infections are affecting people living in South Africa, Nigeria and Uganda, where HIV and AIDS is the greatest cause of life-years lost (Piot et al., 2015; Collaborators, 2016). Women continue to account for a disproportionate percentage of new HIV infections among adults (aged 15 and older) in SSA: they represented 59% of the new adult HIV infections in 2017 (UNAIDS, 2018). However, more men than women are dying of AIDS related illnesses: In 2017, an estimated 300 000 men died of AIDS-related illness

compared to 270 000 women. This reflects higher treatment coverage among women than men (UNAIDS, 2018).

In addition, SSA is experiencing a steady rise NCDs (including diabetes, hypertension, cancer and cardio-metabolic and respiratory conditions) (Plewes & Kinsella, 2012) in the presence of significant, long-standing infectious disease prevalence such as HIV and tuberculosis (TB) (UNAIDS, 2013; Murray et al., 2014). The NCD burden is greatest in the region, while treatment for these diseases is largely unaffordable or unavailable (WHO, 2013; Yusuf et al., 2015; Rasha et al., 2016). In the general population, four major NCDs – cardiovascular diseases (including hypertension, heart attack and stroke), cancer, chronic respiratory diseases and diabetes mellitus are now the most common (Ezzati et al., 2005; Mathers, 2006; Parkin, Sitas, & Al, 2008).

Several factors such as the ageing population, economic transition and urbanisation associated with nutrition transition and obesity have contributed to the increased diabetes prevalence (Kengne et al., 2013; Peer et al., 2014; Vorster et al., 2005) and are the modifiable factors for other NCDs (Day & Cois, 2015). This is attributed to the epidemiological transition that has been fuelled by globalisation – a process in which regions are becoming increasingly interconnected through the movement of people, goods, capital and ideas. Population movement from rural to urban areas has led to economic growth and international investment (Mathenge et al., 2010) such as the influx of cheap food, sugary sodas, cheap oil, and mechanisation of tools and transport (Basu et al., 2012), which have influenced what people eat or drink, and "these changes have clashed with human biology to create major changes in body composition" (Popkin et al., 2012, p. 3), consequently leading to an increase in obesity and diabetes at the population-level (Guariguata et al., 2014).

1.2.2 South Africa

Although South Africa maintained a steady decrease in the level of overall mortality for a long time, this trend was reversed by the HIV/AIDS epidemic that dramatically increased overall mortality from the mid-1990s to the mid-2000s (Karim et al., 2009; Kahn et al., 2007). There has been progress in the number of AIDS-related deaths since 2010, with a 50% decrease, from 140 000 deaths to 71 000 deaths (UNAIDS, 2017). The number of new HIV infections fell from 390 000 to 240 000 in the same period. In 2018, the prevalence of HIV in South Africa was estimated at 13% of the total population (Statistics South Africa, 2018). In addition, South Africa has the largest antiretroviral treatment (ART) programme in the world and this has increased survival and ageing among HIV-infected persons, and national life expectancy, rising from 61.2 years in 2010 to 67.7 years in 2015 (SANAC, 2017).

Concurrently, South Africa is the most urbanised country in sub-Saharan Africa with 62% of the country's population living in cities (Prados-Torres et al., 2014; World Urbanization Prospects, 2004). The rapid and unplanned nature of this demographic shift affects life choices and opportunities; contributing to epidemiological transition with an increase in unhealthy dietary patterns, a decrease in physical activity and a rising NCD burden (Moodley et al., 2015). For example, the 2013 South Africa National Health and Nutrition Examination Survey found that 65.1% of women and 31.2% of men are overweight or obese with a 22.9% of children aged 2-14 years overweight/obese (Shisana & Labadarios, 2013). This has been linked to a significant rise in the consumption of processed and ultra-processed foods, including sugary beverages (Bosire et al., 2020; Igumbor et al., 2012). Recent surveys have also linked the high consumption of sugary beverages with a corresponding increase in NCD risk (Vorster et al., 2014). As a result, researchers have confirmed clustering of chronic infectious and non-communicable diseases – such as

HIV/AIDs, TB, T2DM and Hypertension – confirming the epidemiological transition in the country, especially in peri-urban settlements (Oni et al., 2015).

Given the prevalence and trends in HIV/AIDS, interaction between HIV and NCDs such as diabetes is likely to be prolonged for decades. These trends pose major challenges to economic and social development which the countries' health and social systems are currently unable to address. These overlaps of chronic conditions present opportunities for synergistic care, strengthening the case for an improved primary care response.

1.2.3 Diabetes and HIV/AIDS comorbidities

The International Diabetes Federation (IDF) estimates that globally, there are approximately 451 million adults (aged 18-99) who were living with diabetes in 2017 (Cho et al., 2018), compared to 108 million in 1980. The numbers are projected to reach 640 million by 2040 (Dwyer-Lindgren et al., 2016). In addition, it is predicted that the greatest increase in numbers will occur in SSA, where in 2014, 14.2 million adults aged 20-79 years had diabetes, with over two-thirds unaware of their diabetic status. Studies have also reported that approximately 50% of diabetes cases worldwide are undiagnosed, with the majority of these occurring in LMICs (Hall et al., 2011; Levitt et al., 2011). Furthermore, most deaths resulting from diabetes are now afflicting younger people; 77% of deaths due to diabetes in Africa occurred in individuals younger than 60 years of age (IDF, 2017), and more than two thirds of these deaths occurred during people's most productive working years (IDF, 2015). The cost of diabetes treatment and care is also placing a considerable burden to healthcare systems, particularly in SSA (Seuring et al., 2015). This makes it imperative to implement population-based interventions aimed at prevention, early detection, and lifestyle change together with treatment to prevent or delay its progression to complications.

HIV/AIDS, once a death sentence, is now as manageable as any other chronic disease if the treatment is initiated early and maintained (Johnson et al., 2013; Nakagawa & May, 2013). As a result, PLWHIV are predisposed to similar risk factors to NCDs just as the general population (Bloomfield et al., 2011). This is especially common amongst older populations as opposed to younger populations. For example, Rueda and colleagues (2014) found that, 94% of older populations (over 50 years) living with HIV in the United States have at least three multimorbidity including hypertension, diabetes, coronary heart disease, or major depressive disorder. This percentage is devastating because it implies that not only is being on ART a risk factor to early onset of chronic diseases, it is now a major risk factor to both multimorbidity and the challenges that come with it. This trend is worrisome given that these conditions are becoming more prevalent among low-income populations, and shifting from the affluent to the less affluent (Omran, 1971).

In South Africa, clustering of diabetes and HIV is now common (Oni et al., 2015). For instance, diabetes was found to be nearly as common as HIV, tuberculosis (TB), and hypertension in a peri-urban settlement in Cape Town, making up 45% of adults seeking prescriptions (Oni et al., 2015). In this context patients receiving antiretroviral therapy (ART) are more likely to have T2DM than low-income people without HIV (Clark et al., 2015), and this risk increases exponentially the longer one receives ART (Sobieszczyk et al., 2016).

1.2.4 Biological and social linkage between infectious and non-infectious chronic diseases

HIV/AIDS is inter-connected with diabetes both in terms of risk of development of disease, and severity of progression of disease: HIV increases the risk of developing NCDs and NCDs may have an influence in progression and outcomes of HIV disease (Nigatu et al., 2012). For example, PLWHIV who are on ART have been reported to be at high risk of developing T2DM and hypertension, probably due to cumulative exposure to ART (Brown et al., 2005; Monroe & Glesby,

2015); increased risks of cholesterol and fatty acid imbalance which are associated with dyslipidemia and metabolic syndrome (Gibson et al., 2014; Grunfeld, 2010; Stanley & Grinspoon, 2012); as well as aging. Preclinical studies demonstrate that protease inhibitors (PIs) increase insulin resistance through effects on the GLUT-4 transporter and decrease insulin secretion through effects on β-cell function, but the clinical impact of these changes is unclear (Hruz, 2011).

Furthermore, the association between diabetes and obesity persists in HIV; Galli and colleagues (2012) found the prevalence of diabetes in those with normal BMI was 3.2% in HIV patients and 1.1% in HIV uninfected. However, in the overweight and obese categories; diabetes prevalence rose to 3.9% and 12.7% among HIV-infected patients compared with 3.1% and 7.8% respectively in HIV-uninfected patients.

Other examples of the link between infectious chronic diseases (ICD) and NCDs is between tuberculosis (TB) and diabetes. Traditional risk factors for TB include poverty, malnutrition, overcrowding, and HIV/AIDS; however, diabetes, which causes immunosuppression, is increasingly being recognised as an independent risk factor for TB, and the two often coexist and impact each other (Yorke et al., 2017). For instance, diabetes may lead to severe TB disease, reactivation of dormant TB foci, and poor treatment outcomes. Tuberculosis as a disease entity on the other hand and some commonly used anti-tuberculous medications such as rifampicin can complicate glucose control (Dooley & Chaisson, 2009).

In South Africa, the clustering and complexities of chronic diseases primarily occur among low-income groups who demonstrate marked increases in NCDs and experience the highest burden of infectious diseases such as HIV/AIDs (Mayosi et al., 2009). Recent studies have also revealed how clustering of HIV, diabetes, TB and Hypertension are increasingly occurring amongst the poor in South Africa (Oni et al., 2015). Ultimately, living in constrained settings influences how

individuals experience the clustering of these diseases: the social cost (as opposed to the biological effect) of caring for family members, meeting other daily life demands while managing their chronic illness can have an immense impact of their illnesses (Mendenhall & Norris, 2015). Thus, recognising what social forces interact with the comorbidity or multimorbidity within and between populations is important, because, although biological interactions may be similar between diseases, social interactions could have a differential effect on biological outcomes.

Given the risk factors and interaction of ICDs-NCDs – due to a mix of biological, social-political, and environmental factors – interventions to address such interactions must extend beyond the health system, and could be detected or mitigated by routine engagement with the health system (Beaglehole et al., 2008). There is a need for an integrated healthcare systems, particularly strengthening the primary health clinics to offer routine and comprehensive screening and management for co-occurring conditions (Bloomfield et al., 2011).

In light of this, healthcare systems have begun to rethink and organise chronic care in an integrated manner (Wagner, 1998; Epping-Jordan et al., 2004; Nolte & Knai, 2008) as will be described in the next sections.

1.3 Heath systems and the Building Blocks

A health system consists of all organisations, institutions, resources and people whose primary purpose is to improve health (WHO, 2010). This includes efforts to influence determinants of health as well as more direct health improvement activities, to deliver accessible, equitable and good quality health services which are both responsive to community demands and based on the principle of inter-sectoral collaboration. In order to achieve these objectives, a health system must perform a number of basic functions. These include ensuring appropriate stewardship; developing human resources for health; mobilising and allocating adequate finances and other key resources;

developing and maintaining a well-functioning health information system; as well as ensuring equitable access to essential medical products, vaccines and technologies (WHO, 2010).

In 2007, the World Health Organization (WHO) proposed a framework describing health systems in terms of six core components or "building blocks": Service delivery; health workforce; health information systems; access to essential medicines; financing; and leadership/governance (WHO, 2007) (Figure 2). These six building blocks are considered necessary to improve outcomes through desirable attributes such as access, coverage, quality and safety. They also seek to identify WHO's priorities and provide a means of identifying gaps for addressing county-specific challenges. Even though every health system is unique in its given social and cultural environment, all health systems have common elements that are necessary for functionality. These building blocks not only help us to understand health systems better, but they also provide opportunities for system improvement (WHO, 2010). The WHO, the World Bank, and various governments around the world have a common understanding of these key elements.

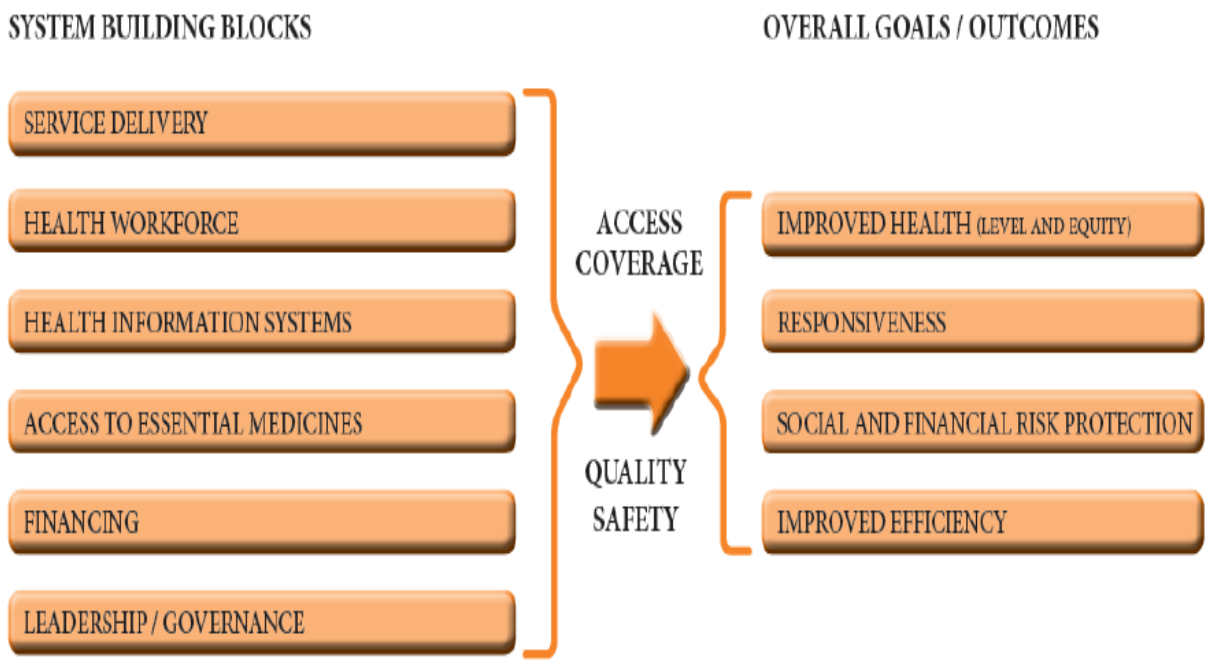

Figure 2: WHO Building blocks
(Source: WHO, 2010)

To achieve the health system goals, every health system must carry out some basic functions, regardless of how they are organised: they have to provide services; develop health workers and other key resources; mobilise and allocate finances, and ensure health system leadership and governance (WHO, 2002).

However, it is important to consider the following points: first, focusing on the WHO building blocks alone without considering the context where these elements are to be applied may be misleading (Saltman et al., 1998). For instance, implementation of the WHO health system building blocks may produce different results in different contexts. This is because, health systems are context-specific (WHO, 2007), and are "strongly influenced by the underlying norms and

values of the broader society within which they function" (Saltman et al., 1998, p. 2). In other words, they mirror the deeply rooted societal normative beliefs of the nature of health care itself. Thus, the healthcare system of each country is determined by its "historical experience, culture, economy, political ideology, social organisation, level of education, standard of living and attitudes towards welfare and the role of the state" (Cockerham, 2010, p. 286).

Second, health systems are made up of both structural (e.g. organisational, policy, legal and financing frameworks) and social (e.g. norms, traditions, values, roles and procedures) elements (Gilson, 2012). These elements work together to determine the success of the health system, which in turn, influence health system performance (Gilson, 2012). In order to identify actions to strengthen health systems, health policy makers and researchers should consider both structural and social components of the healthcare system.

Third, it must be noted that no pure ideal type of health system exists in reality as health systems are highly dynamic entities sensitive to socio-economic and political changes (Van Rensburg, 2012, p. 11). Thus, reforming a health system is not a one-size fit all process because it must balance between the pressures associated with the historical, social, economic and political contexts (Freeman, 1998, p. 395). As such, the unique nature of a health system can only be understood by understanding the historical context from whence it developed.

This background leads us to understand the historical context of South African health system.

1.3.1 South Africa's Health system: A Historical perspective

South Africa's health system cannot be understood outside its societal context (Harrison, 2009; Day, 2007). Many of the challenges within the South Africa's health system can be traced back to the apartheid period (1948–1993) (Packard 1989), during which the health system was highly fragmented, with discriminatory effect, between four different racial groups (black, mixed race, Indian and white) (Baker, 2010, p. 79). The apartheid government developed 10 Bantustans (the so-called ethnic homelands) into which Africans were unwillingly segregated, and each of which had their own departments of health with their professional bodies (Baker, 2010, p. 80). For example, in the early 1970s, one doctor served 15,000 people living in the Bantustans (black African) compared to 1,700 in the rest of the country. Epidemics and deaths associated with diseases such as tuberculosis (TB) were much higher in black and coloured populations than amongst whites (Ataguba & McIntyre, 2012; Coovadia et al., 2009). Utilisation of the then-expanding private health sector was also racially skewed towards white users, and human as well as financial resources were increasingly drawn into private care. By 1980, 40% of doctors worked in the private sector, increasing to over 60% by 1990 (Krugg & Alarcos, 2017; Ataguba & McIntyre, 2012). This led to deterioration in public health system delivery because of lack of resources, and poor communities were especially affected (Chassin & Loeb, 2013, p. 462).

In 1994, a new single deracialised public health system was born with national, provincial and local government services to provide comprehensive healthcare as stipulated in the White Paper on the Transformation of the Health Care System (Department of Health, 1997) and the National Health Act (Department of Health, 2003). These changes were aimed at improving quality, equitable access, efficiency and effectiveness of the health system. Recently, other reforms including the Bill of Rights, Batho Pele (People First) Principles, the National Health Act of 2003,

the Patients' Rights' Charter (Hassim et al., 2007), and a recently proposed National Health Insurance System (NHI) to deliver affordable, quality care to all in need (South Africa Republic, 2015) have been developed to protect human rights and redress health and wealth disparities (these policies or changes are expounded in the subsequent chapters in this thesis). Despite the health reforms, little progress has been made and the country is still grappling with massive health inequities (Coovadia et al., 2009). In addition, significant gaps to access to healthcare still remain (Lam et al., 2011; NDoH, 2011).

The South African constitution guarantees every citizen access to health services (section 27 of the Bill of Rights). With an estimated population of 55.5 million people (NDoH, 2016), about 84% depend on the public health sector for their healthcare needs (Naidoo 2012, p. 149) while private hospital utilisation is largely limited to the relatively wealthy and employed (16%) who have private health insurance (often paid for as part of formal employment conditions of service) (Krugg & Alarcos, 2017). Furthermore, private hospitals are generally better equipped in terms of resources, staffing and infrastructure (Krugg & Alarcos, 2017; McIntyre et al., 2007) attracting an estimated 79% of all doctors, with one specialist doctor serving fewer than 500 people on average (compared to nearly 11,000 people in the public sector) (Krugg & Alarcos, 2017). Thus, the private-public divide (and vast discrepancies in resources consumed by each sector) continues to reinforce unfair, avoidable inequalities in access to services and health outcomes, thereby undermining efforts aimed at enhancing universal health coverage (Fusheini, Eyes, & Goudge, 2017).

Notably, the South African health system infrastructure is also constrained by staff shortages (Coovadia et al., 2009, p. 821; Voget, 2017, p. 16) due to a high demand and the

quadruple burden of diseases: the HIV/AIDS epidemic alongside a high burden of TB; maternal and child mortality; violence and injuries; and a growing burden of NCDs including diabetes (Oni et al., 2015; Oni et al., 2014). In addition, the sudden influx of people into cities has increased demand especially in urban health facilities, and this has forced facilities to function beyond their intended capacity. This has also contributed to overcrowding in urban state facilities, which has negatively affected the quality of care delivered (Kamndaya et al., 2014, p. 581). These problems, to a large extent, are deeply rooted in the structural violence (Galtung, 1969) that was designed during the apartheid period and continue to shape health and illness experience in the South African healthcare system today.

1.3.2 Challenges to health care delivery in South Africa

Health system in South Africa remains strongly fragmented, with decision-making driven more by service than population needs (NDoH, 2011). Some of the key challenges affecting service delivery in health system in South Africa are discussed below:

Leadership and Governance

Leadership and governance have increasingly been recognised as critical as ever for health system reforms and development (Frenk, 2010; WHO, 2008). The particular importance of leadership, was also affirmed by the Alliance for Health Policy and Systems Research (AHPSR) 2016 Flagship Report 'Open Mindsets: Participatory Leadership for Health' (AHPSR, 2016). This is key in the South Africa's health system, where various initiatives such as health system strengthening, PHC re-engineering, introduction of NHI or improved quality assurance are taking place (Gilson & Daire, 2011). However, the nature of existing public sector leadership practices in the South African health system setting shows that individual leaders often exercise power in

quite authoritarian and hierarchical ways (Gilson & Daire, 2011). In addition, lack of accountability, coupled with corruption and misconduct among Department of Health officials (Siddle, 2011, p. 6), has also caused the government to fail in fulfilling its constitutional mandate to deliver quality healthcare.

Furthermore, numerous and complex overlapping issues including erosion of confidence in the Health Professions Council of South Africa (HPCSA), and administrative irregularities have been reported (Mayosi et al., 2015). In addition, the industrial action in three provinces (Gauteng, Limpopo and North West) has reported a dysfunctional and weak public healthcare system (Masweneng, 2018; Postman, 2018), characterised by inadequate or poor dispute resolution mechanisms, failure to finalise the minimum service level agreement in the central bargaining council, and inadequate performance management. These problems impact ultimately on the right of people to access healthcare services, and lead to avoidable deaths and further weakening of a fragile healthcare system (Masweneng, 2018; Postman, 2018). As a result, poor leadership practices have potentially influenced slower adoption and implementation of policies aimed at strengthening primary health care such as the integrated chronic care (Gilson & Agyepong, 2018).

Human resource

Human resources for health (HRH) are critical to the achievement of universal health coverage reforms in South Africa (SAHR, 2018, p. 15). Although South Africa is ranked among the top five countries in the African region in terms of density of physicians and nursing and midwifery personnel per 1 000 population (WHO, 2018), there are several reports of acute staff shortages in the public health sector in general, and in rural and underserved areas in particular (Gauteng Department of Health, 2017; NDoH, 2017; Rural Health Advocacy Project, 2018). In

addition, shortfalls in institutional capacity also extend to insufficient clinical human resources, especially the number of doctors and nurses (Surender, 2017). Again, evidence suggests that South Africa's education system is unable to produce the number of health personnel required (Surender, 2017). The government's attempts to redress the shortage of health personnel by increasing the intake of training institutions and utilising training facilities in Cuba to quickly "grow" the capacity are essential, and must also be accompanied by efforts to stem the drain of the existing pool of professionals to the private sector or overseas (Health Systems Trust, 2013).

The database on the number of practicing health workers in the country also remain underdeveloped and under-utilised (Academy of Science of South Africa, 2018). Further, an updated and accurate information is also lacking on the mal-distribution of healthcare personnel between urban and rural areas, between the public and private healthcare sectors, and within provinces (Day & Gray, 2018).

Human resource issues are pertinent in the South African healthcare system, especially now that the country is experiencing a rapid increase of individuals with multiple chronic conditions. Given health professionals' involvement in all aspects of integrated and patient centred care, the failure to adequately address human resource issues will mean slow implementation of policies aimed at improving chronic patient's care.

Medical products, vaccines and technology

Medicines, vaccines and technology are key health system building blocks and hardware (WHO, 2010); it is a basic function of the health system to have appropriate drugs available to treat patients. The components of the health system that fulfil this function together constitute the pharmaceutical system which includes all the structures, people, resources, processes, and their

interactions with the broader health system, that aim to ensure equitable and timely access to safe, effective, quality pharmaceutical products and related services that promote their appropriate and cost-effective use to improve health outcomes (Hafner et al., 2016).

Medicines are critical for high-quality health service delivery, and when they are used appropriately, they save lives and improve the health of individuals and families.

The unavailability of medicines has been found to be one of the key barriers to accessing essential medicines in South Africa (Magadzire et al., 2014). Over the past three years, stock-outs of TB and ARV drugs in public health facilities have been emphasised in media reports in South Africa (Seunanden, 2014; Bateman, 2013). Most provinces affected by these shortages include Eastern Cape, Gauteng and Free State (Bangalee, 2016). Drug stock out has been attributed to inadequate health workforce particularly pharmacy personnel, poor medicine stock management, and inefficient communication between suppliers, depots and health facilities (Bateman, 2013). The fundamentals have been put in place to ensure that coherent drug and medical products procurement and distribution systems function appropriately. However, issues to do with drug stock-out in the healthcare system in South Africa continue to influence the quality of care provided to patients with chronic illnesses. Improvements on medical supplies including medicine, specifically in PHC clinics which are usually the entry point for citizens into the healthcare system, will be a key marker of the effectiveness of the current public health system and the future system based on NHI and universal health coverage.

Information systems

According the World Health Organization, "the goal of a health information system is often narrowly defined as the production of good-quality data. However, its main goal is to produce

relevant information that health system stakeholders can use for making transparent and evidence-based decisions for health system interventions" (WHO 2008, p. 12). The South Africa Health Review (SAHR) in 2011 highlighted the importance of being able to access good quality data housed in a single, comprehensive data repository for monitoring and evaluating progress towards attainment of health related goals (English et al., 2011). Key developments aimed at strengthening the health information system in South Africa were also presented, including the development of a District Health Management Information Systems policy, improvements in both the quality and quantity of information available using a HST's District Health Barometer (Massyn et al., 2016), which makes available a vast range of cross-sectional and longitudinal information, with comparisons among districts and provinces on key health performance indicators. Despite these data being available, there has been lack of district and provincial synthesis of information; lack of utilization of information for management; and lack of feedback of information, with the result that local staff do not routinely assess the efficiency and effectiveness of their work around the country (Raff & James, 2003).

Lack of a proper system for patient information continue to compound challenges experienced by healthcare providers, as well as patients in developing positive partnerships to care. Thus, there is a need to address issues on patient information systems by adopting a centralised system where patient information can be tracked and used by providers.

1.4 Key health system reforms in South Africa

Twenty years after the election of its first democratic government, South Africa continues to strive for an improved health system – a health system that better meets the needs and preferences for treatment, care, and dignity, of all its population (Department of Health, 2017).

However, the health sector continues to face significant challenges, which include a quadruple burden of disease- HIV/AIDS, non-communicable diseases (NCDs), perinatal and maternal diseases, and violence and injury (Coovadia et al., 2009). In addition, many other factors contribute to the absolute and relative poor health status of South Africans; the widely acknowledged social determinants of health (particularly poverty, income inequality, high unemployment and poor living conditions) (World Bank, 2018) are an important part of the narrative. Other weaknesses in the areas of inequitable distribution of human resources and leadership are also cause for concern.

In order to combat the challenges of an inequitable health system, the National Department of Health (NDoH) has initiated a number of reforms to address the recognised challenges within the health sector. Most of these reforms resonates with the South Africa government's White Paper on re-engineering Primary Health Care (PHC) in South Africa and the National Health Insurance (NHI), which covers all these set of health services, aimed at providing a continuum of care from community outreach, health promotion and prevention (NDoH, 2017). The NHI is being implemented under the umbrella of WHO's Universal Health Coverage (UHC) (Van Rensburg, 2012, p. 47). Some of the key health system reforms are discussed below:

1.4.1 Re-engineering primary health care in South Africa

Primary health care (PHC), delivered through the district health system, was made the cornerstone of the health care reform in South Africa – beginning a shift from the earlier hospital-based curative approach (Department of Health, 1997, p. 4). This ensured that all user fees in public health facilities were abolished for pregnant women, children under six years of age and people living with disabilities. The free care policy at PHC was extended to all users; offering free hospital services to children below the age of 14, pregnant women, pensioners, the formally

unemployed and people on social grants (Department of Health, 1997). It also offered free TB screening and treatment, HIV counselling and testing, prevention of mother to child transmission of HIV (PMTCT), cervical cancer screening and medico legal services for sexual assault survivors (Van Rensburg, 2012, p. 128).

Primary health care re-engineering that is underway in South Africa, places greater emphasis on the delivery of community-based services by 'more pro-actively reaching out to families, with an emphasis on disease prevention, health promotion and community participation (Schaay, Sanders, & Kruger, 2011). This represents a shift away from the predominantly curative focus that characterises the delivery of health services at present.

The model is rolled out in three phases: the first phase involves deployment of District Clinical Specialist teams (DCST) to each of the 52 districts in the country to strengthen clinical governance of district based maternal and child health services at hospitals, community and primary healthcare facilities and home-based levels, in order to promote the wellbeing of the population within a geographical catchment area. The second phase is the revitalisation and strengthening of the School Health Policy of 2003 in partnership with the Department of Basic Education and Social Development. The third phase involves a ward based PHC outreach model (WBOT) which will form an integral part in ensuring continuity of care by interacting directly with the community (National Department of Health, 2011). It is envisaged that the community outreach activities will be facilitated by a PHC outreach team consisting of both nurses and community health workers (CHWs), who in turn are supported by facility-based and specialist support teams of health professionals. The CHWs will form the backbone of the "assisted" self-management for patients with chronic conditions.

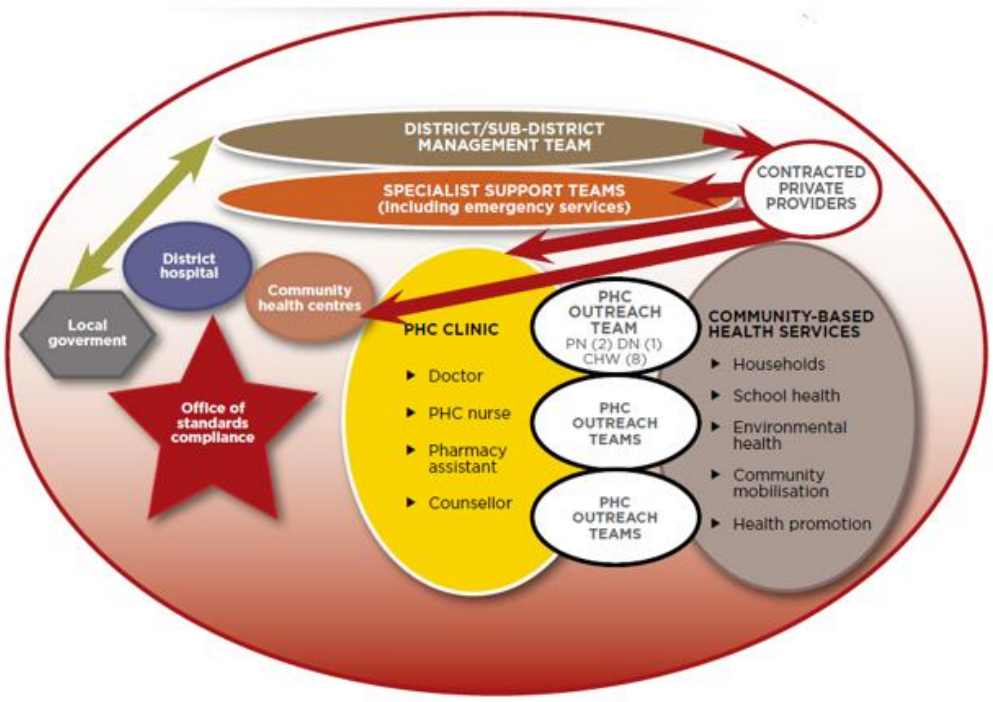

Figure 3: Primary Health Care Re-engineering Model
(Source: The Integrated Chronic Disease Management Manual (NDOH, 2011))

The national initiative to 're-engineer' the PHC approach in South Africa has already gained significant momentum in the Eastern Cape, where a similar model of health care delivery is being piloted in four sub-districts, with the aim of replicating it throughout the province (Eastern Cape DOH, 2011). Given that the establishment of family health teams has been placed as one of the strategic objectives under Programme 4 (Primary Health Care Services) in the National Department's Annual Performance Plan (2011/2012), it is likely that similar initiatives to this will gain momentum in other provinces as well. In addition, it has been postulated that the success of PHC re-engineering will be one of the steps along the way towards a NHI (Schaay, Sanders, & Kruger, 2011, p. 17).

1.4.2 The National Health Insurance (NHI) Scheme

The National Health Insurance (NHI) is a key policy framework for the evolution of the health system in South Africa. The main objective of the NHI is to put into place the necessary funding and service delivery mechanisms to enable the creation of an efficient, equitable and sustainable healthcare system in South Africa (Department of Health, 2017). In order to address the imbalances in access, utilization of services and health care outcomes among the different socioeconomic groups, the NHI's proposals intend a fundamental transformation of the system (Department of Health, 2017). The proposed new NHI system will be underpinned by an NHI Fund which will provide finance for health care and will enter into contracts with public and private hospital specialists as well as public and private GP practices to deliver health services free of charge to every South African citizen and legal resident (Surender, 2017, p. 10). Specifically, the policy envisages that a single purchaser will integrate the private and public sectors and that a unified central fund will reduce the fragmentation and inequities inherent in the system (DOH, 2011; Moleko, 2014). By this, the NHI will ensure that individuals and households do not suffer financial hardship and/or are not hindered from accessing healthcare services. It involves eliminating various forms of direct payments such as user charges, co-payments and direct out-of-pocket payments to accredited health service providers. In effect, the NHI aims at providing a comprehensive package of health services to all South Africans according to need and not ability to pay (Fusheini, 2016). NHI will be funded mainly through general tax sources (from the employed individuals), and the removal of tax subsidies for private insurance (Fusheini, 2016). NHI piloting started April 2012 in ten districts and this paves way for its implementation (Schaay, Sanders, & Kruger, 2011, p. 18).

To date, policy documents outlining the approach to NHI and its phased introduction have been issued in terms of the existing National Health Act (NHA). A white paper was issued in June 2017, which gave additional clarity on the ways in which NHI will be handled legislatively (South African Government, 2017). The commitment to a purchaser-provider split was also re-stated. However, while a range of financing options was outlined, none has been finalised, nor is there evidence of consensus between the Departments of Health and Treasury, despite the modest adjustment to medical scheme tax credits introduced in the 2018 Budget (National Treasury, 2018). In addition, despite the roll out and initial piloting of the NHI, the 'two-tier' private-public split in healthcare are still highly inequitable, with the private sector serving just 16% of the population while absorbing almost half of the country's healthcare expenditure (Department of Health, 2017). Furthermore, there are disagreements between the private and public sector on NHI implementation, and no official statement has been provided on how the Department of Health will reduce private health care costs (Surender, 2017).

Despite its importance, the NHI is still being worked out and some of the issues raised above need to be addressed for its success. Importantly, although the NHI is used by many to describe the many changes planned for making the health system more equitable, NHI is a narrow financing mechanism for public health services. As such, other strategies of strengthening the healthcare system, including implementation of the integrated chronic care particularly in primary healthcare facilities in South Africa is important. In the next section, I look at approaches that are being employed across the globe, and particularly in South Africa to strengthen the health system, in order to improve care for patients with chronic diseases.

1.5 Strengthening health system to manage chronic disease burden

The undeniable shift in health problems, away from infectious and perinatal conditions to chronic health problems, has far reaching implications and poses predictable and significant threats to all countries. Patients' needs require more continuous care coordination and integration across different healthcare providers (Hall, 2015). However, most healthcare systems in low- and middle-income countries (LMICs), including South Africa, are geared towards care for acute conditions with insufficient attention being paid to chronic disease prevention, health promotion, and community participation. As a result, patients with chronic conditions continue to receive fragmented care (Hall, 2015; Oni, 2015; O'Connor, 2014). To reform the fragmented system, new integrated care models are being tried out around the world (Busse & Stahl, 2014; Yip & Hsiao, 2014), including in South Africa (Mahomed & Asmall, 2014, 2016).

1.5.1 Chronic Care Models (CCM)

The chronic care model (CCM) developed in the 1990s by Wagner and colleagues (1996) has been a widely adopted framework, which is considered to be effective in guiding the design of services for chronic conditions (Coleman et al., 2009). The model argues that real improvement in outcomes will occur only when clinical systems reconfigure themselves specifically to address the needs and concerns of chronically ill patients. The CCM applies to a broad range of chronic illnesses and serves as a roadmap for physicians to organise their practices and to meet the complex needs of chronically ill people. It provides a proactive; patient-centred, evidence-based approach and has six major elements that interact to promote high quality care for patients with chronic disease: Health systems organisation, clinical information system, decision support, delivery system design, self-management support and community resources.

Research suggests that practices redesigned in accordance with the CCM have generally improved the quality of care and the outcomes for patients with various chronic illnesses. For example, patients with asthma were more likely than patients whose practices did not redesign care to monitor their peak flows and have a written action plan, and their quality of life improved (Mangione-Smith et al., 2005). Also, patients with diabetes experienced reduced risk of cardiovascular disease; for every forty-eight patients who received care from a redesigned practice, risk declined by one cardiovascular disease event (Vargas et al., 2007).

However, as Beaglehole and colleagues point out, most studies on the organisation of services to deliver quality chronic care are from high income countries and frame-works such as the CCM may not be directly applicable to LMICs (Beaglehole et al., 2008). This is because of the challenges that most LMICs face such as lack of medical supplies, insufficient staff and poor stewardship (Beaglehole et al., 2008), and these factors are usually not considered in the design of these models of care. In addition, chronic care models are labour-intensive, costly hence not sustainable in most LMICs (Ku & Kegels, 2015). Also, these models do not offer practical resources (e.g., financial assistance, transportation) that may help patients in accessing care and self-management (Boehmer et al., 2018). Therefore, the application of such models of care is limited if not adapted to the specific context and constraints of LMICs (Ku & Kegels, 2015).

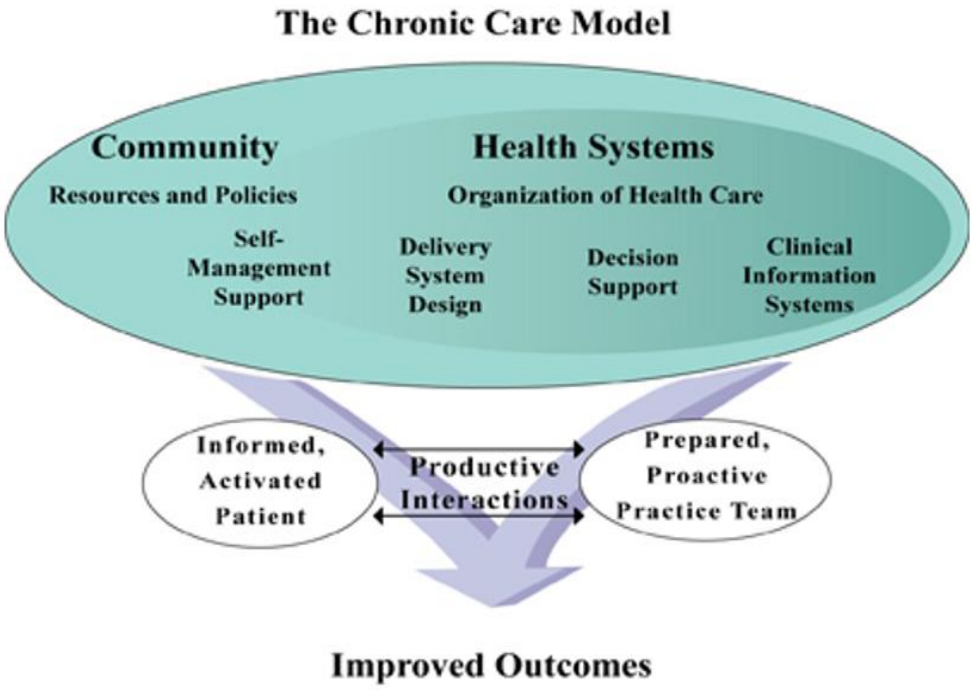

Figure 4: The Chronic Care Model
(Source: Wagner & Austin, 1996)

1.5.2 The Innovative Care for Chronic Conditions (ICCC) framework

Innovative care means re-orienting healthcare systems such that outcomes valued by the system are the ones that are actually produced. The ICCC framework was introduced by the WHO in 2002 (WHO, 2002) as an expansion of an earlier model, the Chronic Care Model, which was developed by Wagner et al. in the mid-1990s (Wagner & Austin, 1996). Innovative care elevates the roles of patients and their families and recognises that they can most effectively manage chronic conditions with the support of their health care teams and their communities. Here, patients, communities, and health care organisations each have important roles to play in improving outcomes for chronic problems.

The key guiding principles of ICCC include: Evidence based decision making – which means that all decisions pertaining to policy-making, service planning and clinical management of chronic conditions should be based on reliable data and information systems. ICCC also focuses on the general population rather than an individual patient; prevention; quality service provision and integrated care. Finally, it also looks at systems that are flexible and well prepared to adapt to changing situations, new information, and unforeseen events (WHO, 2002).

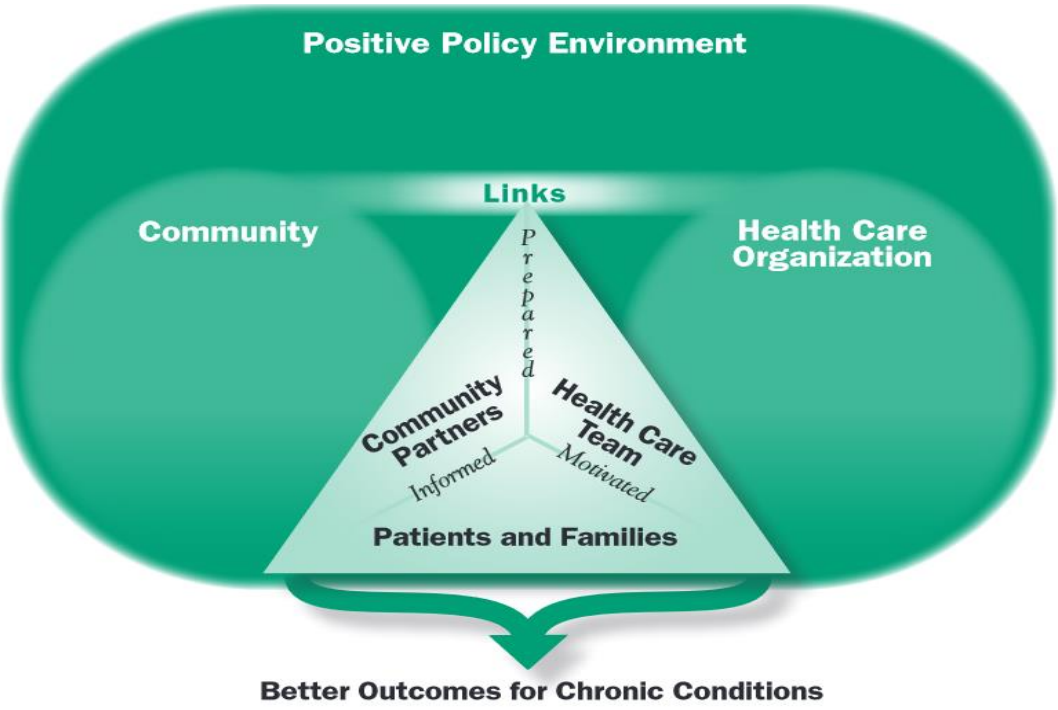

Figure 5: The Innovative Care for Chronic Conditions framework
(Source: World Health Organisation, 2002, p. 45)

At the micro-level, patients and their families are the most undervalued assets in the healthcare system, yet the effect of ignoring them when managing chronic conditions is undeniable. The triad at the centre of the ICCC Framework consists of the patient and family, community partners, and the health care team. This partnership triad is important to the care of

chronic conditions because, whereas successful outcomes for acute health problems can occur with a single health care provider, positive outcomes for chronic conditions are achieved only when patients and families, community partners, and health care teams are informed, motivated, prepared, and working together. However, the triad is influenced and supported by the larger healthcare organisation and by the broader community, which in turn influence, and are influenced by, the broader policy environment. In essence, the meso and macro levels of the system enable the triad of the patient/family, community partners, and health care team to function at its best.

Although the ICCC aims at empowering patients and families in chronic care, it fails to take stock of the various structural vulnerabilities (e.g. poverty, unemployment etc) that creates risk for developing chronic diseases in the first place or hinders patients from accessing or actively participating in care. Thus, the ICCC must be adapted to take stock of structural vulnerabilities at population level. It must also ensure quality communication between health professionals and patients, emphasis on the availability of essential medicines, diagnostics and trained personnel at decentralised levels of healthcare, and care coordination between healthcare providers.

1.5.3 Integrated Chronic Disease Management (ICDM) Model

Integrated health services means different things to different people as well as different levels of care (e.g. primary level versus tertiary level) (WHO, 2008, p. 3). For example, different models have been used to describe integrated care: Integrated community-based screening for HIV and NCDs in the general population; screening for NCDs and NCD risk factors among HIV patients enrolled in care; integration of HIV and NCD care within clinics; differentiated care for patients with HIV and/or NCDs; and population healthcare for all (see Njuguna et al., 2018).

The most commonly used definition is that of the World Health Organization (WHO), which defines integrated healthcare as *"the organisation and management of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money"* (WHO, 2008, p. 5). In other words, healthcare systems need to be organised in a way that will provide a comprehensive, effective, and appropriate service for chronic, long term care while maintaining and improving the capacity and quality of the acute care services rendered (Mahomed & Asmall, 2016).

The ICDM was recently introduced in South Africa to address several elements of managing multimorbidity, including standardised clinical care based on national treatment protocols, and promotion of disease monitoring and management among patients (Mahomed & Asmall, 2014). The National Department of Health (NDoH) with the support of the US President's Emergency Plan for AIDS relief (PEPFAR) developed an ICDM model based on the building blocks set out in the World Health Organization (WHO) document Innovative Care for Chronic Conditions: Building Blocks for Action (NDoH, 2011). This is part of the effort to re-engineer its PHC system (Mahomed & Asmall, 2014). Unlike the HIV care models that are vertical in nature – where interventions are solely focussed on HIV/AIDS and separated from all other activities – the ICDM adopts a diagonal approach to health system strengthening (Mahomed & Asmall, 2014). In other words, integrated care in the South African context means decentralising chronic care clinics where patients with HIV and NCDs (e.g. diabetes) receive integrated prevention, treatment and care at primary healthcare clinics (PHCs). Yet, it is important to note that decentralising chronic care to PHCs does not mean doing away with integrated care in secondary or tertiary levels of care. Integrated care should take cognizant of care across the different levels because, some patients may still require specialist care at a tertiary hospital, while also attending PHC clinic for

another illness. This then leads to my argument that chronic care could be better organised to reduce the negative effect of fragmentation. This will also ensure a seamless transition to "assisted" self-management within the community (National Department of Health, 2011).

The initiation of the ICDM commenced in April 2011 in the Dr Kenneth Kaunda District in the North West Province, West Rand Health District in Gauteng and Bushbuckridge sub-district in the Ehlanzeni District of Mpumalanga. It was implemented at 42 selected primary healthcare (PHC) facilities in a phased approach across the three districts. The lessons learnt during this pilot phase have been used to refine the tools and the methodology employed to ease implementation of the model at all PHC facilities.

However, recent studies that have evaluated the ICDM in South Africa have reported that the ICDM model is underdeveloped in most public healthcare facilities due to health systems challenges (e.g. staff shortages, inadequate equipment, unskilled providers or lack of multimorbidity guidelines) (Ameh et al., 2017; Matima et al., 2018). Consequently, care for chronic diseases is still fragmented and uncoordinated (Kawonga et al., 2013). In other words, healthcare is provided through a multiple level system that requires patients to seek medical care from the primary health centre in their community to higher levels of care, such as Chris Hani Baragwanath Academic Hospital, which provides care upon referral. While this may jeopardise healthcare quality and efficiency for any patient, it is particularly troublesome for those with more than one chronic condition who receive disjointed care with little collaboration amongst providers. For instance, patients with comorbid HIV and diabetes may receive comprehensive HIV care at primary health care clinics while comprehensive care for their diabetes is only provided at secondary or tertiary levels. This then becomes problematic when care is uncoordinated and

providers at tertiary hospital fails to know what other care patient is receiving at PHCs. Thus, it is important to ensure that integrated care is implemented across the healthcare system by ensuring proper communication systems and updated systems on patient records.

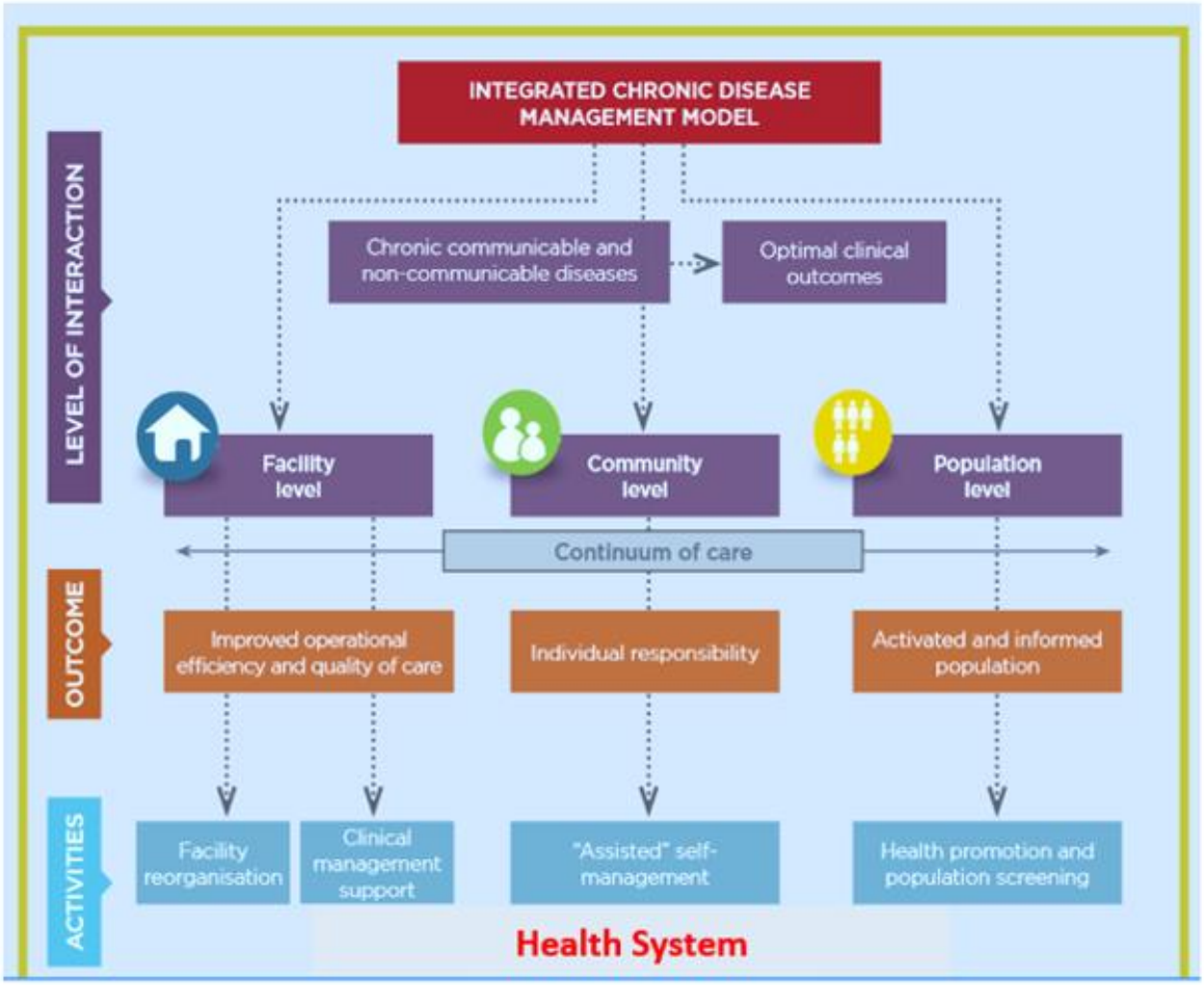

Figure 6: The Integrated Chronic Disease Management (ICDM) model
(Source: Adapted from the Integrated Chronic Disease Management Manual (NDOH, 2011))

1.6 Theoretical framework

Socio-economic and political contexts shape health systems as well how and where health and diseases cluster together among individuals and communities. Beyond systems of health and healthcare, this thesis uses theories of structural vulnerability to consider how broader social, political, and economic factors influence patient experiences, and syndemics to consider how such experiences are revealed in population health. Recognising how myriad synergistic factors produce disease clusters, and how synergistic interactions and oppression may make disease experiences worse, underscore why an integrated approach to chronic care matters.

1.6.1 Structural vulnerability framework

Structural vulnerability has been defined as individual's or a population group's condition of being at risk for negative health outcomes through their interface with socio-economic, political, and cultural/normative hierarchies (Bourgois et al., 2011; Holmes, 2011). In his ethnographic account in a farm in the United States, Homes (2011) describes how hierarchies of ethnicity and citizenship are played out, and how they lead to structural vulnerabilities. For example, social inequalities and racial classifications segregate the poor (mostly undocumented Mexican laborers) in terms of the kind of jobs they do, where they work, and even how they work. In this context, the poor labourers also experience poor housing, minimum wages and poor access to healthcare – which contributes to social disparities in health. Quesada and others (2011) have also described how structural vulnerability may affect patients' access to healthcare and essential public health programs (such as immunisations), generating financial barriers, and those that result from social distance and hierarchies, making supportive engagement between patient and health provider complex.

Among Black South Africans, historical racial segregation, intensified by apartheid, created an inherent structural vulnerability, or what Paul Farmer (2009) defines as how "social forces" are at work to "structure risk." The structural vulnerability found in Soweto can be traced back to policies and laws that have created a social–political economy of risk (Bourgois, 2003). Many Black South Africans reside in racially segregated townships that are low-income, geographically segregated, densely populated, and transient (Msila, 2009; Ndimande, 2009), although Soweto is somewhat different due to its socioeconomic diversity and longstanding residents. Still, its economic deprivation and health burden is much higher than Whites, Coloured, and Indians combined. Rapid economic development, sedentary lifestyles, rural-to-urban migration and persistent inequality experienced in Soweto has cultivated a Soweto that is both the home of an increasing middle class and persistent underclass (Mendenhall & Norris, 2015). These exposures continue to shape how individuals eat and move, exemplified by consumption of high-energy processed foods (Moodley et al., 2015, Bosire et al., 2020), reduced physical activities (Wrottesley et al., 2019), and poor access to health care (Fried et al., 2015; Coovadia et al., 2009). These inequalities are driven by larger structural forces e.g. laws that were structured during the apartheid period and continue to be materialised in individual' suffering today.

The concept of structural vulnerability is an important counterpoint to the common individualistic focus on risk behaviour in medicine and public health. This concept shifts the "clinical" gaze on individual factors to focus instead on the social structures that produce and organise suffering (or what public health denotes as health disparities) in the first place. I argue that, instead of focusing on individual "risk" and "behaviour" (which can often result in blaming poor people for the vulnerabilities they are experiencing, including poor health), the focus should

be on the macro-social structures that produce health and disease. I unpack this further in chapter 3.

1.6.2 Syndemic framework for chronic conditions

The syndemic framework is key for understanding diseases or health conditions that emerge in populations that are aggravated by the social, economic, environmental, and political factors in which a population is immersed. The term "syndemic" was first proposed by Singer (1994), to demonstrate to how socio-economic, political, or environmental factors influenced the frequently co-occurring problems of substance abuse, violence, and HIV (Singer, 2009, 1996). Singer and Clair (2003) have defined syndemics as "a set of intertwined and mutually enhancing epidemics involving disease interactions at the biological level, that develop and are sustained in a community/population because of harmful social conditions and injurious social connections" (p. 429). This theory departs from the traditional biomedical approaches that treat diseases as distinct entities, detached from the social context where individuals live.

The theory of syndemic incorporates three key concepts: 1) two or more diseases cluster together within a population due to harmful social conditions (*disease concentration*); 2) these diseases interact, often biologically, and 3) these diseases are exacerbated by large-scale social, economic and political forces (*disease interaction*) (see Singer, 1994, 1996, 2006). This conceptualisation is significant because rarely does an epidemic work in isolation within a population, especially when it encounters poverty, social exclusion, gender-based violence, climate change, displacement to agricultural or industrial waste, and other forms of social and environmental stress (see Mendenhall, 2017)

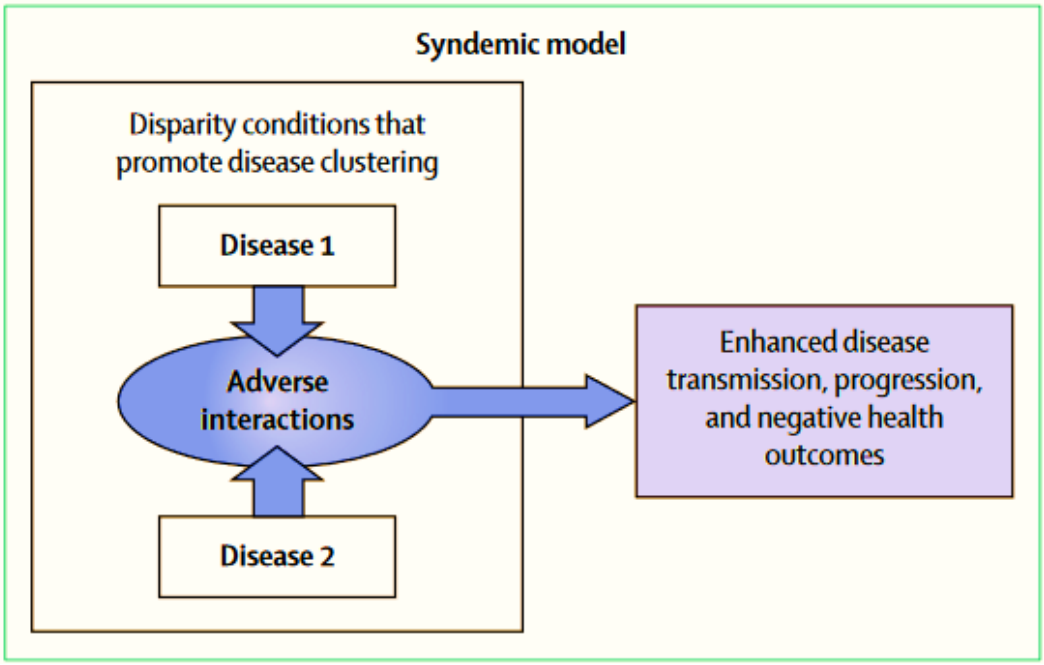

Figure 7: Syndemic framework
(Source: Syndemics and the bio-social conception of Health,(Singer et al., 2017))

Syndemics within Soweto that reflect systemic social inequalities have shifted over the past decades in part due to increasing relevance of co-occurring chronic infectious diseases, such as HIV or tuberculosis, with chronic non-communicable diseases like hypertension and diabetes (Mendenhall et al., 2017). This is evidenced by the high burden of HIV, with South Africa having 17% of the global AIDS burden, and because the increase of non-communicable diseases within South Africa has escalated among low-income populations due to changes in what people eat, activity patterns, and stresses that become part of people's lives (Mendenhall et al., 2017). The syndemic of diabetes and HIV poses an extraordinary threat to patients in Soweto because it begs to exhaust an already burdened health system. A syndemic approach requires that we assess inter-sectoral approaches to health and disease prevention in order to understand the way risks are

concentrated over time in particular people and communities. Understanding the systemic clustering and interactions is key to realising what drives diabetes-HIV syndemic. However, more is needed to understand the ways in which structural vulnerability impedes patient's access to care and in turn, how the health care they receive affects their lives. I have also unpacked this further in chapter 3.

1.7 Conclusion

This chapter provided information on the growing burden of comorbidity and multimorbidity in SSA. The chapter also revealed how the healthcare system in South Africa (like many other countries in SSA), is overstretched and unable to cope with the increasing burden of comorbidities or multimorbidity. This current research endeavours to investigate health and healthcare challenges as well as opportunities among patients with comorbid diabetes and HIV and their healthcare providers in Soweto, South Africa. Overall, the research not only focuses on patients or healthcare providers, but also looks at the functioning of the healthcare system in management of these patients. The use of mixed ethnographic methods allows the researcher to shed light on both clinical and social factors influencing health and healthcare in Soweto, existing gaps in healthcare and recommendations on how care can better be organised to meet the growing demand of people living with multiple chronic conditions. Findings in this thesis also build upon the chronic care model by Wagner, the collaborative care model by Craven and the Integrated Care for Chronic Conditions framework by the World Health Organization by suggesting incorporating patients' contextual factors in care.

CHAPTER 2: RESEARCH METHODS

"I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes..."

(James P. Spradley)

In this chapter, I will describe the mixed methodology used in this research. This ethnographic research involved in depth interviews with healthcare workers and patients as well as participant observation within the clinics and in people's homes to investigate health and healthcare challenges and opportunities among patients with comorbid diabetes and HIV as well as healthcare workers providing care for them at a tertiary hospital in Soweto, South Africa. I will present the study setting, study design, data management and ethics considerations. Reflexivity and positionality during data collection and interpretation of findings are also discussed in this chapter.

2.1 Study Setting

This study was nested within the South African Medical Research Council Developmental Pathways for Health Research Unit (DPHRU), a unit of the University of the Witwatersrand, Johannesburg (Wits)[3] in South Africa**.** DPHRU addresses the national priorities of increasing life expectancy, decreasing maternal and child mortality and strengthening health system effectiveness. The unit forms a unique research platform with substantial infrastructure and equipment, extensive longitudinal data from the Birth to Twenty cohort, and well-established links with the urban and rural South African communities. DPHRU is located at the Chris Hani Baragwanath Academic Hospital (CHBAH) or commonly known as *'Bara'*[4], a tertiary hospital located in Soweto, South Africa, making it an ideal location for this study.

2.1.1 Overview of Soweto

Soweto is one of South Africa's most well-known historically African townships because it is linked to the anti-apartheid struggle and political riots. Historically, the townships constituting Soweto grew out of shantytowns and slums that arose with the arrival of black labourers from rural areas, particularly in the period between World Wars I and II: Its establishment is linked directly to the discovery of Gold in 1885 (Thompson, 2001).

Today, Soweto has a diverse population – in terms of ethnicity, language, low and middle income, with an estimated number of households 237,567: 2,231.9 per square kilometre (5,781 people per km^2). In 2019, the population of Soweto was estimated to be 1.695047 Million people

[3] *Wits- short form for University of the Witwatersrand.*
[4] *Bara- Commonly used to refer to Chris Hani Baragwanath Academic Hospital (CHBAH)*

(World Population Review, 2019). The more than one million residents in Soweto are diverse in socioeconomic status, age, and ethnic identity, including Zulu (37%) to Sotho (15%), Tswana, Tsonga, among others (Morris 1999), making it somewhat unique, compared to other townships that have younger, more fluid populations that are often lower-income.

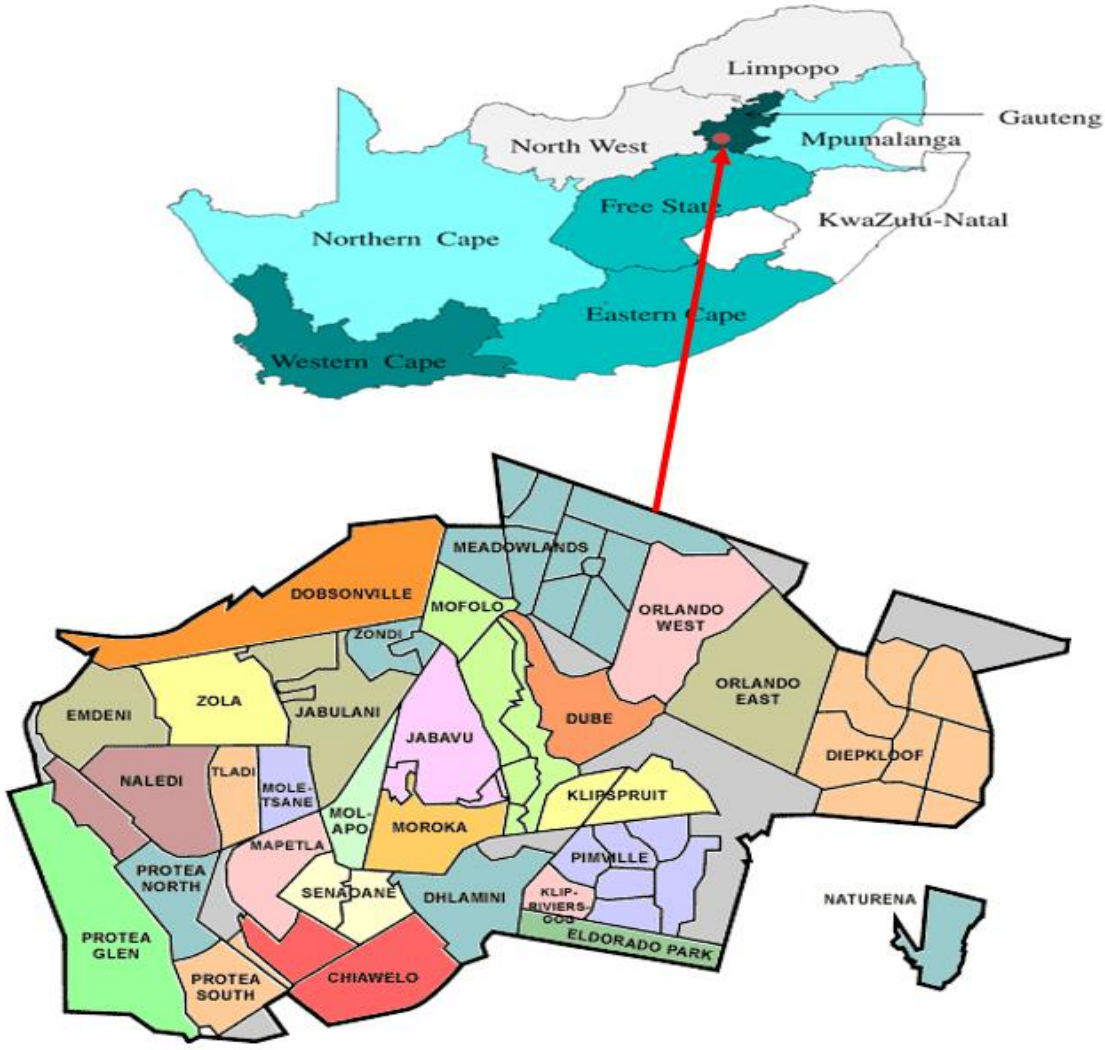

Figure 8: Map of Soweto-Johannesburg in Gauteng Province, South Africa
Adapted: (Richter et al., 2007).

2.1.2 Economic and health transitions in Soweto

The townships have experienced social, economic and health transitions in the past decade. About 99% of households have access to electricity and piped water, children have access to a large network of primary and secondary schools, and communities have access to local clinics and the largest tertiary hospital on the African continent. Soweto has also been transformed in terms of rising incomes and discretionary spending, intense marketing and advertising, and availability of high-energy, processed food and sugary beverages (Moodley et al., 2015). The economic transitions experienced in Soweto have resulted in living environments, often referred to as 'obesogenic' environments (Moodley et al., 2015) characterised by lack of facilities for physical activity, relentless marketing and sales of unhealthy, nutrient-poor foods and beverages (Stacey et al., 2017; Tugendhaft, 2014). All these exposures have been attributed to risks of developing NCDs such as obesity, hypertension and diabetes. For example, studies have reported estimates of 13.1% diabetes prevalence among urban Blacks in the Cape (Peer et al., 2012) and 14.1% diabetes prevalence among urban Black women in Soweto (Crowther & Norris, 2012). These data indicate that diabetes prevalence may be much higher among socially and economically disadvantaged groups – given the socio-economic inequalities that influence what people eat and the activities they engage in. Concurrently, the disadvantaged groups are disproportionately afflicted by HIV (Karim et al., 2009), depression (Mendenhall et al., 2014), and tuberculosis, and most patients experience poor access to health care (Mayosi et al., 2012).

Thus, both economic and health transitions place individuals at unequal and vulnerable positions, that drives clustering of chronic comorbidities or multimorbidity. Although the effects of inequalities on clustering of diseases such as HIV/AIDS, TB and diabetes have been

documented in Soweto (Daftary, 2012; Mendenhall & Norris, 2015), little is known on how these inequalities are reflected within the healthcare system and how they produce poor health care to the patients.

2.1.3 Health care facilities in Soweto

Soweto is served by the famous and enormous Chris Hani Baragwanath Academic hospital (Bara) and its 19 satellite clinics.

Chris Hani Baragwanath Academic Hospital (CHBAH)

Chris Hani Baragwanath Academic Hospital, located in Soweto, South Africa, is recognised worldwide as a leading specialised hospital providing training and medical services of a high standard. The hospital serves approximately 2 million outpatients and 130 000 ward patients annually. This hospital was historically built during the 1940s for Allied troops, but unlike others of its kind, it was constructed to be a permanent hospital structure for black patients. The hospital provides district (level 1) and regional (level 2) hospital services, in addition to tertiary (level 3) referral services. Patients accessing care at CHBAH are referred to the hospital from either regional, district, primary health care clinics or community clinics from outside or within Soweto, where the hospital is located.

Referral systems from PHC clinics to CHBAH

A well-functioning referral system that allows for continuity of care across different tiers of care is central to the delivery of efficient and effective health care and achieving universal health coverage. It is a requirement that all patients follow a referral system as stipulated by the South African Public Health sector – hierarchical referral structure between the hospitals and clinics

(Mojaki et al., 2011). In Soweto, primary care services are offered by 19 satellite clinics or clinics administered from Baragwanath and mostly managed by trained primary health care nurses. The great majority of referrals to Baragwanath Hospital come from these clinics and from a large number of private general practitioners (GPs) who work in Soweto. The clinics refer patients by means of standard forms which have been designed to facilitate referral: a correctly completed form ensures that a patient is properly directed, and that important clinical information is included.

However, due to its location and close proximity, some patients who live in Soweto walk in directly for treatment without a referral. Indeed, some of the ailments treated at CHBAH are minor that could be easily be managed at PHC (Health-E news, 2005). This is partly due to the systemic challenges such as staff shortages, insufficient equipment at the community clinics, that compels patients to by-pass the referral hierarchy and present directly at the tertiary hospital and this creates overcrowding and long waiting time at CHBAH.

2.2 Study design

This was a mixed ethnographic survey study encompassing observations at the clinical level and multiple qualitative interviews with different actors within the health system. I conducted participant observations at the diabetes/endocrine clinic, writing down extensive field notes, observing clinical interactions, and engaging in everyday talk with nurses, physicians, clinical managers, and patients. I worked in the diabetes/endocrine clinic because they were open to having me spend time in the clinic, observe patients, speak to people in the waiting room, follow people from the diabetes/endocrine clinic to MOPD, and engage with clinic staff. I observed patient-provider encounters during clinic consultations, during patient educational sessions, or in queuing spaces. I also conducted in-depth interviews with healthcare providers who were willing to speak

to me about working at Bara, serving residents of Soweto, patients managing multiple chronic conditions, and the challenges of working in a public hospital. I also found it useful to speak with patients to understand experiences of care provision or access to chronic care at Bara, as well as the social challenges and family dynamics that influenced their care outside of the hospital setting; I followed up patients to their homes where I spent time chatting and talking with the patients about their lived experience with chronic conditions and self-management practices. Data collection took 13 months in four interlinked phases as described in figure 9 below.

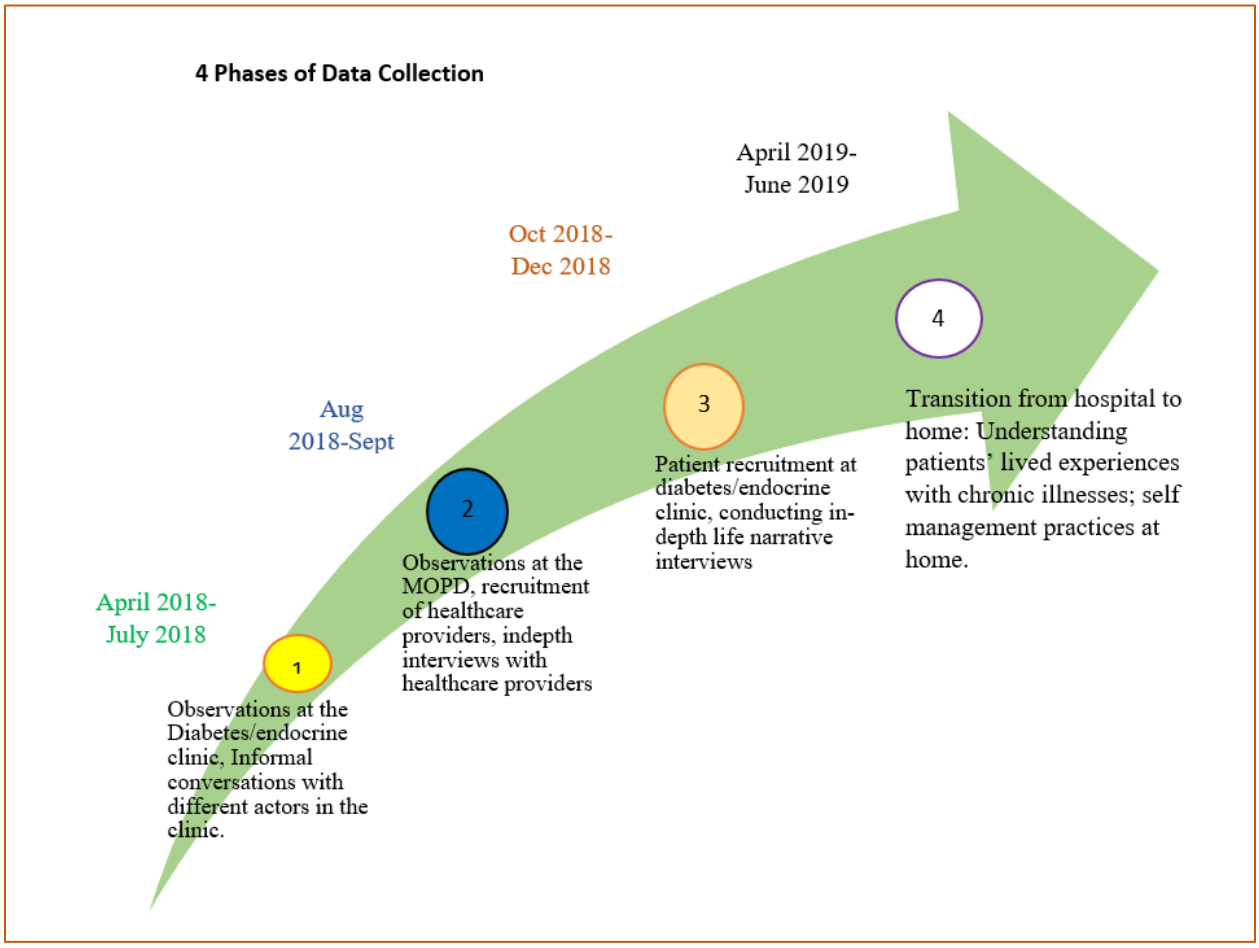

Figure 9: Summary of ethnographic data collection

2.2.1 Ethnographic Methods

Ethnography involves deep "hanging out", spending time learning about social interactions, behaviours, and perceptions by spending time with groups, teams, organisations, and communities (Reeves et al., 2013). Its roots can be traced back to anthropological studies of small, rural (and often remote) societies that were undertaken in the early 1900s, when researchers such as Bronislaw Malinowski and Alfred Radcliffe-Brown spent time learning "the ways things work" in these societies over long periods and documented their social arrangements and belief systems.

In recent years, anthropologists have moved away from studies of the conventional pastoral village in "primitive" societies and turned to critically analyse how Western institutions, including biomedicine, create culture that shapes belief, mores, and social interactions. In addition, whereas in the past medical anthropology has focused on traditional ethnic medical beliefs and practices, more recently, interest has shifted to technologically advanced medicine in clinical settings (van der Geest & Finkler, 2004). Previous researchers who have conducted hospital ethnographic studies (see Caudill, 1958; van der Geest & Finkler, 2004;Yates-Doerr, 2017; Mulemi, 2018) have revealed that, what happens in medical settings reflects realities in wider society. For example, Caudill describes day-to-day personal relations of doctors, ward personnel and patients in a psychiatric hospital; he argues that the hospital is a small society within which the performance of technical tasks takes place. In other words, human interaction in the hospital is largely influenced by social and cultural factors outside the clinic (Caudill 1958, p. 3). Van der Geest and Finkler (2004) have also pointed out that hospitals are often cultures within themselves – where different actors share norms, rules, and unique behaviour and experiences amenable to ethnographic observation. In this light, patient related factors such as ethnicity, class and social status continue

to shape patient –provider interaction and determine the success of care provided in the hospital. Thus, the functioning of hospitals cannot be dissociated from peoples' cultures and where it is located.

This thesis sheds light on the complexities involved in seeking care and providing care for patients with comorbid diabetes and HIV in Soweto, South Africa. Conducting hospital ethnography pointed to the fact that a hospital reflects the broader social and cultural systems and processes which are dynamic and inseparable from members of the society (in this case, patients and providers). As such, the hospital should not be viewed narrowly in the confines of biomedicine but should reflect the overall socio-economic context where it is located. This forms the key argument of this thesis that, integrated care should not only reflect the clinical aspects of care but should extend and equally consider the community and peoples' cultures – including the socio-economic, political and other contextual factors that shape health and healthcare.

Through ethnographic approaches, I employed Laura Nader's approach of studying up to understand the complex biomedical and social interactions between provider and patient, as well as the overall functioning of the health system as described below.

2.2.2 Laura Nader's approach: Studying up

Traditional anthropologists' focus has always been placed on the observation and study of the cultural values, beliefs, and practices of persons occupying the subordinate position of the dominant (that is studying down). In classical anthropology studies, the unit of analysis is identified as being the tribe, or indigenous people of a particular society, culture, or community. In medical anthropology, the less powerful position in the dominant-subordinate relationship is

always identified as being the patient. In anthropological literature, research studies have produced a wealth of knowledge and understanding pertaining to the values, beliefs, and practices of patients.

Laura Nader's (1972) perspective of studying up has been described as studying the values, beliefs, and practices of those who occupied positions of power in society, rather than focusing on the oppressed. Nader poses to ask; "In re-inventing anthropology, what if anthropologists were to study the colonisers rather than the colonised, the culture of power rather than the culture of powerless, the culture of the affluence rather than the culture of poverty?" (Laura Nader, 1972, p. 289). In this context, studying up provided a means and opportunity to observe those directly involved in the provision of care to patients, rather than only focusing on patients.

However, Laura Nader doesn't mean that anthropologists should only study elites and the powerful, but also the less powerful. In a recent keynote address at an anthropology conference, she explained that researchers should study 'up, down, sideways, and through simultaneously' (Nader, 2008), which are all interrelated situated approaches to research and policy analysis. Thus I not only focused on those in power but also those in subordinate positions: I looked at the doctor-patient interactions in chronic care, and this provided an opportunity to understand the social processes in medicine by focusing on those who provide the care and those who receive it (Nader, 1972; Chapman & Berggren, 2005). As a result, the fieldwork and data generated was not skewed in favour of the 'anthropologist' and was not lacking in the degree of understanding regarding informant's involvement in social interactions within clinical spaces.

2.2.3 Data collection process using Laura Nader's approach

The perspective of studying up enhanced my ability to observe and ask questions that facilitated a deeper understanding on the values, beliefs and practices and true meanings associated with access to and provision of care to patients with comorbid diabetes and HIV. Observations and informal conversations were conducted every day that I spent in the clinics.

Phase 1: Ethnographic observations at the diabetes/endocrine clinic

This phase (month 1- 4) of field work involved observations in the diabetes/endocrine clinic. I conducted observations during patient clinical encounters with providers; during patient educational sessions; and in queuing spaces. I participated in everyday activities at the clinic, watching, listening, asking informal questions, sometimes helping nurses to arrange clinic rooms and help to identify patients with diabetes who were admitted in the wards. However, I did not participate in treating or managing the patients. Observations were conducted for six hours, five days in a week for the first three months, this was reduced to three days a week for the remaining months. The main aim was to understand the structure and functioning of the healthcare system, how different actors played their roles in accessing care or providing care for patients. I also explored facilitators and barriers to care provision. Initially, the main focus was to conduct observations at the diabetes/endocrine clinic but having spent more than 3 months in the clinic, I realised that there was a pattern on how patients were referred from the medical outpatient department (MOPD) to diabetes/endocrine clinic. This facilitated an expansion of scope from diabetes clinic to MOPD. I did not use any specific tool to conduct observations. Events, ideas, conversations and other patterns were recorded in my jotting book. At the end of every day, I sat in a private room at the diabetes/endocrine clinic where I compiled all jotted notes and typed a full

account/story of the day. I particularly focused on key issues related to the study objectives e.g. patient-provider interaction, patient queueing time before seeing the doctor, clinics and next clinical appointments. The process of writing and typing observations and informal conversations contributed to my own interpretation of data and an opportunity to reflect, ask questions and liase with the research assistant for any clarifications. Field notes from observations were analysed concurrently with audio files as detailed in the data analysis section (see 2.3.1).

Phase 2: Ethnographic observations and Healthcare provider interviews

Phase 2 (month 5 - 6): This phase involved further ethnographic observations at the medical outpatient department (MOPD). This was necessitated by the need to understand why patients were first managed at the MOPD before they were referred to the diabetes/endocrine clinic. The MOPD covers all specialised clinics at CHBAH. From the registration desk at CHBAH, most patients must pass through the MOPD. These patients were first managed at MOPD (including those with diabetes), then systematically referred to different special clinics within the hospital when required for further specialised treatment/care (see details in chapter 5). Patients with HIV passed through the MOPD when first enrolled in the hospital, then were sent directly to the HIV clinic, also known as ***Ntabiseng*** clinic.

Observations at the MOPD provided deeper insights and understanding of the care pathways for patients with comorbidities, challenges and opportunities that existed in care provision for patients with comorbid diabetes and HIV. Specifically, one of the striking findings was that patients with diabetes were managed at MOPD first before they were systematically referred to diabetes/endocrine clinic, which potentially delayed provision of specialised care.

While conducting observations at the MOPD clinic, I simultaneously started recruiting healthcare providers for in-depth interviews from MOPD and diabetes/endocrine clinic. The sampling strategy is described below.

Sampling and sample size: Healthcare providers

I recruited thirty (30) healthcare providers for in-depth interviews from the diabetes/endocrine clinic (n=25) and medical outpatient clinic (MOPD, n=5) using purposive sampling (Bernard, 2006). The healthcare providers included hospital administrators, clinical managers, physicians, dieticians, endocrinologists, nurses, podiatrists, and social workers.

The inclusion criteria for healthcare providers included; (1) those who were18 years and above and worked at CHBAH (2) those who engaged with patients who had diabetes and or HIV and (3) voluntarily consented to be interviewed. The exclusion criteria were; (1) healthcare providers who worked in other facilities other than CHBAH (2) those who did not interact with patients with diabetes or HIV and (3) those who did not consent to participate in the study.

All interviews were conducted in English, lasted between 30-60 minutes, and took place in a private room at the diabetes/endocrine clinic. An interview guide was used to conduct the in-depth interviews. The interview guide was divided into 5 main thematic areas, each having numerous questions (see appendix 9). Questions addressed the participant's current job, experience managing patients with diabetes or/and HIV, and challenges and facilitators in management of patients. The final portion of the interview addressed their perceptions around integrated, collaborative and patient-centred care in South Africa.

Phase 3: In-depth interviews with the patients

Phase 3 was conducted between month 7 and 8 of field work. This phase involved recruiting patients with comorbid diabetes and HIV from the diabetes/endocrine clinic and conducting in-depth life narratives interviews on their experiences living with comorbidities or multimorbidities, access to care within Soweto and self-management at home. Interviews were conducted in a private clinic room at the diabetes/endocrine clinic.

Sampling strategy and sample size for the Patients

I employed a purposive sampling approach to recruit fifteen (15) patients; men (*n=7*) and women (*n=8*) with comorbid diabetes and HIV from the endocrine clinic in CHBAH. I invited patients who were in the queue, to a private room at the clinic, where I explained the purpose of the study. These patients had visited the hospital for routine clinic appointments. Those who were willing to participate were screened for eligibility according to the inclusion criteria: (1) patients living in Soweto and who were 30 years and above (2) those with comorbid diabetes and HIV (3) those who voluntarily consented to participate in the study. The exclusion criteria included; (1) patients who were intoxicated or active on drug and substance use (2) those who were too sick to participate in the study (3) those who refused to consent to be part of this study. I then asked patients who qualified for the study if they were willing or had time to be interviewed on the same day or later. I set future dates for an interview with eligible patients who accepted to participate later.

Study participants resembled the broader population of Soweto: They were ethnically and linguistically diverse, low and middle income, and identified as Black. All participants signed a consent form after reading the information sheet and understanding the purpose of study. I used an interview guide with both closed and open-ended questions (see appendix 8). Interviews began

with a short survey about participants' socio-demographic characteristics such as age, education status, and marital status. Thereafter, participants took part in an in-depth life history narrative interview that addressed family life, chronic illness, health care experiences and self-management. I encouraged the participants to do most of the talking but was guided by the questions in the guide to probe or seek clarification when something was not clear. The interview did not take a pre-designed approach but was more conversational, moving from either question, probing and linking the conversations to other thematic areas. Targeted questions included: 'Can you tell me about your childhood?' 'Can you tell me about your family?' 'Who are the most important people in your life?' 'Can you describe your neighbourhood?' 'What challenges do you encounter in your neighbourhood?' I then shifted the interview to address participants' understanding of health, illness and disease management. At the end of each interview, I summarised key emerging issues and discussed with the participant to ensure that each participant confirmed the interpretation of issues recorded. All interviews were audio-recorded and lasted for an average of 90 minutes. Interviews were conducted in English, however, a trained multi-lingual research assistant (RA) acted as a translator in cases of language barrier. The RA was also helpful during home visits because, she lived in Soweto and understood the context and different townships. However, the RA did not conduct any interviews. The RA was trained on research ethics principles and on maintaining privacy and confidentiality of patients' information. She also signed a confidentiality agreement form before handling any patient's information (see appendix 14).

Following each interview, I wrote extensive field notes, highlighting the key issues (e.g. experience accessing care, number of clinics attended, patient-provider interactions) that emerged after each interview. After interviews at the clinic, I sought consent from participants to be visited at home later. All participants were given ZAR100 ($5.68) transport back home.

Phase 4: Patients' home visits

Four to five months later, I followed up patients to their homes. The long duration before conducting home visits was to try and understand if anything had changed from the last time they were interviewed. The changes included where participants accessed care, self-management practices, social aspects of life including caregivers/support from family members, dietary patterns etc. I also aimed at matching what the patients said at the clinic with what they were doing at home. Out of the fifteen participants, only thirteen could be reached telephonically and were visited at home. Selection of participants for home visits involved those who were willing to be observed at their homes on different days and also willingness to talk freely on how they managed their illnesses at home. Home visits were conducted during weekdays or weekends (especially for participants who were employed). During home visits, I was always accompanied by the multi-lingual research assistant.

Home visits took a traditional participant observation approach where I participated in some activities in patients' home such as storytelling, watching TV, visiting the market, and simultaneously observing and learning how participants navigated different spaces while managing their chronic comorbidities at home. I conducted detailed ethnographic observations at each participants' home lasting between 5-6 hours per participant. Key areas of interest were activities that participants performed in relation to self-care, diet, physical exercise, medication adherence, and other non-medical activities. I also provided detailed account of their social networks (social capital) while at home, whom they lived with – family or caregiver support – among many other social aspects of their lives. Generally, following up patients at the home helped me to gain a deeper understanding on how structural vulnerabilities influenced patients' access to

healthcare, the quality of care they received at the hospital and how this affected their general wellbeing.



Figure 10: Home visits in Soweto
(Source: Author, 2020)

2.3 Data Management

All interviews were audio-recorded and backed up as a digital file in researcher's portable computer. Immediately after each interview, I spent about an hour to write the field notes (in English) reviewing the main themes and specific topics that emerged in the interview. I also wrote detailed field notes during everyday observations. All data were stored in lockable drawer at

Developmental Pathways for Health Research Unit (DPHRU) offices, a unit affiliated with the University of the Witwatersrand and where this study was affiliated. No identifying information such as names of the participants were written on the surveys. All participants were given serial numbers for anonymity and confidentiality of their information. Audio files were labelled using unique serial codes that were only known by the researcher. After transcriptions, all transcripts were stored in a secured and protected data files on password protected computer and encrypted back up in a hard drive.

2.3.1 Data Analysis

Data collection and analysis were conducted concurrently; however, I analysed data at two levels:

Level 1: Analysing data from healthcare providers

In this phase, data analysis adopted both deductive and inductive approaches. The deductive analysis was based on the pre-identified themes focusing on the research questions and literature reviews while inductive analysis was undertaken for all the emerging theme from data (transcripts and field notes). First, I read all transcripts repeatedly as they were developed after each interview. This process was systematic, and it facilitated re-evaluating data that was already categorised and coming up with new categories (Braun & Clarke, 2018). These categories were refined by the constant comparative method (Kolb, 2012) – which was a concurrent, systematic data collection and analysis. I compared new data with previously collected data. Making comparisons facilitated challenging already grouped data with new categories and this helped in integrating the different categories which provided a wholistic understanding of the phenomena under study. These categories were then reviewed by other researchers involved in the study (study supervisors) and

any identified discrepancies were solved at this level. Discussions with other researchers, including initial meetings with the research assistant facilitated a precise interpretation of data, and ensured that the original meanings were retained. Consequently, discussions between the researchers facilitated a collaborative agreement on key emerging themes. I then developed a codebook which was reviewed by my primary supervisor (a medical anthropologist). The final codebook was uploaded in QSR Nvivo 12 software where coding was done, and emerging codes were added throughout analysis. Initially, I identified 40 parent nodes which were discussed and defined. This led to narrowing the parent nodes to 15, with several child nodes. Subsequent reading enabled the splitting of the parent nodes to child nodes, which provided a fast snapshot of similarities, differences, patterns, and relationships from the data. The analysis led to obtaining the following key themes: providers' definition and conceptualisation of integrated care and patient-centred care; existing challenges and opportunities in chronic care provision in Soweto; and provider attitudes and practices towards integrated and patient-centred care in Soweto. as discussed in chapters 4 and 5.

Level 2: Analysing data from patients

Data from all interviews and observations were transcribed verbatim. I took an inductive approach to analysing data (Charmaz & Belgrave, 2018) because, I wanted to uncover contextual descriptions of chronic care experience and self-management in Soweto. This approach was a systematic, iterative, and reflexive process of collecting and analysing data. Initially, I categorised data (coding) from interviews and field notes, based on phrases or patterned meanings that related to the study aims. I added more categories as new ideas emerged from the data. I cross-checked these categories, compared with new data and refined to identify similarities and differences.

Moving back and forth and evaluating the already grouped data facilitated the drawing up of new research questions and observations. This process also facilitated my own interpretative judgement about when to stop coding and move to theme generation (see Braun & Clarke, 2018). After developing key categories, I involved study supervisors who are experienced qualitative researchers to review the data (Braithwaite et al., 2017). These researchers collaboratively reviewed the data for further analysis and classifications. I then developed new classifications which I used to refine these themes/categories through data comparisons between different participants. These categories were then reviewed by the researchers for the second time and this provided an opportunity to address any questions and resolve any identified discrepancies. Using multiple data sources – from interviews and field notes – facilitated triangulation of research findings, thus enabling transparency, consistency and precision of data. Based on collaborative agreement on data analysis, I came up with key emerging themes as discussed in chapter 3.

2.3.2 Data quality checks

The design and nature of this study demanded considering the issue of subjectivity. One way of doing this was through conducting data quality checks. First, I engaged with the participants after the end of each interviews, through summarising the key issues that emerged during the interview and letting them confirm of the same. Second, I engaged with the multi-lingual research assistant who helped me reflect and provided insights, interpretations and translations that were contextually sound. Lastly, I shared my work with my supervisors, who periodically reviewed the data as it was being collected. This involved reading field notes and pointing out gaps or areas for improvement. Data analysis and interpretation also involved supervisors' insights before a final codebook was synthesised and consolidated. The data was analysed and re-analysed to ensure that

all sub-themes and larger themes were populated with all relevant transcripts, and to ensure no further insight arising from the data was gained. Framework matrixes and cross tabulations were used in comparing different emerging themes and interpreting the data.

2.3.3 Ethical Considerations

Ethical clearance to conduct this study was obtained from the University of the Witwatersrand, Human Research Ethics Committee (HREC) (M171125, appendix 3). Permission to conduct the study at CHBAH was also provided by the research committee at the CHBAH (see appendix 4). All participants provided a written informed consent before they participated in the interview. Participants only signed the consent after reading the information sheets (Appendix 5 & 10) which provided details about how confidentiality, anonymity and privacy were maintained. All interviews were conducted in a private room at the diabetes/endocrine clinic, at the CHBAH. The data gathered was kept confidential by assigning the participants unique serial numbers and storing the files in a lock and key cupboard at DPHRU offices. Due to long in-depth interviews, I anticipated a risk of psychological distress from participants. Any participant who displayed psychological distress was provided with a referral letter to a qualified counsellor at the hospital.

Observations at the clinic: Patients and healthcare providers at the diabetes/endocrine and MOPD were informed by the nurse manager about my study and what it entailed. For example, patients were made aware of my presence and what my study involved, including observations. This process was repeatedly done for the first months of data collection to a point where it was perceived that patients understood what I was doing at the clinic. Observations during patient-provider encounter/consultation in the clinic was conducted only after both providers and patients agreed to be observed.

Home observations: Issues around privacy and confidentiality were considered during home visits. During consenting process, I informed the participants that I would be accompanied by a multi-lingual research assistant to their homes. This facilitated my initial evaluation if participants were comfortable to be observed at their homes or not. The research assistant was also trained on ethical principles of research including confidentiality, anonymity, and respecting participants privacy. Only participants who expressed satisfaction with the process were visited at home.

2.4 Reflexivity and positionality in the field

"*What exactly are you observing?"*

My initial stages of ethnographic work at the clinic was confronted with questions from different individuals – staff, patients and other researchers; they wondered what my study was all about. Healthcare providers were not used to someone 'sitting around' especially when the clinic was under-staffed. My study design was found to be unfamiliar, one healthcare provider asked, *"Are you recording everything we are doing?"* Initially, I would sit with a notebook and take notes as events unfolded but later realised that some staff were uncomfortable with this kind of approach. I changed the strategy by jotting observations in point form and writing a full account of events at the end of each day. On another event, one nurse walked from the patient queuing spaces to the reception space where I was standing and asked, *"Edna, have you recorded that […]?"* an event that she thought was relevant to be captured. Two to three weeks later, I still had to remind different individuals what my study was all about.

In this section, I turn to reflect on my personal experiences of the journey of data collection process. Most of the issues I will discuss here were recorded in daily field notes. I will discuss

about my positioning while in the field, personal feeling, biases and their contribution to the current study. According to Foley (2002), thinking about the ways in which our positionality, shapes our entrance, interactions, and conversations within the field, is a core tenet in ethnographic research.

Conducting ethnography in the hospital brought a number of challenges. First, getting approval to conduct the study was not easy both at the hospital and from the Wits human ethics and research committee. This was because, initially, both committees did not understand how I would maintain patients' privacy and confidentiality as well as ensure that my research did not disrupt the normal functioning of the hospital. I explained in detail how I would ensure that participants privacy, confidentiality and anonymity were to be maintained throughout the study period. I also gave examples of hospital ethnographic studies (see page 56), explained my roles and boundaries while at the clinic, and provided reasons why my study design was important. The challenge of getting approvals to conduct ethnographic studies at the hospital is not new; studies have reported that social scientists who have conducted hospital ethnographies have experienced different degrees of difficulty in entering clinical settings (van der Geest & Finkler, 2004).

Formal approval to conduct this study did not translate to smooth process of data collection. As a matter of fact, the process of how to position myself in the clinic and in patients' homes was a key aspect that was underway. I needed a good rapport with different people in the clinic for the success of this study. This was not always the case based on the busy clinic schedule. One nurse said, "*The clinic is very busy as you can see and honestly nobody would have time to attend to you"*. The nurse was being honest, but she lacked an understanding that I did not need anyone to stop their work and attend to me. In addition, I was always introduced as *"she is a researcher from Wits, and she will now be working with us*". This created more confusion to most people as they wondered whether I was a researcher, physician or both. At least for a month, the nurse would

introduce me to the patients every morning because in many days, there were new patients coming in for their clinic appointments. As time progressed, I clarified that I was a researcher and not a physician.

Although I was enthusiastic to learn and observe issues related to provision and access to care, it was not easy as earlier anticipated. Initially, I was perceived as an outsider; partly because I am not a clinician and also, because I came from Kenya. Staff members would look at me from a distance – not knowing what to do. The few inquisitive ones asked questions about my country, study and personal life. Instead of being a researcher, I became the subject of study. This kind of tension between the researcher and the researched influenced how people behaved, and this potentially affected the quality of data collected during the initial times.

Furthermore, subjectivity and positionality were other issues that this study took into consideration. Conducting observations and interviews demanded my own interpretation which could vary from other researchers conducting similar study in the same context or even participants interpretation. Firstly, having conducted a closely related study in Kenya, I was prone to interpreting things with a Kenyan context in mind. Secondly, the entire ethnographic study was subjective to my own interpretations, and that of other research team. Given these factors, I had to objectively and consciously put aside my preunderstanding of chronic care experience while conducting the current study. According to Hammersley and Atkinson (2007), the researcher being an outsider may influence her views on clues which are regarded as natural behaviours or actions among the participants, thus fail to understand the culture in the community or group. To minimise misinterpretation of the study findings, I wrote intensive filed notes which I discussed with a multi-lingual research assistant who lived in Soweto and worked at the tertiary hospital where this study was conducted. I also engaged participants after every interview to debrief on the key issues

reported or that emerged during the interview – which ensured consistency in interpretations. Putting aside my own understanding and interpretation allowed me to learn new things about patients' lived experiences with chronic illnesses, and providers experiences in providing care to the patients. In this way, reporting of research finding was objective and this increased scientific rigor.

Reeves and colleagues (2008) explain that the strength of ethnography lies in the use of more than one method, allowing flexibility in data collection and triangulation of analysis and findings. This research adopted different ethnographic strategies such as observations and multiple in-depth interviews with different actors, as well as field notes, which helped in triangulations of research findings. I spent time going back and forth between each story on its own and the collective emergent understanding of the phenomenon under study. I negotiated between the meaning of each interview and case observations and the collective understanding of chronic care in Soweto. This contributed to my whole understanding of lived experiences of chronic care in Soweto. In addition, I periodically discussed my field notes with my supervisors, had meetings with them and this helped to reflect further on data collection processes, shaped research interpretation and consistency in reporting.

Ultimately, demarcating boundaries during field work was not easy. During my stay at the clinic and in patient's homes, I developed friendship which was not easy to separate from the work that I was doing. I had to learn how to be responsive and sensitive to the people that I was studying while at the same time, take a step back to reflect on my role to remain focused with data collection. While in patients' homes, I was perceived as a physician and patients requested me to educate them more on how to manage their illnesses. I continuously reminded the patients that I was not a physician and referred them to the care provider whenever they asked medical related questions.

Even after completing data collection, providers especially the nurses would still call me whenever they failed to see me in the clinic. I officially thanked my participants and informed them of the end of my research and departure from the clinic.

Ethnography in patients' homes

As was with the clinic, gaining entry at patient's homes was not easy. Although patients had earlier shown their enthusiasm to be visited at home, home visits only commenced 4-5 months later, after initial contact with the patients at the clinic. This gap between clinic interviews and home visits influenced the rate at which patients provided permission to be visited. Some delayed providing a confirmation to be visited at home. For example, two participants who had earlier agreed to be visited were not reached by phone (possibility that they could have changed their phone contacts). In addition, home visits were dependent on when the patients wanted to be visited. This potentially influenced the data collected because, participants were aware that I was studying them and may have acted in ways other than their usual ways of doing things. Despite this challenge, the long hours spent in the patient's homes made the participant relax and return to their actual way of doing things.

Language barrier was an issue during home visits because I did not understand the South African local languages, and not all participants could speak in English consistently for the 5-6 hours that I stayed in their homes. As a result, I was accompanied by a multi-lingual South African research assistant (RA) to patients' homes, who acted as an interpreter. The RA worked in the clinic and was therefore conversant with most patients. She also lived in Soweto and she understood the different townships. However, studies have shown that use of a translator may alter the meaning of the participant's original words (Squires, 2009; Temple & Young, 2004).

Consequently, RA's interpretations were backed up with observations and thus, multiple data collection tools were important at validating each other. Another challenge was that the presence of the RA may have compromised participants' privacy and confidentiality. To counter this, the RA was trained on ethical principles to research and she signed a confidentiality agreement form (see appendix 14) before being involved in the study.

Safety issues in Soweto was a limitation for home visits. Crime rates and insecurity are high in Soweto including pick pocketing, mugging and shooting (Pillay, 2008). Some patients lived in insecure townships. During home visits, the RA and I always used public transport to identify with the locals. Both of us did not wear any clothing items that could attract attention. Yet, the locals could still pick up individuals who were not from their neighbourhoods. This was a challenge, I ensured that we minimised movement outside the patient's home and was always accompanied by RA and a local person while walking outside the patient's compound. Although this was helpful, there remained many spaces that I would have wanted to explore but could not cross over due to safety issues.

Finally, all patients were excited to be visited at home. They expressed interest to be visited again while some revealed that they felt better having shared their illness journey to someone else. Some became emotional, cried during the interviews and at the end revealed that they felt much better. Patients who showed signs of distress or discomfort were referred to a nurse for counselling. The eagerness in patients' final remarks and willingness to be visited again could possibly signal a need for bringing care to patients' home.

In the next three chapters, I will present the research findings in form of 3 separate manuscripts.

CHAPTER 3-5: RESEARCH FINDINGS

"If we keep on doing what we have been doing, we are going to keep on getting what we have been getting"

(Abraham Wandersman[5])

[5] Wandersman A, Duffy J, Flaspohler P, Noonan R, Lubell K, Stillman L, et al (2008). Bridging the Gap Between Prevention Research and Practice: The Interactive Systems Framework for Dissemination and Implementation. Am J Community Psychol, 41(3-4):171-81.

CHAPTER 3: PhD PAPER 1

Title: Comorbid Experiences with HIV/AIDS and Diabetes in Soweto, South Africa: From Hospital to Home

Author: Edna N Bosire.

Paper 3 Status: Manuscript has been revised twice and resubmitted. It is currently being considered for publication (*Qualitative Health Research)*

Abstract

More people with HIV live in South Africa than anywhere else in the world. As people with HIV increasingly confront comorbid conditions, such as Type 2 diabetes, the need for integrated chronic care continues to grow. Integrated care is under-developed in South Africa, despite its need for patients seeking care in public hospitals. This ethnographic study describes patients' experiences seeking care for comorbid HIV and diabetes at a public tertiary hospital in Soweto, South Africa, and self-management at home. Findings illustrate how fragmented care, multiple clinic appointments, conflicting information, and poor patient-provider communication impeded patients' abilities to manage their co-occurring illnesses. Socio-economic factors such as poverty, costly transport to the hospital, food insecurity impeded management of multimorbidities. Integrated care for patients with multimorbidities in Soweto is imperative and must recognize the critical role social and economic conditions play in shaping the experiences of living with HIV, diabetes, and their overlap.

Keywords: Diabetes, HIV, Integrated care, Ethnographic study, South Africa.

Introduction

> *"I am paying rent but at the moment, hey, I am owing lots of money […], I don't sleep at night, everyone is looking up on me […] my children, my sister, my sister's children […] my sister is also diabetic, she is not working and depends on me. When will I ever think of my diseases?"*
>
> (Karabo [pseudonym], 60 years old, diabetes and HIV)

Karabo cannot prioritize her medical conditions because financial and social demands are too much. Like many other patients seeking care at public hospitals in South Africa, Karabo's case introduces how medical care in Soweto, a large township in Johannesburg, South Africa, cannot overlook underlying social and economic stressors that impede patients' abilities to manage their one, two, or more co-occurring conditions. Managing multimorbidities – coexistence of two or more chronic conditions in the same individual (WHO, 2016) can be overwhelming because not only are there competing self-management tasks but also numerous social and financial costs (Liddy et al., 2014). In many ways, these social and medical challenges "cascade" together and feed off one another, such as the compounded effects of disability, pill burdens, new self-care routines, and recurrent clinical visits (Manderson & Warren, 2016). This can also be challenging for patients living in contexts like Soweto, where access to healthcare for people with multiple chronic conditions is limited (Lopes & Norris, 2013). Scholars have described how patients with multimorbidities, seeking care within constrained settings face "a virtual cascade of medical, emotional and social hardships" (Sells et al., 2009, p. 95), or "recursive cascades" – interweaving and compounding of social and health problems at multiple levels (Manderson & Warren, 2016, p. 491), or a "syndemics" – clustering of two or more diseases that interact biologically and are driven by social and economic inequalities (Mendenhall et al., 2017).

Social, political, and economic hierarchies, which cultivate structural vulnerability, influence individual or group risk for negative health outcomes among people with multiple clustered social and medical conditions (Quesada et al., 2011; Holmes, 2011). Quesada and colleagues (2011) have described structural vulnerability as "a positionality that imposes physical/emotional suffering on specific population groups and individuals in patterned ways" (p. 339). Amongst Black South Africans, historical racial segregation, intensified by apartheid, created an inherent structural vulnerability (Coovadia et al., 2009). The structural vulnerability found in Soweto can be traced back to policies and laws that stratified people along racial lines and have created a social–political economy of risk (Bourgois et al., 2017). Rapid economic development, urbanization, social (im)mobility, and persistent inequality have cultivated an increasing reality in Soweto where there is an increasing middle class and persistent underclass, and frequent interaction of social and medical problems (Mendenhall & Norris, 2015). These factors have contributed to decreased physical activities and increasing consumption of high-energy processed foods (Moodley et al., 2015, Bosire et al., 2020a), which have been attributed to the massive increase of non-communicable diseases (NCDs) like diabetes (Micklesfield et al., 2013).

Structural vulnerability is perpetuated through a financially strapped and overburdened public health system in Soweto (Fried et al., 2015; Coovadia et al., 2009). On one hand, the healthcare system in South Africa is inequitably structured (Ataguba & McIntyre, 2013) where private hospitals, funded by private healthcare plans, are well-equipped with higher expenditures when compared to public hospitals (which are weak and under-resourced) (Fusheini et al., 2017). On the other hand, the majority of uninsured Black South Africans largely rely on the public health system for diagnosis, treatment, and care (Naidoo, 2012), and this system provides longer waiting

times, poor provider-patient relationships and fewer screenings due to lack of equipment (Ameh et al., 2017). Consequently, there is delayed diagnosis, missed clinic appointments, and poor health outcomes (Fusheini et al., 2017). In this way, structural vulnerability fundamentally shapes how people access and engage with the health system, in terms of the financial cost of care-seeking, unresponsive healthcare systems (Horrell et al., 2017; Matima et al., 2018), social cost of caring for family members, and emotional cost of managing food and the physically disabling body (Mendenhall, 2016).

These inequities are deepened by health disparities between the rich and the poor. For instance, the prevalence of HIV (Human Immunodeficiency Virus) in South Africa is estimated at 13% of the total population (Statistics South Africa, 2018), and up to one in four people in townships like Soweto. Type 2 Diabetes (hereafter, diabetes) prevalence is estimated to be 5.2% (International Diabetes Federation, 2017), and up to 12% in Soweto (Crowther & Norris, 2012). The clustering of these diseases is common especially amongst the poor, in urban low socio-economic settings (Mendenhall & Norris, 2015) and in rural areas (Chang et al., 2019), compared to higher income neighborhoods. In these contexts diabetes has become syndemic with HIV, fueled by social and political factors, and further compromised by social and economic impacts of individual and collective disease (Mendenhall, 2016; Mendenhall & Norris, 2015). Syndemic theory suggest that not only are there powerful structural factors at play in perpetuating disease experience and clustering, but also biological factors influence why and how diseases emerge and interact (Singer & Clair, 2003). Biological factors such as aging and improved anti-retroviral treatment (ARVs) for HIV have resulted to people living longer, thus placing them at risk of other chronic conditions like diabetes (Brown et al., 2005). But poverty, poor living conditions, food insecurity, and compromised feeding patterns play important roles in how these diseases converge

among low-income groups and collide in people's lives (Cois & Day, 2015). Moreover, where those with higher risk for and experience of disease are less likely to access healthcare in the first place and delaying care-seeking until people become very sick is common (Mendenhall et al., 2019). These factors underscore the need for medical care that recognizes social inequities while tending to the complex and interactive medical conditions people face concurrently while seeking care.

Integrated chronic care has been proposed as a potential way to mitigate the syndemic effects of comorbid chronic conditions, such as HIV and diabetes. Integrated chronic care has been defined by the WHO (2008) as "the organization, management and coordination of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money", and UNAIDS has recommended integrated care as a viable solution in managing patients with chronic multimorbidities (UNAIDS, 2011). In light of this, the National Department of Health (NDoH) in South Africa introduced the integrated chronic disease management (ICDM) framework between 2011 and 2013 (O. H. Mahomed & Asmall, 2015) as a response to the dual burden of disease. A national pilot of the ICDM model commenced in forty-two (42) selected Primary Health Care (PHC) facilities in three out of nine South African provinces i.e. Gauteng, North West and Mpumalanga. The ICDM model has three key components: health facility level (entails facility reorganization that aim at improving operational efficiency); community component (aimed at facilitating self-management and creating awareness of chronic diseases) and population component (aimed at health promotion and population level screening) (Mahomed & Asmall, 2015). The main aim of the ICDM model was to leverage the innovative HIV treatment programme for NCDs in order to improve the quality of chronic disease care and health outcomes of chronic disease patients. Despite these improvements, the ICDM

model is under-developed in most public healthcare facilities due to health systems challenges (e.g. staff shortages, inadequate equipment, unskilled providers or lack of multimorbidity guidelines) (Ameh et al., 2017; Matima et al., 2018). Consequently, care for chronic diseases is still fragmented and uncoordinated (Kawonga et al., 2013). Understanding a truly integrated chronic care model requires investigating the experience of chronic conditions and care for social and medical problems from multiple perspectives.

Recent studies have evaluated the ICDM model in South Africa but have largely focused on the clinical components of integrated care (Ameh et al., 2017). In this study I use ethnographic approach to explore patients' experiences of accessing healthcare for comorbid HIV/AIDS and diabetes in Soweto, and how they self-managed their concurrent chronic illnesses at home. Findings reported in this study are useful for policies that aim to strengthen chronic care in South Africa and other similar contexts.

Methods

Study design: An Ethnographic approach

This study is part of a larger ethnographic research conducted between April 2018 and June 2019 that explored health and healthcare for patients with both diabetes and HIV at a large public tertiary hospital in Soweto, South Africa (Bosire et al. 2020c). The study was approved by the tertiary hospital research committee and the Human Research and Ethics Committee at the University of the Witwatersrand (M171125). The tertiary hospital (providing specialist services) is one of the largest hospitals in the world and serves residents of Soweto and surrounding areas. Soweto (south western townships), is located about 15km south west of Johannesburg's central

business district, covers more than 200 km2 and has a population of approximately 1·3 million (Statistics South Africa, 2012).

I conducted life history narrative interviews (Anderson & Kirkpatrick, 2016) with patients in the clinic and spent time observing their lives. This included spending time with people apart from the clinic, as well, observing how people managed their chronic illnesses at home, who helped them, and how they navigated different social spaces like going to the market or caring for their family members alongside themselves. Spending time with patients in the clinic—where we first met while I was conducting clinical ethnography—and meeting them in their homes, and spending time walking with them through their day, neighbourhood, and in some cases to other clinics from which they sought care, provided a more robust perspective on their lives, health, and care.

Sample selection

I used purposive sampling (Suri, 2011) to recruit 15 patients (8 women and 7 men) managing comorbid diabetes and HIV from a diabetes/endocrine clinic at a tertiary hospital in Soweto. I invited patients who were in the queue, to a private room at the clinic, where I explained the purpose of the study. These patients had visited the hospital for routine clinic appointments. Those who were willing to participate were screened for eligibility according to my inclusion criteria: patients who were above 30 years (this was the youngest age that was reported in the clinic for type II diabetes as at the time of the study) and receiving treatment for both HIV and diabetes. Those who qualified for the study were asked if they were willing or had time to be interviewed on the same day or later. I set future dates for an interview with eligible patients who accepted to participate later.

Data collection

Study participant resembled the broader population of Soweto: They were ethnically and linguistically diverse, low and middle income, and identified as Black. Participants were aged between 40 and 70 years, more than half were unemployed and only a quarter had completed secondary school. All participants signed a consent form after reading the information sheet and understanding the purpose of study, before they took part in the interview. An interview guide with both closed and open-ended questions was used (see appendix). Interviews began with a short survey about participants' socio-demographic characteristics such as age, education status, and marital status. Thereafter, participants took part in an in-depth life history narrative interview that addressed family life, chronic illness, health care experiences and self-management. Targeted questions included: "Can you tell me about your childhood?" "Can you tell me about your family?" "Who are the most important people in your life?" "Can you describe your neighbourhood?" "What challenges do you encounter in your neighbourhood?" I then shifted the interview to address participants' understanding of health, illness and disease management, including questions like "What do you think caused your HIV/AIDs? Diabetes?" "Any other disease?" "Where do you go for your health care and/ get medication for: HIV/AIDs? Diabetes?" "Do you visit different clinics/hospitals?" "How do you manage your illnesses at home?" "Who supports you in disease management?" At the end of each interview, I summarized key emerging issues and discussed with the participant to ensure that each participant confirmed the interpretation of issues recorded. All interviews were audio-recorded and lasted for an average of 90 minutes. Interviews were conducted in English, however, a trained multi-lingual research assistant acted as a translator in cases of language barrier. Following each interview, I wrote extensive field notes, highlighting the key issues (e.g. experience accessing care, number of clinics attended, patient-provider interactions) that emerged after each interview. After interviews at the clinic, I sought consent

from participants to be visited at home later. All participants were given ZAR 100 ($5.68) transport back home.

Home ethnographic visits (see also,Yates-Doerr, 2017) were carried out on different dates. Thirteen participants were available for home visits, two could not be reached. These participants were visited after they read the information sheet, understood what home visit entailed and signed a consent form to be visited. During home visits, I was always accompanied by a multi-lingual research assistant who helped in translations. The research assistant was trained on principles of research ethics including respecting the participants and maintain participants' confidentiality. The aim of home visits was to understand participants' lived experiences with chronic conditions and illness management. Observations were conducted at each participants' home – lasting between 5 to 6 hours per participant. Key areas of interest were activities that participants performed in relation to self care – including diet, physical exercise, medication adherence, and other non-medical activities. I also provided detailed account of participant's social relationships e.g. whom they lived with at home.

This being an ethnographic study (see Van Der Geest & Finkler, 2004), issues around reflexivity and subjectivity were considered. First, as an "outsider" (non- South African), I may have influenced my views on patients access to care and self-management (Hammersley & Atkinson, 2007). In addition, language barrier and use of an interpreter may have distorted participants' original meaning of words. However, a constant thoughtful process in reviewing field notes, observations and interviews with the participants and other researchers involved in this study allowed flexibility in data collection, analysis and reporting of study findings (Reeves et al., 2008).

Data analysis

Data collection and analysis were conducted concurrently. Data from all interviews were transcribed verbatim. I took an inductive approach to analysing data (Charmaz & Belgrave, 2018) because, I wanted to uncover descriptions of chronic care experience, which entailed access to care and self-management at home. This approach was a systematic, iterative, and reflexive process of collecting and analysing data. Initially, I categorized data (coding) from transcripts and field notes based on phrases or patterned meanings that related to the study objectives. More categories were added as new ideas emerged from the data. I cross-checked these categories, compared with new data and refined to identify similarities and differences. Moving back and forth and evaluating the already grouped data helped me to come up with new research questions and observations. This process also facilitated my own interpretative judgement about when to stop coding and move to theme generation (see Braun & Clarke, 2018). I then involved my research assistant who had extensive knowledge of Soweto, and three other researchers (study supervisors) who are experienced qualitative researchers to review the data (Braithwaite et al., 2017).These researchers collaboratively reviewed the data for further analysis and classifications. I developed new classifications which I used to refine these themes/categories through data comparisons between different participants. These categories were then reviewed by the researchers for the second time and this provided an opportunity for me to address any questions and resolve any identified discrepancies, thus enabling transparency and precision of data. Based on collaborative agreement on data analysis, I came up with two main themes: a) patients' experiences accessing chronic care in Soweto, and (b) patients' experiences of self-management at home. Within each main category, there were numerous sub-themes which I will unpack in the results section.

Results

More than half of the participants were unemployed, and three quarters reported household income ranging from ZAR1000 ($60.72) – ZAR2000 ($121.45) a month. Five participants who were above 60 years of age reported that they received government social grants. However, the grant was said to be insufficient in taking care of recipients' social and medical needs – given that most households depended on the grant, and were not only poorer but also larger in size (Burns et al., 2005). Other than HIV and diabetes, participants also reported that they managed other chronic illnesses. Hypertension was commonly reported by almost half of participants, followed by depression, arthritis and tuberculosis. In addition, participants revealed that they had at least two people in their households who also managed chronic illnesses.

In what follows, I present study findings under the two key emerging themes: (a) Patients' experiences accessing chronic care in Soweto; and (b) Patients' experiences of self-management at home.

Patients' experience accessing chronic care in Soweto

Findings showed that patients experienced many challenges accessing care for their illnesses in Soweto. Firstly, it was reported that chronic care at the tertiary hospital was fragmented, partly due to the structure of the tertiary hospital that offered specialty care, as opposed to managing all patients' diseases together, in one place. Observations in this clinic revealed how patients with multimorbidities moved from one clinic to another for consultations and treatment, a process that was said to be overwhelming and confusing (see also, Bosire et al. 2020c). A middle-aged female participant said: "I always get my ARVs from Ntabiseng clinic, and my diabetes pills from the diabetes clinic." For those with comorbid diabetes and hypertension,

care and management of these two diseases were managed together in the diabetes clinic. However, patients had to visit other clinics for any other illness that they had. Notably, some participants revealed that they sought care from both PHC and tertiary hospital: “It’s hard because the local clinic [PHC] only gives my ARVs, but for diabetes, I must come to Bara [tertiary hospital].” This indicates that diabetes care has not been integrated in PHCs in Soweto (Kawonga et al., 2013).

Secondly, patients received numerous clinic appointments based on the number of conditions they were suffering from. This was found to be challenging especially for those who were struggling with transport to the hospital. A middle-aged man said: “Transportation is difficult because I am not working. I attend four clinics […]. Today I am here, then next month I’ll attend two other clinics.” In addition, participants who were employed revealed that numerous clinic appointments led to conflicts between them and their employers; and sometimes their salaries were deducted on days not worked: “I explained this [clinic visits] to my boss but he doesn’t understand. He always deducts my money for any day that I don’t work.”

Moreover, some participants revealed that challenges accessing the hospital, e.g. distance to the hospital and lack of transport led to them defaulting clinic attendance. As a result, nurses and clerks at the hospital were said to be scolding and shouting at patients who missed their clinic attendance, a factor that constrained patient-provider relationship and sometimes, forced patients to continue defaulting their clinic appointments: “If you do [come late] or don’t come, the nurses will be shouting at you. But nobody really cares to know why I did not come […], that’s why I choose to stay at home some clinic days.” Others said that failure to attend clinic appointments led to them being punished by nurses, by being asked to wait for long hours in the queue during subsequent visits: “I came to the clinic after two months and the nurse asked me to wait in the queue until all patients for that day were attended to.” Moreover, although patients wanted

clinicians to answer some of their questions, it was reported that some clinicians were disinterested, had no time for such questions or lacked knowledge on how to address patient's social challenges: "I don't think they want to hear all these stories, they are busy [….]; it's just about the disease and medication, that's all." Another participant said: "I was explaining to the doctor that I don't have money for recommended food [….], she dismissed me and asked me to call another patient in."

Lastly, visiting numerous uncoordinated clinics led to patients receiving conflicting information from clinicians. Participants revealed that clinicians rarely collaborated or cross-talked while managing their multiple illnesses (see also, Bosire et al., 2020a, c). Angie (pseudonym) a 64-year-old woman with multimorbidities (HIV, diabetes, hypertension, and arthritis) explained her case as follows:

> …they [doctors] don't talk to each other. I see different doctors for each disease [...]. Last week, the doctor [Rheumatologist] told me that my bones are getting closer to each other, they have inserted metals in my right foot. When I attended the diabetes clinic [earlier], the doctor asked me to exercise because I was adding more weight, but I can't exercise because of the surgery they did on my leg. My ARVs have amplified my appetite. I eat a lot and I am worried about my weight too. Last time I asked the endocrinologist what else I could do to deal with my appetite, my weight gain and inability to exercise, but he just looked at me without saying a word.

In this context, participants expressed their frustrations and confusion, not knowing what to do or how to deal with their multiple chronic illnesses after they left the clinic. This leads to the next section where I will present findings on self management practices at home.

Patients' experiences of self-management at home

In this section, I use two cases, whose stories reflect the complexities of chronic multimorbidity, structural vulnerability, caregiving roles and chronic care in Soweto. Stories from the two interlocutors that I will call Mpho and Bongani (names anonymized) reflect key emerging themes in self-management, from all participants in this study. Mpho's case demonstrates the clustering of social-economic, political and medical factors which underscores syndemic suffering in Soweto. Bongani's case demonstrates how patients navigate self-care and caring for others in context of multimorbidity and structural vulnerabilities. These two cases tie together to reflect the complexities and overlaps involved in chronic care (both medical and social) in Soweto.

Case 1: Intermingled thread of socio-economic, political factors and chronic illnesses

I first met Mpho, a 46-year-old woman, in the diabetes/endocrine clinic at a tertiary hospital where she received care. Mpho doesn't understand English, so she is accompanied by her twin sister who does the interpretation. This is how she survives during most clinic days. Mpho lost both her parents to HIV/AIDS —her father and mother died when she was six and seven years respectively. Talking about her background, she says:

> My father was originally a South African, but my mother was from Lesotho. During the Apartheid period, my father was against the Apartheid regime, he was outspoken […] then he was threatened many times and he decided to flee to a neighbouring country – Lesotho, for fear of his life. […]. Many years later, my family relocated to South Africa where we all started life again in Soweto. Shortly after, my parents succumbed to HIV/AIDs […] but they had not documented us, as being South Africans.

Mpho explains in detail how her sisters have tried to get the relevant documents that would qualify them as South Africans but in vain. She says;

> That is why our children have been denied child support grant. I also applied for a disability grant, but I was not given because, I lack the required documents […]. When I was young, I contracted polio that paralyzed one of my legs. That's why I cannot stand well.

Indeed, Mpho is supported by her twin sister whenever she walks, she is not using crutches – perhaps she cannot afford them. Many years now, Mpho lives with her twin sister, her younger sister (27 years), her two children (aged 9 and 7) and two other children from another sister. In total, seven people live in a single-roomed shack in a township in Soweto. Her younger sister is mentally ill, and they are yet to figure out which illness; but in 2015, Mpho says, "She became violent and was admitted to Bara, […] she sometimes uses some injections to tranquilize her." Mpho herself lives with HIV, diabetes and hypertension. Her twin sister too does not have it any easier. She narrates her story, "I am also sick, I have HIV, hypertension and breast cancer." Mpho's household has three individuals managing different chronic illnesses. In her account, Mpho narrates how managing her multiple chronic conditions is difficult. She says; "I can't walk by myself; I always need support. This disability has made it difficult for me to get a job. I depend on my sister who is running a small business at home."

I later learn that Mpho's twin sister is a *sangoma* (traditional healer). She conducts her business from the same single roomed-shack where they live in, making an average of ZAR400 ($24.92) a month, which enables them to get by. When I ask Mpho to describe what she eats at home, she says;

> Nobody is guaranteed of eating in our house. We depend on a feeding program in a nearby public primary school. […] we walk to the school, eat and come back home […]. On clinic days, we miss the food because, by the time we get back from the clinic, [we find that] all food has been finished by school children.

Initial meeting with Mpho at the clinic provided a snapshot of how her physical illnesses were compounded by an array of socio-economic and family issues. Five months later, my research assistant and I embark on a journey to visit Mpho at her home in Soweto. Mpho and her sisters are renting a small single roomed shack behind a main house. Although the shack seems to be of average size from the outside, the inside is too small. This day, Mpho's twin sister is not at home. She has been admitted at Johannesburg General Hospital for her chemotherapy sessions. Mpho is at home with her younger sister (who is mentally sick), their children have gone to school. The last time I saw her at the clinic, she looked strong and healthy. Today, her hair is covered with an old white and pink checked scuff, she has also lost some weight. Despite this, Mpho is now the caregiver of her mentally ill sister. She says, "Although she (sister) is calm now, someone must be looking after her". These introductory remarks are very troubling as I become implicated in her narrative. I keep on wondering how she is taking care of herself, their children and mentally ill sister despite her disability. Mpho continues;

> Life has become miserable since my sister got admitted at the hospital. We all depend on her. My landlord has knocked several times, she wants her rent, but I have nothing […]. I am tired of life. I have thought of killing myself, dying and forgetting my troubles. Even today, I feel like killing myself, but I wonder who will take care of my children and sisters if I die?

We spend some time indoors trying to catch up with how she manages her conditions. Our conversation is quite informal. Mpho continues;

> These days, my CD4 count [a test that measures the number of CD4 cells in someone's blood] has improved and I collect my ARVs from a local clinic in my neighbourhood. However, I still attend the tertiary hospital for my diabetes care. This is because, my diabetes is uncontrolled.

Mpho's house is about 30km to the tertiary hospital where she gets her treatment. She says, "Travelling to the hospital is so difficult, I have to pay ZAR100 ($5.68) every clinic visit […]." When she cannot afford this, she says, "I don't go to the hospital. I just stay at home but sometimes I use the traditional medicine that my sister sells." Mpho is stressed with her multiple illnesses. Worse still, she is more stressed because of her sick sisters, inability to pay rent and lack of food- she cannot afford even the cheapest foods; "This is why I have to skip taking my insulin because my body gets weak, I shake and feel like going mad," she explains. Despite these challenges, "The nurses and clerks at the clinic are always shouting at me without giving me a chance to explain why, why my diabetes and blood pressure are getting worse."

The clustering of social-economic, political and medical factors as exemplified in Mpho's case underscores syndemic suffering in Soweto (Mendenhall et al., 2017). These factors tend to interact synergistically in consequential ways, having a substantial impact on individual health, that of their family and the whole population (Singer et al., 2017). Mpho asserts that lacking basic needs such as food has influenced her non-adherence to diabetic medication. Also, she only attends the clinic whenever she can afford transport. An overlap of medical and social conditions are driving Mpho into depression and suicidal ideations. As Manderson and Warren (2016) posits, the everyday circumstances where individuals live in (e.g. poverty, food insecurity, stress) makes them

vulnerable to chronic diseases such as diabetes and depression. These diseases tend to interact both biologically and socially. For example, studies have shown that diabetes and depression maintain a bidirectional relationship (Holt, 2014), by which diabetes contributes to depression (Nouwen, Winkley & Twisk, 2010) and depression in those with diabetes is associated with non-adherence to diabetes treatment (van der Feltz-Cornelis et al., 2010). The intersection of these diseases are then exacerbated by poverty which inhibit them from accessing care and adhering to medications or making recommended lifestyle changes difficult (Manderson & Warren, 2016).

But Mpho's case is even deeper; her structural vulnerability is conjoined with the apartheid regime and current ethnic discrimination that denies her "citizenship". In this way, lacking the necessary documentation that would qualify her as a South African, denies her the opportunity to access basic needs, including those provided by the government (see also Quesada et al., 2011). South Africa's historical legacy of the apartheid regime played a key role in shaping structural vulnerabilities that is witnessed in society today (Coovadia et al., 2009). Political, economic, and land restriction policies structured society according to race, gender, and age-based hierarchies, which greatly influenced black people's economic activities, social organization, cultural and access to basic resources for health, and health service (Fried et al., 2015; Coovadia et al., 2009). Other structural vulnerabilities reflected in Mpho's case include poor housing and unemployment, all which negatively impacts her comorbid suffering.

Despite the numerous socio-economic hardships faced by many participants who attended the diabetes clinic, healthcare providers lacked this knowledge. For example, interviews with healthcare providers revealed that many were not aware of the social challenges that the patients faced. In addition, providers never took time to understand patients who frequently skipped their clinical attendance. Observations at the clinic revealed how clinicians and dieticians were more

focused on teaching patients how to manage their illnesses without considerations of patients' contextual factors (such as income, availability of food, family, culture) (Bosire et al. 2020a). These findings parallel other studies in South Africa which have revealed that healthcare providers manage patients (using biomedical frameworks) without recognizing the social-cultural aspects of patients' lives (Moola, 2019), or a lack of cognizance how these structural problems influenced development of chronic diseases in the first place (Ravn et al., 2016). Consequently, providers would interpret non-adherence to medications or inability to pursue healthy lifestyle modifications to be the willful moral choices of their patients rather than effects of social structural inequalities (Bourgois et al., 2017). Ignoring patients' socio-cultural or contextual factors (e.g. poverty) may lead to misdiagnosis, mistreatment or harm (Holmes et al., 2020).

Importantly, the ICDM model that was implemented in South Africa has a community level component that aims to facilitate assisted self-support and empowering individuals to take responsibility for managing their own conditions (Mahomed & Asmall, 2015). This component seemed to be under-developed or lacking in Soweto. For instance, none of the participants in this study reported having received any clinical support while self-managing their illnesses at home. Observations at home and the long hours I spent with Mpho chatting about her illnesses also revealed how she poorly adhered to her medication, yet, she lacked support on what she needed to do in order to be healthy. Mpho's case highlight how individuals living in poor settings have poor access to health care, fewer opportunities to engage in health prevention, as well as disease management programs (Horrell et al., 2017).This necessitates a need to develop community support systems that will link community with hospital; such that patients like Mpho can get the required support in time.

Furthermore, many participants revealed that they had other family members with chronic illnesses. Participants narrated how self-management in this context was challenging, given that there were limited shared resources amongst all family members who were sick. This narrative is exemplified by Bongani's case below.

Case 2: Managing self and others in context of multimorbidity and structural vulnerabilities.

Bongani is a 67-year-old man who lives in Soweto, together with his wife and 17-year-old son. He suffers from three medical conditions: HIV, diabetes and hypertension. His wife suffers from HIV and psychosis. Bongani was diagnosed with HIV 16 years ago in a private clinic in Soweto. Five years later, he was also diagnosed with diabetes and hypertension. He says;

> Managing the three conditions is stressful, especially now that I am not working. I also have to manage my wife's two conditions because she is mentally sick, she has psychosis and HIV. In total, it's like I am managing five diseases […] this is too demanding both financially, physically and emotionally.

Bongani is unemployed and relies on government's social grant worth R3400 ($212.43) for both himself and his wife – each earns R1700 ($ 106.22) per month. However, he adds that;

> The money is not enough. I can't even afford my rent and diabetes foods. I also need to buy foods and medication for my wife. I only try to buy whatever I can, but I never get to achieve what the doctor recommends […]. Although I adhere to my medications, I do not see much changes. My diabetes and blood pressure seem to be getting out of control.

To deal with these challenges, Bongani has opted to pay for a gym, which he finds to be affordable at R340 ($22) a month, compared to buying healthy foods which he says, "are expensive". For

Bongani, he can eat unhealthily but must engage in physical exercise. Bongani spends more time supporting his wife than managing his own conditions. He vividly describes his daily routine as follows:

> I usually start my daily activities at six o'clock in the morning. First, I take my bath, brush my teeth, and prepare breakfast for my wife and my son. My son must eat before going to school. My wife and I will then eat our breakfast at around 8.00 a.m. Thereafter, I will clean the dishes and house, and when done with domestic chores, I will cook a meal for lunch and then rush to the gym. […]. In the evening, I will leave my wife at home for a moment and step out to meet my friends at a nearby shopping centre, where we would play cards and tell stories. Later, I would rush back home to prepare dinner for my family before we retire to bed […].

Although Bongani looked strong, determined and energetic, his description of day-to-day activities and taking care of his wife seemed quite demanding. He continues; "I visit two separate clinics for my diseases: HIV clinic and a diabetes clinic for diabetes and hypertension." Bongani attends these clinics every 3-4 months as recommended by a physician. As if this is not enough, he must take his wife to an HIV clinic and occasionally, to psychiatric clinics. This is problematic, because "sometimes, my wife's clinic appointments collide with mine." He also adds that "I must pay transport for all these clinic visits." To Bongani, managing his wife is more engaging and draining than managing his own conditions, he says; "I spend much of my time on her, sometimes I forget about myself, my medications […], this has affected my health."

Many other interlocutors reported challenges of self-care while caring for others (in terms of food, physical support, or clinical visits). Specifically, managing multiple chronic medical and social conditions within contexts of financial insecurity compounded the challenging

circumstances that individuals like Bongani encountered, leading to a vicious cycle of poverty and poor health (see also, Jenkins et al., 2009; Barrett et al., 2014, Bosire et al. 2020a). In their findings, Jenkins and colleagues (2009) found that individuals who reported 'strain' associated with their caregiving responsibilities, had significantly higher rates of mortality and poor health. Other recent studies have also reported that caregiving burden can have a negative impact on individual's physical and mental health (Kızılırmak & Küçük, 2016; Jagannathan et al., 2014), social relationships and financial stress (Durmaz, 2014; Jagannathan et al., 2014). This could possibly explain why Bongani repeatedly mentioned how his health was deteriorating each day.

Allocating time to manage self and others and attending to other household duties was found to be difficult. This was quite disturbing for individuals like Bongani who spent more time taking care of other family members rather than focusing on their illnesses, placing their own health and well-being at risk. Corbin and Strauss (1985) have described chronic illness in terms of work, including illness-related work (such as managing symptoms, going to hospital), everyday work (such as household tasks, child rearing), and biographical work (such as managing emotions or identity). "Management of an illness in the home" they write, "is not accomplished without difficulty and a great deal of effort, unless the regimens are relatively simple and do not greatly interfere with the normal flow of life" (p.172). A lack of balance between the three types of work often leads to poor health outcomes.

Discussion and Conclusion

This study sought to explore patients' experiences seeking care for comorbid HIV and diabetes at a large public tertiary hospital in Soweto, South Africa, as well as how they self-managed their concurrent chronic illnesses at home. Findings from this study show that patients received fragmented and uncoordinated care for their chronic illnesses. Moreover, chronic

illnesses were found to be intimately entwined with patients' socio-economic factors (e.g. poverty), as reported in other studies (see Mendenhall, 2016; Manderson & Warren, 2016). These key findings will be unpacked further in the summary below.

Integrated and coordinated management of clustered conditions requires care that is centered on patients' needs, so that people get the care they need, when they need it and in ways that are user-friendly (WHO 2008). Interlocutors in this study illuminate lack of integrated or holistic care provided to the them, for their chronic illnesses. Previous studies in public hospitals in South Africa have reported lack of integrated services for chronic diseases (Ameh et al., 2017; Matima et al., 2018). This has been attributed to health system challenges such as staff shortages, inadequate equipment, unskilled providers or lack of multimorbidity guidelines (Ameh et al., 2017; Matima et al., 2018, Bosire et al. 2020c). There are also poor developed systems that link community care with formal public healthcare services (Matima et al., 2018). Lack of integrated care is particularly challenging for patients with concurrent HIV and diabetes—who requires routine medical care and treatment for each singular disease, costing time, effort, and lost wages (Mendenhall, 2017). This problem of non-integration and disease-specific clinics is not unique to South Africa; indeed, it reflects biomedical systems around the world, which systematically separates medical problems by disease due to specialties, or medical problems from social problems (Nolte et al., 2012). Elsewhere, lack of integrated care is recognized as an important cause of low quality of care and unnecessary health care spending (Bodenheimer, 2008).

In addition, this study reports patient-provider divide in terms of providers lacking a clear understanding of how to manage patients' illnesses, while considering their social-economic challenges (Ravn et al., 2016). We have extensively reported a lack of patient-centered care at the tertiary hospital where this study was conducted (Bosire et al. 2020a). Healthcare providers' lack

of understanding of patients' socio-economic factors may lead to poor quality of care provision (Holmes et al., 2020). Recent studies have revealed that patients are happier when involved in their own care (Harris et al., 2016). Yet, provider's inability to offer patient-centered care may not be an individual problem; rather it's a reflection of clinical and organizational functioning of healthcare (Valentijn et al., 2013). Taking a patient-centered care approach will help in broadening the conventional medical approach to include the patient as an active participant in his or her care, and to promote the physician-patient partnership in care (Entwistle et al., 2018).

Access to care and self-management was largely influenced by patients' socio-economic conditions. For instance, many households had more than one person managing chronic conditions which underscores the colliding epidemics of chronic diseases in South Africa (Oni et al., 2015; Chang et al., 2019). Further, the rapid increase of chronic illnesses at household level could reflect shared social, economic, and familial factors such as economic constraints, shared food patterns, unemployment, and delayed care-seeking due to cost (Cockerham et al., 2017). Given these factors, living in context with limited resources e.g. poverty, food insecurity was found to be stressful especially as patients navigated care for their multiple social and medical conditions. This finding demonstrate how closely tied stress and distress are to chronic illnesses, and how both physical and mental health are reinforced by social-economic factors which render individuals vulnerable to other bodily or affective conditions (Mendenhall et al., 2019).

Some patients also spent a great deal of their time managing others, while neglecting their own health. This finding is similar to what has been reported in Botswana (Lindsey et al., 2003) and India (Weaver, 2019). For example, in her studies with women with Type II Diabetes in Northern India, Weaver (2014; 2019) has elaborately described how women were "vulnerable" to exploitation in the context of caregiving responsibilities; and that women prioritized other family's

needs and care while neglecting their own care. Participants such as Bongani reported how they spent more time caring for their families – wives and children, while spending limited time managing their own diseases (see Kenny et al., 2020). In the context of aging, chronic multimorbidities and structural vulnerabilities, these findings suggest that increased attention should be given, especially to the role of men in caregiving responsibilities. This is especially true in context like South Africa where both men and women are equally affected by the colliding epidemics of HIV and NCDs like diabetes (Oni et al., 2015) and mental illnesses (Mendenhall, 2016). Although this study did not delve deeper into the issue of gendered dimension of care, findings reported here are useful for future researchers who may want to explore further on men's experiences as caregivers in context of multimorbidities.

Policy implications and recommendations

Findings from this study show that vulnerabilities exist within individual's everyday interactions with chronic illnesses and recommends that integrated care is imperative for improving the lives of individual patients and communities at large. There is need to ensure that all components of the ICDM model, and particularly the community component, are fully implemented in Soweto. In addition, policy makers must ensure that chronic care models e.g. the ICDM are adapted to fit the local context that will take consideration of peoples' socio-economic conditions. Taking a more holistic understanding of what integration is, and how it must function will reduce misdiagnosis, mistreatment or harm (Holmes et al., 2020).

Second, integrated care should be designed in a way that people get care for all their conditions together (or are able to see multiple clinicians in one clinic visit) – including comprehensive counselling. This will work better in primary healthcare clinics as opposed to

tertiary hospitals which largely provides specialized services (Bosire et al., 2020c). Thus, PHCs need to be strengthened in terms of provision of adequate medication, equipment and increase number of trained or skilled staff who can manage patients with multimorbidities. Within tertiary hospital, there is need for collaborative or a team-based care – where specialists at tertiary hospital must engage and communicate amongst themselves when managing patients with multimorbidities and engage with providers at PHC clinics to enhance patients' improved outcomes.

Third, caring for patients should be centered on patients or individual needs as opposed to diseases. In part, this requires a shift from the conventional biomedical healthcare approach to a more patient-centered care (Moola, 2019). This may entail strengthening communication within the health system broadly and clinics specifically. If medical settings are too slow to integrate care for patients who present with multiple conditions, then there must be better communication between clinics so that clinicians know when patients visit other clinics, what medicines they are taking, and how competing social and medical demands affect their care-taking of one disease or another. Working in a collaborative manner will minimize conflicting recommendations. In this way, healthcare providers must understand structural and cultural competence, or what has been more recently referred to as 'cultural humility' in order to care for the complex competing demands among patients in places such as Soweto (Metzl & Hansen, 2014). This involves not only understanding these non-medical factors that affect communication but also consider how prescriptions of medicines or behavioural modification may be affected by the sociocultural contexts. Thus, structural and cultural competence skills will be helpful in confronting the health problems caused by inequitable social structures.

Further, findings from this study shows that informal care settings play a central role in chronic care and management (social networks, social resources and support systems) and must

be linked to the formal health systems (Carpentier & Grenier, 2012; Hayes, 2006). Yet, informal care systems are often overlooked in health policy and practices. There is need to understand the complex interaction that occur amongst patients and their social networks away from the clinics, and how individuals balance between family needs and personal needs in context of chronic illnesses and structural vulnerabilities (Mendenhall et al., 2019; Weaver, 2019;Kenny et al., 2020). This knowledge will help to identify strategies that will make patients active in their own care, make informed choices about their care, adhere to their medications and practice more effective self-management (Langins & Borgermans, 2015). In other words, by understanding the complex dynamics that challenge normative self-care domains, patients can be more agentive in recognizing what they need to feel healthier and live the life they strive for amidst multiple, interacting chronic conditions (see Hansen et al., 2011).

Lastly, policy interventions must address structural vulnerabilities that place individuals at vulnerable positions to development of these chronic conditions. To achieve health promotion and the prevention of disease, comprehensive integrated health promotion strategies that address individual factors (such as lifestyle behaviour and health literacy) and socio-economic factors (such poverty and housing) together with improved health services, are required for improved patient outcomes and increased wellness.

Study limitations

This study is not without limitations. Participants were recruited from one tertiary hospital in Soweto; as such, findings in here may not be indicative of the experiences of patients in other settings. However, the goal of qualitative research is not to generalize findings (Tracy, 2010), but to fully explore lived experiences. Thus, this study sought to understand patients' experiences

seeking care for comorbid HIV and diabetes in Soweto, South Africa, as well as how they self-managed their concurrent chronic illnesses at home. Future studies should explore patients' experience with chronic care in other levels of care such as primary or secondary levels. Language barrier was a key challenge in this study because, being a non-South African, I did not understand any of the local languages in Soweto. The use of a multi-lingual research assistant for translations may have distorted the original meaning of words, or her presence may have influenced participant's responses. Furthermore, I may have influenced my own views on participant's access to care and self-management at home. Despite this, findings reported in this study sheds light on patients' experiences in accessing care and self-management for multimorbidities in Soweto and may be considered as exemplary in other similar settings as well as inform policies on chronic care.

In conclusion, management of chronic multimorbidities is complex and challenging not only to the patients but also to the healthcare system and society. Integrated care, with enough staffing and paying attention to cultural humility might help mitigate some of the problems. As such, primary health care facilities in Soweto must be strengthened through provision of adequate medication, equipment and increase number of staff who can manage patients with multimorbidities. In addition, tertiary hospitals must also be strengthened to offer collaborative care or team-based care to patients with multimorbidities. This may minimize conflicting recommendations provided to patients. Ultimately, policies on chronic care management must incorporate socio-economic conditions which shape the experiences of living with multimorbidities – this involves both the toll one's illnesses take on those who love them (with cost of food, medicine and transport to clinics) but also how the illnesses of others afflict them in their daily lives and personal need to self-manage their conditions.

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CHAPTER 4: PhD PAPER 2

Title: Patient-Centred Care for Patients with Diabetes and HIV at A Public Tertiary Hospital in South Africa: An Ethnographic Study

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Original Article

Patient-Centred Care for Patients With Diabetes and HIV at a Public Tertiary Hospital in South Africa: An Ethnographic Study

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Abstract

Background: Healthcare systems across the globe are adopting patient-centred care (PCC) approach to empower patients in taking charge of their illnesses and improve the quality of care. Although models of patient-centredness vary, respecting the needs and preferences of individuals receiving care is important. South Africa has implemented an integrated chronic disease management (ICDM) which has PCC component. The ICDM aims to empower chronic care patients to play an active role in disease management process, whilst simultaneously intervening at a community/population and health service level. However, chronic care is still fragmented due to systemic challenges that have hindered the practice of PCC. In this article, we explore provider perspectives on PCC for patients with comorbid type 2 diabetes and HIV at a public tertiary hospital in urban South Africa.

Methods: This study utilizes ethnographic methods, encompassing clinical observations, and qualitative interviews with healthcare providers (n = 30). Interview recordings were transcribed verbatim and data were analyzed inductively using a grounded theory approach.

Results: Providers reported various ways in which they conceptualized and practiced PCC. However, structural challenges such as staff shortages, lack of guidelines for comorbid care, and fragmented care, and patient barriers such as poverty, language, and missed appointments, impeded the possibility of practicing PCC.

Conclusion: Health systems could be strengthened by: (*i*) ensuring appropriate multidisciplinary guidelines for managing comorbidities exist, are known, and available, (*ii*) strengthening primary healthcare (PHC) clinics by ensuring access to necessary resources that will facilitate successful integration and management of comorbid diabetes and HIV, (*iii*) training medical practitioners on PCC and structural competence, so as to better understand patients in their socio-cultural contexts, and (*iv*) understanding patient challenges to effective care to improve attendance and adherence.

Keywords: Diabetes, HIV/AIDS, Patient-Centred Care, South Africa

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Key Messages

Implications for policy makers

- This study emphasizes the need to strengthen health systems in South Africa and other similar contexts, by increasing the number of staff and developing multidisciplinary guidelines for managing comorbidities. This would also facilitate implementation of integrated and patient-centred care (PCC).
- Policy-makers can improve care for people with comorbid diabetes and HIV by ensuring sufficient equipment and trained staff at primary healthcare (PHC) clinics in South Africa.
- Medical institutions need to invest in training and equipping medical practitioners and students with cultural humility and structural competence skills that would help them adopt PCC.

Implications for the public

While this research focuses on healthcare providers' perspectives, and not directly on the patients, the findings demonstrate a need for a close relationship between healthcare providers and patients in terms of chronic disease management. Patients' socio-cultural and economic backgrounds cannot be ignored within clinical spaces. As such, patients' voices, perspectives and lived experiences of chronic diseases are important especially when designing chronic care programs that are contextually appropriate. Providers need to support patients with and often also, their informal carers' in improving their knowledge and skills and encouraging them to actively participate and collaborate with providers in decision-making and self-management.

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Background

The number of people that require chronic disease care is projected to increase in sub-Saharan Africa as a result of expanding HIV treatment coverage, rising life expectancies,[1] and a rapid increase of non-communicable diseases (NCDs).[2] This trend is expected to continue challenging today's health systems, particularly as the shift in the burden of disease increases the need for people with multi-morbidities to have continuing contact with multiple practitioners in the health system.[3] HIV and NCDs require ongoing attendance at appointments, adherence to tests and medications, healthy living and self-management. This is exemplified by diseases, such as type 2 diabetes (hereafter, diabetes) that require constant glucose monitoring, healthy eating, foot care, and exercise that involve active self-management away from the formal health system. As a result, healthcare systems are adopting integrated and patient-centred practices that aims to deliver quality care and value for money, while acknowledging the role that patients play in chronic care.

In South Africa, convergence of chronic diseases such as HIV and diabetes are now becoming common and are overburdening the healthcare system.[4] This reflects the high prevalence of HIV in the country, estimated at 13% of the total population[5] and a rapid increase of NCDs including diabetes.[6] One study in a South African peri-urban settlement found that one in 4 patients seeking primary care had multi-morbidities and that 45% of adults sought prescriptions for HIV, tuberculosis, diabetes, and/or hypertension.[4] Recently, a study conducted in rural settings in South Africa has reported a rapid increase of patients with multi-morbidities, exemplified by a clustering of cardiometabolic conditions and HIV.[7] Simultaneously, most South Africans afflicted by multiple morbidities rely exclusively upon the public health system for detection, treatment, and care.[8] Yet, the state of public hospitals is overburdened: healthcare personnel are inadequately trained, there is erratic drug supply and frequent stock outs, and resource allocation of finances and essential equipment is inadequate.[9] The staff shortages especially hinder providers' abilities to develop relationships with patients and impede long term care.[10] This may in part be exacerbated when differences between patients and providers, such as race and class, make it more difficult to understand one another.[11,12] Thus, there is need to improve patients' access to care, reduced cost of care and improve patient-provider relationships by adopting integrated and patient-centred care (PCC) models.

There is no unifying definition or common conceptual understanding of integrated care, but integration involves a set of methods and models for the funding, administrative, organization, service delivery, and clinical levels designed to create connectivity, alignment, and collaboration between the cure and care sectors.[13] The World Health Organization (WHO) defines integrated healthcare as "the organization, management and coordination of health services so that people get the care they need, when they need it, in ways that are user-friendly, achieve the desired results and provide value for money."[14] Following evidence that integrated chronic disease care improves patient health outcomes,[15] the Joint United Nations Programme on HIV/AIDS (UNAIDS) recommended an integrated approach for chronic disease management. This approach leverages the innovations of the HIV programme to support or scale up services for NCDs[16] using the WHO's building blocks described in the Innovative Care for Chronic Conditions (ICCC) framework.[17] The ICCC emphasizes the importance of offering quality healthcare services, the integration of chronic conditions services, and adaptability to changes in burden of disease.[17]

In South Africa, the ICCC was adapted through formulation of the integrated chronic disease management (ICDM) framework between 2011 and 2013.[18] This framework is based on a Public Health approach to empower the individual to take responsibility for their own health, whilst simultaneously intervening at community/population and health service levels. The ICDM argues that optimal clinical outcomes for people living with single or multi-morbid conditions can be achieved through primary healthcare (PHC) re-organization involving improved clinical management support, clinical practice guidelines for integrated care, and the use of community healthcare workers to assist patients with self-management.[18] In addition, unlike the HIV care models that are vertical in nature, the ICDM adopts a diagonal approach to health system strengthening, ie, technical interventions that improve the quality of care for chronic patients coupled with the strengthening of the support systems and structures to enhance the health system.[18] Thus, ICDM is centred around service users, and it forms the core foundation in providing PCC.

There is no universally accepted definition of PCC,[19] but there is general agreement that it broadens the conventional medical approach to include the patient as an active participant in his or her care, and to promote the physician-patient partnership.[20] PCC is a philosophy built around the needs of the individual and contingent upon knowing the person through an interpersonal relationship.[21] In this way, patients must also understand their role as partners in care and be willing to collaborate with providers as well as share their self-care experiences and concerns. This requires patients to acquire adequate knowledge, motivation, skills, and confidence[22,23] to participate in their own care and manage their conditions, a concept known as 'patient activation.'[24]

A shift to integrated and PCC requires services and roles to be re-designed and re-structured to be more conducive for implementation of ICDM and PCC. However, recent studies have reported that chronic care in most public hospitals in South Africa is still fragmented and patients with comorbid chronic conditions such as diabetes and HIV continue to receive care for their illnesses in separate clinics at PHC.[25] In addition, although patient up referral for NCDs like diabetes is recommended for complications that need specialized treatment and care, health systemic issues at PHC facilities such as inadequate staff, equipment and drug stock out necessitates patient referrals to higher levels of care (E. N. Bosire, S. A. Norris, J. Goudge, E. Mendenhall, unpublished data, 2020).[26] Due to lack of integrated services, providers struggle to manage patients with multiple chronic conditions due to poor communication amongst providers on issues

around polypharmacy, lack of guidelines and decision-making tools for multiple conditions, and the difficulty of trying to manage multiple problems in a single, fixed-time consultation.[27,28]

While the ICDM framework is being implemented in different parts in South Africa, little is known about healthcare providers experience managing patients with chronic comorbidities, and their perceptions on PCC. This study sought to investigate provider's perspectives on PCC for patients with comorbid diabetes and HIV at a public tertiary hospital in Soweto, South Africa. We explored the challenges and opportunities that exist to practice PCC.

Methods

Study Design

This study used an exploratory research design – which aimed to gain new insights and understanding of PCC.[29] The study was conducted between April 2018 to June 2019 and explored health and healthcare for patients with both diabetes and HIV at a public tertiary hospital in Soweto, South Africa. The first author (ENB) engaged in extensive participant observation at the clinic and conducted multiple qualitative interviews with various actors within the healthcare system. The use of both observations and in-depth interviews complimented each other and facilitated triangulation of study findings.

Settings and Study Population

Soweto is a peri-urban neighborhood located about 15 km south west of Johannesburg's central business district. The township played a historically significant role in the anti-apartheid struggle and political resistance.[30] Within Soweto, the double burden of HIV and diabetes is escalating,[31] presenting the health system not only with a greater disease burden, but the challenge of responding to patients with comorbidities.

Sampling and Data Collection

We used ethnographic methods of participant observation and in depth interviews with various stakeholders in diabetes-HIV care – from doctors, endocrinologists, dieticians, podiatrists, nurses, hospital administrators, data managers and social workers – to capture a broad and deep understanding of how care for patients with concurrent HIV and diabetes was provided. The first author (ENB) conducted observations during patient clinical encounters with providers, during patient educational sessions, or in queuing spaces. She participated in everyday activities at the clinic, watching, listening, asking informal questions, helping nurses arrange clinic rooms and sometimes help to identify patients with diabetes who were admitted in the wards. However, she did not participate in treating or managing the patients.[32] Observations were conducted for 6 hours, 5 days in a week for the first 3 months, this was reduced to 3 days a week for the remaining months. In this article, we draw on 30 semi-structured in-depth interviews (30–60 minutes) and observations, conducted with healthcare providers. Providers were recruited using both purposive sampling and snow-ball methods. First purposive sampling was used to recruit one healthcare provider from the various professions: doctors, endocrinologists, dieticians, podiatrists, nurses, hospital administrators, data managers and social workers. These providers were recruited on the basis that they interacted with or managed patients with diabetes, HIV or both. Once interviewed, providers were asked to suggest contacts to approach for recruitment of subsequent interviews. We therefore used a snow-ball sampling method[33] to recruit other providers, until saturation point was attained.

Formal interviews with providers were carried out in English in a private clinic room in the hospital; questions addressed the participant's current job, experience managing patients with diabetes and HIV, and challenges and facilitators in management of patients. The final portion of the interview addressed their perceptions around the ideas of integrated and PCC in South Africa. Providers' responses in relation to whether they practiced PCC enabled further probing on their understanding of the concept, opportunities or barrier to practice PCC. Audio files from the interviews and field notes from observations were transcribed verbatim. All transcripts were checked against the recordings to verify accuracy.

Data Analysis

Data collection and analysis were conducted concurrently. Our data analysis adopted an inductive approach– drawing from a grounded theory approach. The main aim here was not to generate a new theory but to use tenets of grounded theory to develop a systematic, iterative and reflexive process through the multiple steps of the research program. We collected and analyzed data, re-evaluated and questioned insights developed, and followed leads emerging from the analysis to inform newly refined research questions, observations, and analysis.[34] This process enabled the researcher to capture all potentially relevant aspects of integrated and PCC as soon as they were emerged. Transcripts from audio files and field notes were read repeatedly by the first author, employing an inductive approach of immersion in the text through repeated reading (and studying any drawings in a similar way), thereby developing provisional analytic categories. These categories were refined by the constant comparative method; comparisons were made across themes emerging from field notes and audio transcripts. Making comparisons facilitated challenging already grouped data with new categories and this helped the researcher to guard against bias, thus enabling consistency and precision of data. These categories were then reviewed by the second author, and any identified discrepancies were solved at this level. This involved discussions between the first and second author. Lastly, the third and fourth author were involved in discussions about the key themes that emerged from the transcripts. Once all the 4 authors were in agreement, the first author developed a codebook which was reviewed by the second author. The final codebook was uploaded in QSR Nvivo 12 software where coding was done, and emerging codes were added throughout analysis. Initially, 40 parent nodes were identified, discussed, and defined, which fell into 15 parent nodes with a number of child nodes. Subsequent reading enabled the splitting of the parent nodes to child nodes, which provided a fast snapshot

of similarities, differences, patterns, and relationships from our data. The analysis led to obtaining providers,' definition and conceptualization of PCC, their attitudes and practices of PCC and existing opportunities and barriers to practice PCC.

Results

Thirty study participants between 25-56 years of age represented varied professional disciplines within the hospital (Table 1). Most had served for more than 10 years at the hospital. Half (n = 15) of the participants spoke both English and vernacular languages; they included nurses (n = 6), social workers (n = 2), dieticians (n = 1) and administrators and data managers (n = 4). Only 2 doctors (n = 2) spoke vernacular languages.

In what follows, we describe 3 key themes and sub-themes that emerged iteratively from our data:

a. Provider's understanding, attitudes and practices of PCC
b. Barriers to the practice of PCC in a public tertiary hospital
c. Enabling PCC: provider's perceived needs and recommendations

a. Provider's Understanding, Attitudes and Practices of Patient-Centred Care

In this domain, we present findings on provider's conceptualization and understanding of PCC, their attitudes and practice of PCC at a tertiary hospital in Soweto.

Table 1. Demographic Characteristics of Participants

Characteristics	N = 30 (%)
Gender	
Male	12 (40)
Female	18 (60)
Age	
25-35	9 (30)
≥35	21 (70)
Language(s)	
English only	10 (33)
English and vernacular	15 (50)
English and other(s)	5 (17)
Ethnicity	
Black	16 (53)
White	11 (37)
Indian	3 (10)
Profession	
Administrators and data managers	6 (20)
Dieticians	4 (13)
Doctor and endocrinologists	9 (30)
Nurses	6 (20)
Podiatrists	3 (10)
Social workers	2 (6)
Years of service	
≤10	11 (37)
>10	19 (63)

Conceptualization of Patient-Centred Care

Our findings show that providers had varied perceptions and understanding of what PCC was about. Many related PCC to the "*Batho Pele*" principles- roughly translated from the Sotho language means "people first."[35] The "*Batho Pele*" principles seek to introduce a new approach to service delivery that puts people first, and encapsulates the stated values of public service in South Africa, including healthcare. One nurse said: *"The patients have to come first, we have the "Batho Pele" principles which means people first. That is what we follow."* For others, the meaning of PCC was derived from the name itself, which was understood to mean placing the patient at the centre of care and taking patient's interests first. One doctor said, "*PCC means that the patient and his or her needs must be at the center of care.*"

PCC was also perceived to mean treating the patient as a person, a human being capable of engaging in other social events and leading a normal life in spite of illnesses:

> *"We all know that they are humans, they must attend to social functions like weddings or funerals […] Sometimes it is a challenge to start requesting for special foods in such social functions. So I must understand the patient from this perspective"* (Provider 8, nurse).

Some providers, especially nurses and dieticians described PCC to encompass understanding patient's social contexts. This included availability of resources to manage their illnesses, social support among others (see Box 1). In addition, some related PCC to empathizing with the patients:

> "*PCC means that you must empathize with the patient and encourage her or him to continue with the medication*" (Provider 4, nurse).

On the contrary, other providers reported that PCC meant following treatment protocols, which focused on ethical principles of treating a patient- such as respect and empathy. Accordingly, they felt there was nothing new about PCC because they always practiced it:

> *"Maybe it's the training we receive. I usually try to treat the patient based on my professional training and experience which shows you must respect the patient"* (Provider 10, doctor).
>
> *"I am trained to take care of patients and they [patient] also entrust their lives on us. So, I always apply these principles […]"* (Provider 1, nurse).

Attitudes Towards Patient-Centred Care

Although most providers understood the importance of PCC, some especially nurses, perceived PCC to be overly representing patient's interests and well-being without taking account of the healthcare providers as key actors in patient-provider relationships:

> *"Our managers should support us too, and show appreciation. It shouldn't just be about the patients, we are working hard, and they should also be there to support us"* (Provider 4, nurse).
>
> *"Like I said no one wants to listen to you, it's always the patient first. Just like now if a patient can come and says this nurse was rude to me, then you will be summoned to quality office, you are forced to say I'm sorry and nobody cares if the*

Box 1. Observations in a Diabetes Education Session

"Three things are important in management of your diseases: Compliance to your medication, right diet and exercise." During an ongoing diabetes education session, a dietician is busy educating patients on how to manage their conditions. About 10 patients who have just finished their clinical encounter are seated at a round table. Reinforcing the dietary requirements, the dietician uses a white board marker and a pen to draw 2 columns, one with permissible foods. As she lists the different groups of foods, she engages the patients who mention different foods as she writes them on the board. The dietician uses her expertise to reinforce dietary requirements that patients should follow. Suddenly, a doctor walks in accompanied by a middle- aged male patient. He [doctor] addresses the dietician saying; *"His glucose is very high. He still uses sugar in his coffee and everything else he eats is wrong!"* [His face looks sad], the doctor walks away. The dietician continues educating patients before she picks a colored plate from the table. The plate is partitioned into required food portions. Patients' eyes are glued on the plate as she raises it and explains what the different portions mean. She emphasizes *"You should always follow these dietary requirements: 3 meals and 2 snacks in a day."* One male patient asks, *"But how can I afford all these foods that you are talking about? They are very expensive."* The dietician answers; *"You may not modify your diet at once but slowly you need to change from the non-permissible foods to the permissible foods."* The patient sits back. Immediately, another middle-aged patient asks; *"I too don't think I can afford this […]."* The dietician says; *"I understand all your concerns. If you don't have money for the fruits or other foods that I have talked about, you can take whatever is available at home in small portion […] take a little pap [local maize meal] In between the 3 main meals, just ensure you take something in small portions."*

patient was wrong or not" (Provider 12, nurse).

One doctor revealed how patients were taking advantage of the "*Batho Pele*" principles when he said:

"We've got a problem of litigation and one of the loopholes is that patients are taking advantage of the "Batho Pele" policy which states people first. A patient may come in when her or his sugars are really bad and they expect you to do everything to salvage the situation, if not, they will sue the hospital."

Practices in Patient-Centred Care for Patients

Although providers cited various ways in which they understood PCC, many endeavored to ensure that patients received appropriate education and knowledge that would facilitate self-management of their diseases. However, our findings revealed that knowledge provision was mostly done in group sessions, such as during diabetes education sessions, as opposed to a one-on-one session between provider and patients. This limited a closer understanding of the patients' issues. The 4 key approaches that emerged as successes in providing PCC are described below: (*a*) providing collaborative care; (*b*) understanding the patient better and cultural competence; (*c*) structural competence; and (*d*) empathizing with the patients.

First, providers mentioned instances in which they provided collaborative care to patients. They mostly talked about engaging with other providers and used phrases such as *"I would try"* or "*we are trying to*" when describing how they offered care to patients. One nurse said: *"Right now we are trying to do that [collaborative care], we include the dieticians and podiatrists so that the patients can see all the specialists."* Such phrases show that although providers were trying to offer PCC, the process was not always easy. Some mentioned that they involved not only the patients but also their families or caregivers. In addition, providers mentioned how they viewed the patients as a whole, placing them at the centre of management as described by a one podiatrist: "*If patients are not placed at the centre of management of their diseases, then you'll miss out important things. For example, I can prescribe the most expensive drug, but if I only look at the diseases and not social or psychological issues, then it's all useless."*

Second, understanding the patients better, including their culture, languages and socio-economic status were identified as important in enhancing PCC. This was identified as a key strategy to minimize patient-provider distance. One dietician said: *"when it actually comes to the practicality of care, we have to asses if the patient can afford the required food, if not, we do refer them to the social workers to take action."* On occasion, providers would deviate from the guidelines and accommodate patients' treatments or to take stock of their social realities (see Box 1). Many described how being culturally competent enabled them to work well with the patients because, the patients felt much respected. One nurse said; *"Some of these patients strongly believes in cure from traditional healers and spiritual people, it depends on what their culture is all about. So I can't ask them to stop their beliefs because, if I do so, they will default their appointments."*

Although many variations exists in literature in definitions of cultural competence,[36] it is widely acknowledged that cultural competence is the attitudes, knowledge, and skills necessary for providing respectful and quality care to diverse populations.[36,37] However, researchers have paused to ask; is cultural competency the same as cultural sensitivity or awareness? For instance, when a nurse achieves cultural competency with a specific culture, is the nurse now culturally competent with all persons of that particular cultural background[38]? This notion, that through education, providers can truly understand the lived experience of patients, has proven problematic. Others have argued that cultural competence may be perpetuating stereotypes about what members of a particular "culture" believe, do, or want, and how they should be dealt with.[39] As such, a shift towards concepts such as cultural humility and structural competence is recommended.[37]

Cultural humility is "the ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the [person][40]" Cultural humility focuses on self-humility rather than achieving a state of knowledge or awareness.

Structural competence emphasizes recognition of the economic and political conditions that produce health inequalities in the first place.[41] The concept pushes the needle on what competence means – unlike cultural competence, structural competence begs the provider to think in terms of structural challenges – such as income, location, access, etc as

opposed to beliefs or culture.

Thus, providers in this study described how recognizing structural barriers (economic and political conditions that produce inequalities in health) to patients' abilities to follow clinical recommendations was a fundamental way for providers to demonstrate they understood their patients' needs.

Sometimes, nurses in the diabetes clinic used their own money to buy some loaves of bread and milk during clinic days to feed the patients who had nothing to carry from home. Although neither an adequate nor a sustainable solution to deal with patients' structural vulnerabilities, such charitable acts were said to make the patients feel appreciated and also, reduced the divide between providers and patients, something that fostered PCC. Elsewhere, this has been referred to as "doing with the patient"[42]; where providers work closely with the patients, while understanding their needs and empower patients to make informed and practical choices. This is opposed to "doing to" or "doing for" the patients, where providers follow strict clinical guidelines when managing patients with little understanding of patients' social needs.

Third, many providers described empathizing with patients through listening to them and giving them time to talk, especially when their health seemed to be deteriorating. This was said to facilitate a good rapport between providers and patients. In addition, most providers, especially nurses, were culturally sensitive to the patients they attended to. For instance, during one observation in the clinic; a woman in her late 50's said; "*I don't believe that diabetes can be managed in the hospital, only God can heal me.*" A nurse quickly concurred with the patient and she commended the patient for trusting God, a factor that was seen to encourage the patient. A summary of examples of practicing PCC is shown in Table 2.

Despite their efforts in practicing PCC, providers mentioned many challenges that inhibited the quality of care they provided to the patients and practice of PCC as discussed below.

b. Barriers to the Practice of Patient-Centred Care in a Public Tertiary Hospital

Many providers described feeling powerless to provide adequate care for patients with comorbid diabetes and HIV. In many cases, provider narratives involved personal frustrations they experienced by failing to deliver higher quality care because of systemic failures. For instance, a doctor in her mid-forties exclaimed, "*I feel inadequate when I see patients dying, I am well trained to manage these patients, but I don't have the right tools to do my work.*" As such, providers used words such as being "*frustrated,*" "*incapacitated*" or "*inadequate*" when describing how they were rendered powerless in care provision:

i. System Failures

These frustrations were exemplified in the lack of equipment or frequent malfunction or breakdown of diagnostic services. Providers were often frustrated because they had no control over equipment failure or lack of availability of treatments for their patients. For instance, an endocrinologist said; "*Sometimes you can diagnose a condition, but the treatment is not available. So what good have you actually done to the patient?*" Another doctor expressed; "*I got really frustrated in the service delivery for not being able to do everything in my power to best serve my patients because of limited resources, we are running out of drugs.*" For some, it was lack of equipment for specific tests that made it impossible to offer clinical advice for common conditions; "*We don't have the cholesterol machine, which is important. We can't offer advice on what they should avoid eating, we can't help.*" In these cases, lack of specific equipment had enormous impacts on the care people received.

Many physicians expressed concern about the use of clinical guidelines for people with comorbidities or multi-morbidities, which were generally developed for single clinical conditions. Use of multiple guidelines to manage patients was said not only to be frustrating to providers but also to the patients. One endocrinologist explained; "*The guideline may indicate how to manage a patient with diabetes and hypertension or other close related comorbidities but does not take account of those with multi-morbidities or complex diseases.*" Another doctor said; "*Sometimes, I am not sure what advice to give to patients due to lack of guidelines for comorbidities.*" Lack of comorbidity guidelines was exacerbated by poor communication between

Table 2. Examples of Patient-Centred Practice

Themes	Excerpts
Collaborative care and putting patients at the centre of care	*"I'll discuss with the patients, I will counsel them to make sure they understand, and then I'll reinforce or get the nurses to do it"* (Provider 3, doctor). *"We would try and find out if the family members are available for us to discuss simple things like, are they able to take care of the patient [...]"* (Provider 21, podiatrist).
Understanding the patient better and respect for patient autonomy	*"So, you need to know if the patient is going to dress their wound at home, is there anyone who can assist in taking care of the patient [...]"* (Provider 14, podiatrist). *"You know, you have to respect the patient's rights and their beliefs and their cultures. If they communicate that they want to seek alternative care, we try and inform them of the risks of doing so but respect their wishes should they want to. And we will never deny them treatment should they come back"* (Provider 22, endocrinologist).
Structural competence	*"Patients are not able to attain good health because of lack of money to buy the required food, I do teach them what is required as per the nutritional guideline but sometimes end up giving them alternatives that are practical in their settings"* (Provider 28, dietician).
Empathizing with the patients	*"Like she is smart, she will tell me the truth that 'I did not inject because it's sore [...]' and I would feel for her"* (Provider 1, nurse). *"I always feel for them because I know it's not easy. I would change their appointment dates to what fits them"* (Provider 4, nurse).

providers; where most providers managed patients with comorbidities based on their own discretion, with little cross-talk amongst them. This situation was evident especially when patients were sent to meet with various providers for different health conditions.

Our findings also show that care for patients with comorbid diabetes and HIV was fragmented with lack of integration in terms of administrative and consultative functions. Patients attended different clinics as exemplified by a nurse; "*We see the patients in different clinics. They will visit this clinic for diabetes and go to the other clinic for HIV/AIDs.*" This kind of fragmented care, characterized by physical separation of space, was partly due to the design and structure of the tertiary hospital, which focused more on providing specialty care. This limited provision of PCC. One doctor explained; "*It is even worse when they have other complications which may force them to see a dietician, podiatrist, or an ophthalmologist.*"

Observations in the diabetes clinic revealed the strain caused by staff shortages and heavy workloads. It was evident that most clinics were overstretched, exemplified by long queues and waiting time for the patients. The long queues were attributed to both patients coming earlier than expected and staff shortages. One nurse reported that; "*the patients come early and start queuing outside the clinic.*" As a result, the long queues added more pressure to providers who were forced to rush the patients through, just to clear the queues. Second, rampant staff shortages in most clinics exacerbated the issue of long queues; a doctor explained that: "*we have to treat patients in the ward first and by the time we come back to the outpatient clinics, the queues have built up.*" These sentiments were also echoed by one hospital administrator; "*The greatest challenge that we have is staff shortages, this explains why the queues are long in most clinics.*"

Many providers described that staff shortages had a large impact on the limited time available for them to engage in lengthy discussion with the patients. This hindered them from understanding their patients fully: "*I know I must take at least 20 minutes but due to long queues, I take about 5-7 minutes; which is not sufficient in getting to understand the patient.*" Moreover, many providers stated that staff shortages were linked to clinicians quitting their jobs. One doctor mentioned, "*They [doctors] are always on a transit,*" leaving for better opportunities. Another middle-aged dietician described this: "*The challenge is today patients see this doctor, tomorrow another doctor […]. Doctors resign or look for better opportunities.*" Equally, during an in interview with a doctor, she fought her tears back when she said, "*I am tired of working in such conditions; overworking, no equipment, patients dying […]. The best thing is to quit.*"

ii. Patient Barriers

Many providers also described how the patient-provider divide impeded them from providing PCC. With vast differences between patients and providers in income, education, culture, and ethnicity, many providers felt they could not fully understand or deliver care or advice that would be attainable by their patients. The sub-themes that emerged in this domain includes: culture, class, language and patient's socio-economic realities as discussed below:

Culture, Ethnicity and Language

Cultural factors are crucial to diagnosis, treatment, and care. They shape health-related beliefs, behaviors, and individuals' value.[43] This study drew from both patients' and healthcare provider's cultures – arguing that not only patients and their communities have cultures, but that there is also a "culture" of medicine,[43] and both cultures can hinder or foster healthcare seeking and provision. Patient's cultural beliefs and practices impacted on the practice of PCC. For instance, a middle-aged podiatrist narrated his concern with the impact of patient preferences or self-care once they left the hospital: "*I used the most expensive dressing for the patient's wound but when he went home, he visited the sangoma [traditional healer] who asked him to remove the dressing to allow the wound to dry. This can be so disappointing but what can I do?*" In this case, providers were faced with tension between respectful support for autonomous agency and the promotion of particular clinical goals based on their training (biomedical culture). Furthermore, many described patients' educational status as influencing the seriousness and attitudes they expressed in managing their diseases. For instance, one nurse stated, "*some are not educated, others don't see the need to come back for appointments or take our instructions seriously.*" As such, some acknowledged that it was difficult to strike a balance in their efforts to enable or activate the patients. Sometimes, [provider said that] patients concealed or were reluctant to provide potentially useful information as said by one nurse; "*They [patients] lie a lot. They will intentionally provide wrong glucometer readings in their diary, you will be surprised.*" This hampered providers from getting a clear understanding of patient's thoughts or feelings.

Providers also revealed that some patients were demotivated to engage in treatment goals or plans as revealed by a nurse; "*we encourage them to join the diabetes school but some feel it's a waste of time.*" Despite the few who were demotivated, some patients were more motivated and worked hard towards achieving pre-set goals. One endocrinologist said; "*Some patients themselves feel motivated and they want to join management program. One patient moved from 135 kilos to like 80 kilos.*"

South Africa is an ethnically diverse nation, which provides a complex and intriguing picture of multilingualism. The country has 11 official languages, namely: Sepedi, Sesotho, Setswana, siSwati, Tshivenda, Xitsonga, isiNdebele, isiXhosa and isiZulu, English, and Afrikaans.[44] In Soweto, most people speak 1 or 2 of the 9 Bantu languages listed first, and few use English and Afrikaans. Given the divergence in backgrounds between patients and providers, language barriers were constant and challenging during clinical encounters, similar findings have been reported elsewhere.[45] Moreover, many patients visiting the tertiary hospital outside of Soweto were referred from both within and outside South Africa. Most patients speak limited English, preferring African languages that few providers speak. Most doctors, endocrinologists and dieticians spoke exclusively in English, with few who could speak African languages. Nurses and social workers

spoke African languages but this did not cover the diversity of languages patients spoke. One nurse explained, *"we offer good education in our clinics, but we are not really checking whether they understand it or not."* In addition, a dietician said, *"Especially patients from Mozambique, they are the ones that really, really are finding it difficult to understand what we are saying."*

Patient's Socio-Economic Realities

Patient's socio-economic status – including employment, availability of food, transport to the hospital, or living environment, influenced how they adhered to their treatment regimes and also, the care they received from providers. Furthermore, these factors were said to largely hinder patient-provider partnership in care and hence, diminished practice and success of PCC. For example, providers felt powerless when they experienced patients who could not adhere to clinical advices due to unaffordability of the recommended diet. One dietician said, *"It is so frustrating for me when I design the right nutritional plan for the patient, then the patient cannot afford."* Patients often failed to show up for clinical appointments. Nurses would often shout at patients who defaulted their appointments. Yet, many described this was due to lack of transport to the hospital or, as one doctor explained, *"The old people will be telling me that I don't have money, there is no one to bring me."* Another endocrinologist said, *"Sometimes they would say that they were sick, or they had to travel for a family funeral […]."* Similarly, a podiatrist stated that: *"some of them come from far places, like Lesotho or Limpopo, defaulting is because of the distances they travel to see us."* Defaulting clinical appointments hindered continuation of care and follow-up, on patients' progress in managing his/her illnesses. It is with these barriers that many providers (especially those who were keen on practicing PCC) became the most frustrated. Yet, the limited flexibility in patient scheduling and appointments was difficult. This was even more complicated for patients with multi-morbidities who had to schedule and attend more than 2 clinical visits. This contributed to some patients missing appointments and showing up when least expected as described by a nurse:

"The challenge is, we don't have a flexible appointment dates due to staff shortages. We see type twos [T2DM] on Monday and Thursday, and type ones [T1D] on Tuesdays […]. Imagine I have 200 patients coming in today and 20 defaulters shows up. That means we will see 220 patients that day. This creates workload for us."

Thus, both institutional limitations and patient's social economic factors created a social distance between providers and patients, a factor that many described as impeding them from practicing PCC.

c. Enabling Patient-Centred Care: Provider's Perceived Needs and Recommendations

Despite the existing opportunities and limitations to practice PCC, providers cited different strategies that can be employed to enable practice of PCC. First, it was mentioned that a proper implementation of integrated care could enhance practice of PCC. One nurse said: *"I think the best way to approach PCC will be to manage all the condition in totality, we shouldn't just concentrate on one. We must bring everything in, there should be social workers coming, doctors and all other providers."* Another doctor recommended strengthening of PHC facilities when he said: *"But this hospital [tertiary level] is not the right place for doing integrated care. Primary centres need to be strengthened to provide integrated care."*

In addition, providers also cited that addressing the issue of staff shortages and providing necessary equipment would enable them to practice PCC efficiently. One doctor said; *"These challenges wouldn't be as bad if we had enough monitoring equipment. That is a huge challenge I experience everyday and it need to be addressed"* her sentiments were echoed by one endocrinologist who said: *"So infrastructure is a big problem, we don't have enough resources for us to manage patients well. […] the government should look into this."*

Providers also mentioned the need for more training on how to offer integrated and PCC. One doctor recommended that providers working at PHC clinics must be trained using a family physician approach: *"As a South African doctor, for the majority of the time you are trained by a family physician and this is the model they should be applying because it is more integrated. So in the primary health sector, I would expect providers to be trained using similar approach."* Another doctor concurred when he said: *"Yes, definitely the knowledge needs to be improved quite a bit. Also, we do not have a good training program, the nurses need more training on PCC given the number of patients they see […]."* Providers mentioned that there was a need to train patients on the importance of PCC, while stressing out the importance of patients understanding their roles and responsibilities in chronic care. Others mentioned that it was important to conduct community awareness on NCDs so as to prevent these diseases at the first place: *"More information has been provided on HIV and TB, but most patients don't know about diabetes and its management. At the moment I would say knowledge is very limited at the community level and people must be educated and trained on how to prevent these diseases."*

Discussion

This is the first study to employ ethnographic methods to investigate healthcare providers' perspectives and practices of PCC for patients with comorbid diabetes and HIV in Soweto. First, providers mentioned different ways in which they conceptualized PCC, most relating it with the "*Batho Pele*" (people-first) principles. Others understood PCC to mean placing the patient at the centre of care, empathizing with the patients or treating patients as a person. Second, this study found that the practice of PCC was hampered by both health systemic barriers and patient-related factors. Health systemic issues such as lack of equipment and guidelines for multi-morbidities, staff shortages and the structure of the tertiary hospital which promoted specialty care as opposed to integrated care, diminished possibility of practicing PCC. Patient-related factors such as language barrier and poverty constrained their involvement in decision-making pertaining to their disease management. In most cases, the practice of PCC was inconsistent as patients were activated in group

sessions with no further personalized engagement with providers that would facilitate interactions and partnership in care. Finally, our findings show provider perceived needs and recommendations that might enhance their practice of PCC in Soweto. We will discuss these points in turn.

Provider Understanding, Attitudes, and Practices of Patient-Centred Care

Providers largely related PCC to the *"Batho Pele"* principle, one of the South African government public service policies, which means "people first" and aims on transforming public service delivery.[35] Our findings are in line with earlier studies in South Africa, which have reported that nurses equated PCC to practicing *"Batho Pele"* principles.[46] In this context, providers narrated how they respected the patients and considered their views in care. Others derived their understanding of PCC to mean placing patient at the centre of care. Unlike the "*Batho Pele*" principle that considered patients first (by respecting and prioritizing their needs), placing patients at the centre of care was said to be above and beyond this: It ensure that patients were treated as a whole – here, providers not only looked at patients' illnesses but also, tried to understand their socio-economic issues that were outside the purview of medicine. In addition, some providers mentioned that PCC meant empathizing with the patients and treating them as persons or humans capable of making informed decisions. Our findings parallel earlier studies which have pointed out that the concept of PCC can be variously interpreted.[20,21] However, there is general agreement that PCC broadens the conventional medical approach to include the patient as an active participant in his or her care, and to promote the physician-patient partnership.[21] Although most conceptualizations were aligned with PCC as reported in literature, few providers deviated from the key principles of PCC; their understanding of PCC was about implementing knowledge from their medical training and following clinical guidelines and protocols. Such an understanding is not fully congruent with the PCC constructs described in the literature. For the others, they perceived PCC to be overly representing patient's interests and well-being without taking account of the healthcare providers' needs. Thus, there is need for provider training on the key tenets of PCC.

Barriers to practice of Patient-Centred Care in Soweto

First, providers experienced frustrations, inabilities, and burnout when managing patients due to the poor working conditions characterized by staff shortages, workload, and insufficient equipment; factors that constrained their abilities to deliver high-quality care to patients. Our findings validate earlier studies which have reported how hospital shortages and poor working conditions have limited providers from managing patients with comorbidities in South Africa[26,47] and in other low- and middle-income countries.[48] In addition, such factors have been frequently mentioned as major barriers to implementation of PCC.[40,50] Due to inadequate resources and overstretched tertiary level hospitals in South Africa, decentralization and integrating diabetes care into PHC facilities may reduce such challenges. Although the ICDM has been implemented in most PHC clinics in South Africa, the implementation is not smooth across all provinces; places like Soweto continue to experience slow implementation rates due to structural challenges such as lack of medication and staff shortages. There is need for the South African Department of Health to ensure that these challenges are addressed for successful integration of diabetes care at PHCs. Decentralization of chronic care will facilitate closer working relationships between patients, nurses and community healthcare workers at PHC, thus improving patient clinical attendance, clinic functioning, understanding the patient better and easier implementation of PCC.[51]

Second, lack of guidelines for comorbidities and multi-morbidities, with none extending to address patient's cultural or social realities compounded providers' frustrations. Earlier studies have reported that most guidelines are generally written for managing sole conditions and do not account for the unique circumstances of each patient.[52,53] Furthermore, this study revealed that patients attended separate, fragmented clinics, a finding that has been reported in earlier studies.[25,54] Inadequacies of using a single guideline for comorbidities and patients visiting separate clinics limited provider shared decision-making and flexibility to respond to patient's complex, personal experiences. Instead, this study shows that guidelines should accommodate conditions that cluster together, while supporting providers to deliver a more personalized, integrated and comprehensive PCC.

Third, this study conveys a complicated story around how patient social challenges such as financial insecurity, unaffordability of healthy diets, and lack of transport to the hospital impeded providers' ability to offer quality care to patients and further hampered practice of PCC. Previous studies have shown how unaffordability of clinically recommended foods especially for people with diabetes[55] and patients' lack of transport to the hospital[56] has led to poor health outcomes. Indeed, this finding underscores how significant structural competence can be for clinical care in contexts like Soweto. As opposed to cultural competency, which can reify cultural stereotypes, Metzl and Hansen have argued that structural competence emphasizes how structures shape clinical interactions, develop deeper structural divides within and between patient-provider relationships, and beg for interventions and understanding of structural divides as well as structural solutions for care.[41] Harris and colleagues have pointed out that patients are happier, more cooperative and productive, and more likely to make positive changes in their behaviour when providers do things with them, rather than to them or for them, which is a key tenet in PCC.[42] As revealed in our study, although health systemic challenges and patient social challenges hindered the practice of PCC, some providers (especially dieticians) deviated from clinical guidelines for managing patients to discuss with the patients on the practicality of care they designed (see Box 1). This was based on patients' social and economic circumstances; thus designing care involved engaging the patients rather than designing care for them. We recommend that clinicians should consider the upstream determinants of health if PCC is to be practiced in resource-constrained settings like Soweto.

Unsurprisingly, language barriers severely limited physician-patient communication and engagement in care. Our findings concur with recent studies which have elucidated how the language barrier remains a crucial challenge to providing equitable and quality healthcare to patients in South Africa[57,58]; thus limiting patient participation in care.[59] Although it is easy to explain these systemic problems away by highlighting the linguistic diversity of Soweto, there are multiple employable interpreters, nurses, clerks, and other staff who either already speak many of the languages that doctors do not. In some ways, this is an upstream problem that highlights the need to identify and incentivize medical institutions to encourage multi-lingual South Africans to train in the field and fill these roles after completing medical school, as evidenced in other settings.[60]

Provider Perceived Needs and Recommendations

Providers recommended strategies that would enhance successful implementation of PCC. First, many reported that PCC was more practical at PHC clinics rather than at tertiary hospitals. Understanding this disjuncture is critical – why might it be difficult to focus on patient needs within the tertiary hospital setting? Perhaps, within hospitals, shifting from focusing primarily on the specialist, to the needs of the patients, would provide an opportunity for more integrated HIV and diabetes care – even in the most serious of cases. Many also cited that there was a need to address staff shortages and provide necessary equipment at hospital. Furthermore, some recommended further training for providers on how to better provide PCC. In practice, providers sometimes find it hard to shift from biomedical approaches of care to more person-centred approaches.[61] This calls for training and equipping healthcare professionals (especially in medical schools) with both cultural humility[37] and structural competence skills that can promote the change that is required to accomplish PCC in South Africa.

Providers reported a need to provide training or education to patients – so as to understand their role as partners in care and be willing to collaborate with providers as well as share their self-care experiences and concerns.[22,23] However, it is important to note that within the bureaucratic system of a large hospital, it's difficult to place the burden of systemic transformation on patient advocacy alone. These unexhaustive recommendations taken together may strengthen the practice of PCC in public health facilities in South Africa.

Study Limitations

This study is not without limitations. First, this study did not involve patients, thus lacking the patients' voice. Second, all participants were drawn from one tertiary hospital in Soweto, and experiences at PHCs even in Soweto may differ. Therefore, it's unclear whether all patients sent to receive care at the tertiary hospital were experiencing complications, or if it was serving as an alternate PHC option. Third, findings from this study may not reflect clinics in other provinces in South Africa. Nevertheless, the findings provide important insights for those managing patients with comorbid diabetes and HIV because even in one of the best public hospitals, care is not integrated across conditions that people encounter. In addition, participant observation and in depth interviews with healthcare providers across the health system provided an in depth study of integrated care possibilities and pitfalls within this very specific context.

Conclusion

Policies advocating for integrated care and PCC for people with comorbidities and multi-morbidities in South Africa may fail to achieve the intended outcomes if health systems do not work toward alleviating institutional limitations and addressing the challenges experienced by healthcare providers. There is a need for healthcare systems to change approaches that meet the challenges and complexity of patients with comorbidities or multimorbidity by developing guidelines that take account of these conditions. It is important to strengthen PHC clinics in South Africa by ensuring access to necessary resources that will facilitate successful integration and management of comorbid diabetes and HIV. Training medical practitioners and students on PCC, and equipping them with cultural humility and cultural competence skills may also enable a better understanding of patients in their socio-cultural contexts. Lastly, training patients is also key in ensuring they too, understand their roles as partners in chronic care, and they should be willing to collaborate with healthcare providers in care and treatment.

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Ethical issues

Written informed consent was obtained from the study participants after reading out the content of the information sheet and explaining the purpose of the study. This study was approved by the tertiary hospital's research committee and the Human Research and Ethics Committee at the University of the Witwatersrand, Johannesburg, South Africa (Ethics number: M171125).

Competing interests

Authors declare that they have no competing interests.

Authors' contributions

ENB conceptualized, conducted the study, analyzed data, and wrote the manuscript; EM, SAN, and JG conceptualized the study, provided supervision, and reviewed and approved the manuscript.

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CHAPTER 5: PhD PAPER 3

Title: Pathways to care for patients with Type 2 Diabetes and HIV/AIDS comorbidities in Soweto: A Health Systems Perspective.

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Abstract

South Africa is experiencing the colliding epidemics of HIV/AIDS and non-communicable diseases (NCDs). In response, the National Department of Health (NDoH) has implemented integrated chronic disease management (ICDM) aimed at strengthening primary health care (PHC) facilities to manage chronic illnesses. However, chronic care is still fragmented. This study explored how the health system functions to care for patients with comorbid Type 2 Diabetes (T2DM) and HIV/AIDS at a tertiary hospital in Soweto, South Africa. We employed ethnographic methods encompassing clinical observations and qualitative interviews with actors within the health system (n=30). Data were transcribed verbatim and thematically analysed using QSR NVivo 12 software. Findings reveals that health systemic challenges such as the lack of medication, untrained nurses and limited number of doctors at Primary Health Care (PHC) clinics necessitated patient referrals to a tertiary hospital. At a tertiary hospital, patients with T2DM were managed first at the Medical outpatient department (MOPD) before they were referred to a specialty clinic. Those with comorbidities attended different clinics, with little to no collaboration; partly because of poor communication, non-centralised patient information, and staff shortage.

There is need to strengthen PHC clinics in Soweto – by training nurses to diagnose and manage patients with T2DM, and also ensuring adequate medical supplies. We recommend that the MOPD at a tertiary hospital should also be strengthened to offer integrated and collaborative care to patients with T2DM and other comorbidities. Addressing key systemic challenges such as staff shortages and non-centralised patient information will create a patient-centred as opposed to disease-specific approach to care.

Key words: Diabetes, HIV/AIDs, Health Systems, comorbidities, South Africa

Introduction

> *Nokuthula [pseudonym], seeking care at a specialty diabetes clinic in a large urban hospital, left her doctor's office with a confused look. In her mid-sixties, she had been to the clinic many times for her Type 2 diabetes and other co-morbid conditions, including hypertension. But this time, she had several physical complications that she needed to deal with. When she left the clinical encounter, she held a file, which she handed to the clerk at the reception, while she scrambled to manage several loose papers in her other hand. These loose papers were several referrals to other clinics, which she eventually placed on the reception desk. As the clerk was busy working on her file, Nokuthula lifted one of her loose paper, read it and asked, "Where is the podiatrist clinic?" The clerk, without looking up, pointed to the far end, right side of clinic. Nokuthula did not understand what the clerk meant and asked again. The clerk said this time, "that room labelled Podiatry!" She then picked up the second sheet of paper and asked, "Where is the dietician clinic?" The clerk answered, "Use the stairs up to the second floor". Then she picked up the third sheet of paper, read it, and asked; "Where is the St. Johns eye clinic?" The clerk, looking irritable, answered; "You have to walk up on the bridge from the hospital to the taxi rank just outside Bara [CHBAH] then ask from there. The eye clinic is outside Bara. Looking confused, Nokuthula reassembled her papers and walked out.* (ENB notes on the diabetes/endocrine clinic at a tertiary hospital, 2018)

Living with a chronic condition like Type 2 diabetes (T2DM) can pose extraordinary social and medical costs for people residing in cities like Johannesburg, South Africa. This is in part because the convergence of multiple chronic and acute conditions has become a fundamental challenge for health systems across the world (WHO 2014). Chronic non-communicable diseases

(NCDs) accounts for about two-thirds of all deaths worldwide with 80% of these deaths occurring in low- and middle-income countries (WHO 2014). In addition, NCDs are now occurring alongside chronic infectious diseases such as HIV/AIDS, due to advances in healthcare that keep people alive for long (Nolte, Knai & McKee, 2008). Changing disease patterns demands strengthening health systems to provide consistent and sustainable care to patients (Kruk et al., 2018).

In South Africa, a middle-income country, non-communicable diseases (NCDs) like T2DM have risen swiftly among communities afflicted with a heavy burden of HIV as well as other infections, such as tuberculosis (TB) (Oni et al., 2015). For instance, T2DM was found to be nearly as common as HIV, TB, and hypertension (HT) in a peri-urban settlement in Cape Town, making up 45% of all consultations (Oni et al., 2015). In this context patients receiving antiretroviral therapy (ART) are more likely to have T2DM than low-income people without HIV (Clark et al., 2015), and this risk increases exponentially the longer one receives ART (Sobieszczyk et al., 2016). Concurrently, those most afflicted by this double burden of disease, largely depend exclusively upon the public health system for detection, treatment, and care for both acute and chronic conditions in South Africa (Mayosi et al., 2012; Mayosi, Flisher, Lalloo, Sitas, & Tollman, 2009)

As a response to the disease burden, the National Department of Health (NDoH) in South Africa initiated the Integrated Chronic Disease Management (ICDM) model, which uses a diagonal approach to health systems strengthening (Mahomed & Asmall, 2014). The diagonal approach integrates the vertical HIV programme with the horizontal general health system (Knaul, Bhadelia, & Atun, 2015). The ICDM model aims to improve the convenience and quality of chronic disease care for the majority of patients in primary health care (PHC) at a single delivery point, thereby integrating PHC into the health system.

Few studies have evaluated the quality of ICDM in South Africa. Despite having a greater potential to deal with the barriers experienced by patients with multiple chronic diseases, a recent study found ICDM has been more useful to patients with HIV because of reduced stigma, but did not show benefits for patients with NCDs, such as hypertension (Ameh, Klipstein-grobusch, Lucia, Kahn, & Tollman, 2017). Other studies have also reported that infrastructure limitation have negatively affected the sustainability and scale-up of the model (Mahomed & Asmall, 2016). Recent studies have reported that the ICDM model has not been implemented in most public PHC clinics due to health systems challenges (e.g. staff shortages, inadequate equipment, unskilled providers or lack of multimorbidity guidelines) (Ameh et al., 2017; Matima et al., 2018). This has necessitated patient referral to higher levels of care which are over utilised, congested and overburdened, leading to an escalation of healthcare cost (Atun et al., 2013; Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009).

In addition, the referral system and care pathways are often part of integrated care, and may help to guide the delivery of integrated care for patients while clarifying roles and responsibilities in the care process (Pinder, Petchey, Shaw, & Carter, 2005). Further, collaboration between different professionals, such as primary care physicians, hospital specialists, nurses, and social workers is central for integrated care for people with co-morbidities (Boult, Green, Boult, Pacala, & Snyder, 2009; Nuño, Coleman, & Bengoa, 2012). Collaborative care has the potential to make it easier to work as a team with colleagues from other professions when managing patients, allowing them to provide patient-centred care (Petersen et al., 2019). However, building effective partnerships requires relationships, procedures, and structures that can be different from the usual ways of working (Lasker & Weiss, 2001). These structures seem to be lacking in most public health care facilities in South Africa due to insufficient financial and human resources to manage

the health care system (Fusheini, Eyes & Goudge, 2017; Mayosi & Benatar, 2014). Besides, failure to use electronic health records or a centralised system for patient's information in most public hospitals in South Africa (Bantom & Retha, 2016; Raff & James, 2003) poses a huge challenge to integrated and collaborative care for patients. While researchers have reported about the benefits of integrated and collaborative care in South Africa, little is known about how the healthcare system functions in terms of coordinating care through multiple clinics for patients with chronic comorbidities in Soweto, South Africa.

We draw from Atun and colleagues' (2010) conceptual framework of integration of targeted health interventions into health systems. This framework proposes that each situation uniquely affects the adoption and diffusion of new health interventions and the extent to which they are integrated into critical health system functions. Atun et al. (2010) identify variants as the nature of the problem being addressed, the intervention, the adoption system, the health system characteristics, and the broad context. The implementation of the ICDM in South Africa is undergoing a slow adoption and has not been scaled up to most PHC spaces. This has resulted to patients bypassing the primary health clinics to attend hospitals for the initial contact visit, thereby increasing the cost of the service (National Department of Health, 2009). In addition, patients with T2DM are mostly managed at secondary or tertiary levels while HIV is managed at PHCs. Recent work on improving the quality of clinical practice have postulated that integrating chronic diseases, such as T2DM into PHCs in South Africa can only be feasible provided that systemic challenges and change management are addressed (Mahomed & Asmall, 2015).

We use a case study of two clinics that provide care for patients with comorbid T2DM and HIV/AIDS at a public tertiary hospital in Soweto to investigate care pathways and explore how the health system functions to care for such patients. We interviewed 30 health care providers who

care for patients with T2DM, HIV or both, in order to better understand the challenges and opportunities within the current system for care of these conditions alone and together.

Methods

Setting and structure

This tertiary hospital-based study was conducted in Soweto, a peri-urban neighbourhood, located about 15km southwest of Johannesburg's central business district and with a population of approximately 1.3 million (Stats SA, 2011). In Soweto, there are no designated secondary (regional or level 2) hospitals because a tertiary hospital provides district (level 1) and regional (level 2) hospital services, in addition to tertiary (level 3) referral services. Patients accessing care at the tertiary hospital are referred to from regional, district, or primary health care clinics or community clinics from outside or within Soweto. This study focuses on two clinics within the tertiary hospital: The Medical Out-Patient Department (MOPD) and the diabetes/endocrine clinic.

The MOPD covers all specialised clinics at a tertiary hospital. Apart from patients who enter the hospital through the Emergency Department (ED), other patients accessing the hospital passes through the MOPD. Most patients are first managed at MOPD and then systematically referred to specialty clinics within the hospital when need for specialised care arises. Diabetes/endocrine clinic is situated right opposite the MOPD. It is a special clinic for patients with all endocrine conditions, including diabetes.

This ethnographic study was conducted between April 2018 and November 2018, comprising of observations and semi-structured interviews. Observations (by first author) were conducted in different spaces of the two clinics: the triage room, the doctor's room, the reception area, patient queuing space, and diabetic education class. The first author's role fluctuated between

an observer and participant observer; she participated in everyday life of staff in the clinic- helping, watching, listening and asking questions pertaining to care for patients. However, she did not participate clinically in helping manage patients. She recorded a summary of field notes in a small jotting notebook and wrote up a full ethnographic account before the end of the day. Sometimes, the first author asked unstructured questions during the observations, which were collected and comprised in her field notes.

Thirty semi-structured interviews (30–60 minutes) were conducted with health care providers to understand their experiences in managing patients with T2DM and HIV/AIDs co-morbidities. They included doctors, endocrinologists, dieticians, podiatrists, nurses, hospital administrators, data managers, and social workers. Purposive sampling was used to select health care providers across the disciplines in the diabetes/endocrine clinic; this involved approaching existing contacts to interview and follow from within the clinic. As the first author uncovered how patients navigated care in the hospital, it was revealed that some patients with T2DM were first managed at MOPD and were only referred to the diabetes/endocrine clinic when experiencing complications. This necessitated understanding care pathways from the MOPD to diabetes/endocrine clinic. One provider from the diabetes/endocrine clinic recommended a provider working at the MOPD, this snowballing method facilitated recruitment of other health care providers at the MOPD (n=5). Data collection continued to a point that no new ideas were emerging from the data. A semi-structured interview guide included questions about care for patients with T2DM and HIV/AIDS, referral system, integrated and collaborative care, barriers to care, and opportunities for care. Interviews were transcribed verbatim.

Data Analysis

Data were thematically analysed using Qualitative Solutions for Research (QSR) NVivo 12 software. A combined deductive and inductive approach was used for data analysis. The deductive analysis was based on the pre-identified themes focusing on the research questions and literature reviews, including: Factors that contribute to individuals' vulnerability to illness and diseases in Soweto; care provision for patients with chronic diseases; experience managing patients with multiple chronic diseases; availability of resources for managing patients with comorbidities; understanding of integrated care; collaborative care; patient-centred care; challenges experienced while administering care to patients with comorbidities/multimorbidities; recommendations to improve care. Inductive analysis was undertaken for all the emerging theme from the transcripts and field notes (from observations at the clinic). Transcripts and field notes were read and re-read by the first author to familiarise with the data and to come up with the coding frame. The last author read a sample of data and considered whether the coding frame was adequate. She also reflected on the coding frame developed. The two authors then held a meeting where together, they refined the coding frame based on their shared reading of the data and their discussion. This process happened several times as the first author continued to read new data and re-read previous data and a final coding frame was able to be applied. We came up with a codebook that was developed in NVivo by the first author (indicating parent and child nodes) for coding and analysis. Nodes were then applied to relevant blocks of text in the transcripts. Emergent new nodes were added to the codebook, and all transcripts were reviewed again in an iterative process. Nodes were summarised in analytical memos and verbatim excerpts were used to report the key identified themes (with numerous sub-themes): 1) Organizational-care pathways and the referral system; 2) Managing patients with T2DM and HIV/AIDs comorbidities; and 3) Patient support and involvement of family members or caregivers. Case stories that reflected aspects of chronic care

and complexities navigating through the healthcare system were developed after overall analysis of data. These cases represented many other patients that sought care at the hospital.

In our analysis, we used Atun and colleagues' framework as a diagnostic tool. This process allowed a detailed mapping and understanding of how the healthcare system functioned in terms of care provision. Specifically, we looked at the healthcare intervention, which in this case was integrated care – while identifying its purpose, extent or implementation, identified gaps and recommendations. In other words, the framework provided a detailed mapping of chronic care at a tertiary hospital in Soweto while evaluating the purpose, extent, and nature of ICDM integration in Soweto. By examining how the health system functioned to manage patients with comorbid T2DM and HIV, we analysed what works and what doesn't work within the health system as a primary focus of analysis.

Ethical Considerations

Written informed consent was obtained from the study participants after reading out the content of the information sheet and explaining the purpose of the study. Consent was also sought from study participants during observations e.g. during clinical consultation. Research Committee at a tertiary hospital and the Human Research and Ethics Committee at one of the largest university in Johannesburg approved this study (M171125).

Results

Table 1 describes the 30 health care providers who were recruited from the diabetes/endocrine unit (n=25) and MOPD (n=5). Participants' median age was 40 years. Majority had worked for more than 20 years and were trained in diverse disciplines (*see table 1*). Three overarching themes in this study emerged: 1) Organizational-care pathways and the referral system; 2) Managing

patients with T2DM and HIV/AIDs comorbidities; and 3) Patient support and involvement of family members or caregivers. We discuss these emergent themes in turn.

1. **Organizational- care pathways and the referral system**

Health care providers described how most patients used two main structured channels in accessing the tertiary hospital: 1) A referral from PHC clinics, or 2) patient who came directly through the emergency department (ED) (*see figure 1*). One nurse described this process as follows:

> *"There is a referral system, patient need to start there [PHC]. The doctor must write a referral letter for them to come here [tertiary hospital]. Some will come in through the emergency department. Once they are treated here, they are down referred for management and collection of pills at the community clinics."* (Provider 1, nurse)

a. Limitations in the current system

Health care providers reported that this referral system design failed to meet patient needs for various reasons. First, providers often referred patients from the PHC to tertiary hospitals because of health systemic challenges (such as lacking medication, equipment, doctors) as opposed to patients needing the specialist care often associated with such referrals:

> *"Due to lack of necessities at Primary clinics, sometimes the GP understand it's pointless to write the letter to send this patient to PHC, only for the patient to be sent back to us [a tertiary hospital]."* (Provider 2, doctor)

> *"Primary health care clinics have got limited resources; they can't do the blood tests required for diabetic care".* (Provider 3, doctor)

Many argued that because the PHC clinics in Soweto were managed by nurses, as opposed to doctors who only worked in the clinics on rotational basis, many nurses were overburdened by their patient load, or were untrained to manage patients with diabetes, which caused them to initiate more up-referrals from PHC to tertiary hospital:

> *"Doctor's come on a specific day, let's say on Wednesday, if a patient comes on Monday and it's beyond the sister's scope, they will refer the patient to [name masked for blind review]."* (Provider 4, nurse)

> *"Some nurses at PHC are not well trained to diagnose patients with diabetes early enough. They only suspect that a patient is diabetic when patients are already experiencing complications, and this makes them refer them to tertiary hospital."* (Provider 11, endocrinologist)

Some opined that patient's self-referral from PHC to a tertiary hospital were simply due to geographic convenience or perceived better quality there:

> *"Some patients will walk in because [name masked for blind review] is very close to where they live compared to a primary clinic in Soweto".* (Provider 5, hospital administrator)

> *"They [patients] don't want to go to the local clinic, they will say there are no medication."* (Provider 6, nurse)

This pattern of skipping the PHC, and therefore not following the traditional referral process was described as common negligence because, a patient who walked in without a referral would still be allowed to access the hospital:

"The problem is that here [tertiary hospital], they cannot turn the patient away. The person at registration will give them a number and allow them in." (Provider 7, doctor)

Many suggested that such deference to protocol were central to reinforcing these structural factors, such as overwhelming workloads, that played a primary role in creating bottlenecks at a tertiary hospital, thus compromising patients' quality of care.

b. Down-referral, medication, and challenges

The existing referral system design requires that once patients have received treatment and are stable at tertiary hospital, they are down-referred to community clinics for management and continuous collection of their medications:

"We have a down referral form, this is what we use to send them back to the community clinics." (Provider 1, nurse)

A MOPD doctor also described how pre-packaged medication is sent to local clinics:

"Medication is prepared at the chemist here [tertiary hospital] and then sent to the local clinic. Then at the local clinic, there is a chemist staff who just takes the medication out of the shelf and dispenses to the patient."

Many healthcare providers reported that in Soweto, there are six main clinics that were selected to be central for medical supplies and refilling to patients with chronic conditions. These clinics were: Lilian Ngoyi, Chiawelo, Mofolo, Stretford, Lenasia South and Zola. Medications were distributed to these clinics and patients could select any of the six clinics, which was close to them for repeat medical supplies. Unfortunately, this did not work as expected because of drug stock outs:

"Patients will always complain that they missed their medications at the primary clinics due to drug stock outs." (Provider 8, nurse)

Drug stock out at PHC was attributed to various reasons. First, this was said to be a trickledown effect of drug stock out at tertiary hospital, which in turn influenced non-supply of medications to PHC:

"The hospital does not pay the drug suppliers on time. If you want to confirm this, they keep on changing the suppliers because, some have stopped supplying the drugs." (Provider 9, data manager)

Over supplying of medication to patients was also linked to drug stock at tertiary hospital:

"They will issue extra medication to patient and at some point, you will be told this and that is missing from the pharmacy. This affects supply to primary clinics too" (Provider 10, doctor)

In addition, the system of pre-packaging medication and sending to PHC was said to be failing as described below:

"There are so many steps in the system; it could be that the courier dropped the parcel, could be someone stole the medication and so on." (Provider 11, endocrinologist)

Ultimately, challenges experienced in the referral system were majorly attributed to poor communication between different providers at different levels of care:

"You imagine the patient coming here, from Orange farm to say, 'I didn't get medication' Already they are in turmoil […], poor communication is the biggest challenge in the referral process." (Provider 12, nurse).

2. **Managing patients with comorbid T2DM and HIV/AIDS**

This study revealed that there was limited integration of chronic services at the tertiary hospital. This is partly because of the design of the tertiary hospital which is specialised into different clinics. Patients with comorbid T2DM and HIV were attended at in two separate clinics: at the MOPD or diabetes/endocrine clinic for their diabetes, while those who tested HIV positive would receive care at the [name masked] (HIV/AIDS) clinic—a separate stand-alone clinic that was three minutes' walk from a building housing diabetes/endocrine clinic. One doctor explained this:

> *"We don't do the HIV treatment itself here, they go to Bara. Then they will come back here [MOPD] on the same day or different days for diabetes care.*"

Another doctor said that:

> *"Patients go in the morning in one clinic and as soon as they are done with that clinic, they'll go and queue in the other clinic." (*Provider 10, doctor)

Diabetes/endocrine clinic only managed patients with endocrine conditions:

> *"We only manage patients with endocrine conditions in this clinic. Patients with HIV must be managed at HIV clinic."* (Provider 10, doctor)

Not unsurprisingly, those with both T2DM and HT often received care in tandem; however, for every other physical and psychiatric condition, patient would visit specific clinics. Patients with diabetes complications, such as neuropathy in hands and feet and kidney nephropathy, visited other, specific clinics (as illustrated in Nokuthula's case). Some of these clinics for physical complications associated with diabetes were situated outside a tertiary hospital. Although these clinics are a very short walk from the hospital, this can be difficult for someone with a disability.

Such were instances when health care providers emphasised that collaboration and coordination of care was an imperative aspect, which rarely occurred.

Even though it was said to be rare, providers acknowledged that collaboration between different professionals, such as primary care providers, specialists at a tertiary hospital, nurses and social workers would be a good thing and an improvement to patients' quality of care:

> *"Working together means we are treating the patient well by providing what we are thinking is best for the patient. If she's amputated and she's the bread winner for example, then nothing else will be happening at home. So, with that consideration we might motivate the surgeon to do amputation that is not so intrusive."* (Provider 14, Podiatrist)

In this context, the podiatrist implied that she would motivate the surgeon to do a partial amputation, after weighing both medical and social risks of performing a full amputation. They would settle at a procedure that was favourable to the patients' medical and social aspects of life. They also gave examples on instances where they collaborated in caring for patients:

> *"Yeah, we work as a team. We [educators] will teach them about the disease, the dietician teaches about what they need to eat, then the podiatrist will teach them on the foot care."* (Provider 15, diabetes nurse educator)

However, providing integrated and collaborative care for patients with HIV and T2DM was said to be difficult due to poor communication, non-centralised patient information, staff shortage and limited resources among others *(see table 2*)

a. Poor communication

Poor communication affected both vertical and horizontal collaboration. This occurred in two levels: between providers at the tertiary hospital and those at PHC and, amongst health care

providers in different specialised clinics at the tertiary hospital. For instance, nurses reported that some doctors at a tertiary hospital down-referred patients to PHC clinics in Soweto, without a detailed report on further management at the PHC level. This led to most patients being referred back to a tertiary hospital, especially when nurses at PHC did not know how to manage the patients. In addition, rarely did providers at the tertiary hospital communicate with each other when managing patients with comorbidities or multimorbidity; some providers would provide a double prescription to patients with comorbid conditions especially those that cluster together (such as T2DM and HT) without realizing that the patients had already received similar prescriptions in a different specialty clinic. This led to cases of oversupply of medication, drug duplication, and mismanagement of patients.

Ethnographic case observation of communication problems:

> *Patients with T2DM and other co-morbidities come to the clinic with unused medications. There are empty drawers at the clinic reception where all unused medication is kept. Sometimes, patients would return the unused medication to the pharmacy when they come to collect new supplies. Nurses would shout at the patients for being non-adherent to their drugs. It became clear after a series of observations and non-formal communications with patients that patients were given extra medications especially when they attended other clinics for comorbidities.*

One nurse expressed her amazement when she said:

> *"When they come to the clinic, you will be surprised that they still have enough medication for another month or so."* (Provider 4, nurse)

Probing further, a doctor revealed circumstances in which oversupply of medication occurred:

"The patient has a file in dermatology, he gets his medication and then when he come for his diabetic clinic, it's a different file that they have and there is no communication between the two clinics. In such cases, double prescriptions may occur." (Provider 10, doctor)

Poor communication also led to treating diseases in isolation of the other for those with comorbidities:

"We try to ask if they have any other diseases but with workload, and if the other diseases are not indicated in the file, I just treat the disease I know of." (Provider 3, doctor)

b. Non- centralised patient's information system

Ethnographic case observations of unlinked medical records

At MOPD clinic, there were computers but were mostly not linked to other departments due to network connectivity challenges. In most cases, data was captured manually. Diabetes/endocrine clinic is one of the three specialty clinics at a tertiary hospital that has implemented an electronic health record system (the Intellovate system). This system captures patient's information through biometrics. The system also scans through patient's file every time a patient has a clinical encounter with the doctor. The up-to-date information captured in this clinic cannot be shared with other clinics because, this system has not been rolled out to other clinics.

This case observation reveals that the lack of a centralised patient's records system in a tertiary hospital challenged collaborative care efforts. This attributed to manual capturing of patient's information through their files. Thus, providers complained of spending more time checking in patient's files, and the poor quality of care provided for patients requiring more than one clinic; still, some patients' files were lost at the hospital registry *(see table 2).*

c. Staff shortage

Staff shortage and workload was reported to negatively affect care collaboration across discipline because providers did not have time to organise meetings with their peers on a case management:

> *"Collaboration is not that easy. If you find there is something urgent you have to address, and you have other patients in the queue waiting, this makes it difficult…".* (Provider 3, doctor)

Another provider shared the same sentiments when she said:

> *"The problem is we have few doctors and many patients".* (Provider 1, nurse)

In addition, integrating services and working as a team was also a challenge due to the existing professional hierarchical structures for managing patients:

> *"A podiatrist is not exactly authorised to prescribe antibiotics. When the doctor is not around maybe once they've left the clinic when they finish, you find that it becomes a challenge. Because I always need a medical doctor to prescribe certain drugs for me".* (Provider 14, Podiatrist)

Inter-professional conflicts were also highlighted as another reason why collaborative care was not working well. For instance, one podiatrist reported how foot surgeons undermined their work and felt that podiatrists were inferior to them, when she said:

> *"Most of the time, surgeons will override anyone's decision, I don't know why it's like that. So […] we will screen the patient and find a wound, write our notes and say that we want to manage this patient with wound care. Then the following day when you go, the surgeons*

have taken over the patient and maybe the patient is already prepared for theatre, this makes me feel they think we don't know our work". (Provider 21, podiatrist)

Proximity to other clinics were also reported to negatively influence collaborative care. For example, HIV, Renal and Psychiatric clinics were said to be meters away from the diabetes/endocrine clinic:

"Some clinics like psychiatric are far away […] It is difficult to start looking for a psychologist when they cannot be reached by telephone." (Provider 7, doctor)

3. **Patient support and involvement in care**

Patient support was said to be imperative especially for those who managed more than one chronic condition. However, it was mentioned that due to workload, providers never spent much time for personalised care with the patients:

"We try to involve them [patients] but the workload is too much, we have not much time for this." (Provider 16, doctor)

Support was mostly done in-group forums such as during the diabetes education sessions. Yet, this support was not always taken up well especially when some patients had attended such sessions before or when they were in a hurry to join queues in other clinics.

"They are always in a hurry to leave the education class. They will complain that they are getting late for other clinics […]." (Provider 6, nurse)

"They [patients] feel it is a waste of time because they have been in the sessions before." (Provider 17, diabetes nurse educator)

Although patient's family or caregivers were invited to join diabetes education sessions, this was challenged especially;

> *"For those patients who live alone or those who don't have family at all."* (Provider 18, doctor)

Similarly, social workers reported some of the challenges they experienced while involving family members in patient's care:

> *"Sometimes, we don't receive a good welcome from the patient's relatives or other caregivers."* (Provider 19, social worker)

> *"We make all the family and patient sit down and talk about the patient's condition […] the problem comes when they [family] abandon the patient and don't want to be involved in the care."* (Provider 20, social worker)

Discussion

This study investigated integrated and collaborative chronic care at the tertiary hospital in Soweto to examine how the health care system functions to manage those with T2DM and HIV. We found that patients with comorbid T2DM and HIV visited different clinics with limited collaboration amongst health providers within the different clinics at the tertiary hospital and with PHC clinics in Soweto. This is not because of lack of will from health care providers; rather, it reflects health system deficiencies such as staff shortage, non-centralised record keeping, poor communication, and medication stock outs. Lack of communication impeded people from addressing major health concerns. In addition, patients with more advanced T2DM symptoms who

arrived at MOPD at the tertiary hospital were required to seek care at this level first. Then, they were referred to the diabetes/endocrine clinic only when their condition worsened. This often delayed more specialised care for about two months, and arguably made them sicker. In what follows, we address some of the major findings around care provision for patients and recommendations for improving care for patients with T2DM and comorbidities in Soweto, and other similar settings in low-middle income countries (LMICs).

Patients with co-occurring chronic illnesses require complex models of care, involving integration and collaboration of services among professions and institutions that have traditionally been separate. South Africa has already implemented the ICDM model to strengthen PHC facilities to care for patients with chronic comorbidities (Mahomed & Asmall, 2014). However, this model has not been implemented in most PHC clinics in Soweto. Although patients with HIV can be managed at PHC, those with T2DM are mostly referred to a tertiary hospital. This is because of systemic challenges such as staff shortages, lack of equipment and medical supplies, and poor outcomes. Such systemic barriers were also found in a Cape Town study that reported two separate clinics for patients with T2DM and HIV even within PHC clinics (Matima et al., 2018). These findings substantiate those from this study by indicating that reorganization of PHC according to the ICDM model is still experiencing challenges throughout the country.

Furthermore, the spaces in which chronic care is differentially provided matters. Atun and colleagues (2010) argued that these clinical arrangements are essential to the health system and the context where interventions are being implemented. It is therefore important to recognise that integration of chronic care models is impeded at the level of the health system in public health facilities in South Africa. Studies conducted in other low-resourced settings have found readiness of health services scale up for the management of chronic conditions through an integrated chronic

care approach failing due to lack of staff, lack of access to treatment protocols, inconsistent supply of essential drugs, and other systemic barriers (Katende et al., 2015; Leung et al., 2016; Peck et al., 2014). These aligned with what was found at the tertiary hospital in Soweto. To bolster integration of chronic care through the health system therefore requires more investment in detection, diagnosis, treatment of non-communicable diseases alongside and in tandem with HIV care at the PHC level. This will reduce cost, improve care, and enhance patient outcomes.

Care pathways for patients through a well-structured referral system is requisite for integrated care for those with co-morbidities (Pinder et al., 2005). This study revealed several limitations in both up and down referral. For instance, some patients walked into the tertiary hospital without a referral letter, while some doctors and nurses referred patients who did not qualify for a referral to the tertiary hospital. All these gaps and frequent bypassing of a structured referral system led to clogs and long queues experienced at a tertiary hospital, contributing to overstretching its services. Indeed, most health care providers revealed that some of the patients seen at tertiary hospital could easily be managed at the PHC clinics, further emphasizing the point that more investment in human resources is needed for PHC. Mojaki and colleagues (2011) have reported similar findings whereby, most patients seen at MOPD and casualty had bypassed the referral system. More than half of the patients seen at these units could have been managed at the PHC facilities, which is similar to findings at King Edward VIII Hospital in Durban (Rutkove & Karim, 1990), a factor that is overburdening tertiary care and leading to high cost (Kamau & Onyango-Osuga, 2017). Atun and colleagues (2010, p. 3) similarly describe concern for how these communication networks break down to influence the rate at which an intervention is integrated into the general health system. Thus, targeted focus on identifying and addressing referral cogs in the health system may lead to improved and integrated NCD-HIV care.

Integrated care at the PHC level may alleviate many of the challenges patients with multiple chronic conditions face at the tertiary hospital. Because most clinics were specialised, collaboration of services were limited, and care was focused on only one disease at a time. This findings are similar to other low-resource setting studies that revealed how service provision for T2DM remains very limited at PHC, with services being offered at standalone in hospitals and higher levels of care (Bosire, Mendenhall, Omondi, & Ndetei, 2018; Katende et al., 2015; Peck et al., 2014). Yet, there were important management issues that impeded a more integrated chronic care approach for many patients: poor communication between clinicians and patients, poor communications amongst health care providers, and interprofessional conflicts and competition among specialised clinics. Some providers were not aware that patients had other comorbidities beyond the immediate disease they were treating; as such, they treated one condition in isolation of the other. Yet, even when they were aware of other comorbidities, some ended up giving a double prescription to patients. This lack of a centralised patient's information led to parallel care, drug duplications, and a disjointed care between providers and patients. Unfortunately our findings are not unique: patchy health care provision for patients has been reported elsewhere (Atun et al., 2017; Jaffar, 2016; Manne-Goehler et al., 2016).

Ultimately, health care providers rarely provided personalised support to patients or their caregivers due to workload and time constraints. This was despite the fact that many recognised the need for it; inherently it was health systems levels barriers that impeded this integrated care. Patient support was provided apart from clinical interactions and primarily in group forums. The most common was diabetes education sessions, which many patients attended only one session. Social workers also experienced challenges with families who were uncomfortable, disengaged, or absent. A growing body of research highlights the importance of meaningful engagement with

families in clinical practice and a refocus on the providers contribution in supporting families (Deek et al., 2016). Chronic conditions such as T2DM, however, require significant participation by informed patients, and this may necessitate an ongoing collaborative process between patients and professionals to optimise long-term outcome.

The ICDM model is patient-centred, proactive, and well-coordinated multidisciplinary care, using new technologies to improve collaboration between patients, providers, and caregivers (Mahomed & Asmall, 2014). To achieve this in Soweto requires PHC clinics to be strengthened to manage patients with chronic comorbidities. Only should the most severe cases be referred up to the tertiary level; this is important not only to be time and cost-effective but also to enhance people's health through the PHC. Enhancing PHC interventions within the health system, especially within this context, can save time for the patient, enhance engagement in clinical visits for the patient and their family members, and ensure that further symptoms or health conditions are diagnosed early and cared for holistically. Patients continue to experience myriad of challenges at both PHC clinics to tertiary care. Even as chronic care escalates (Boehmer et al., 2018), the ICDM model must incorporate the complexities associated with multi-morbidities, especially HIV and NCD co-occurrence, to meet the emerging needs of the burgeoning number of patients with the concurrent diagnoses.

Policy and Research Implications

As South Africa's health care sector undergoes important reforms (Fusheini et al., 2017), there still exists numerous health systemic challenges that hinder the implementation of integrated and collaborative care models. In particular, integrating diabetes care into HIV care programme is yet to be fully achieved due to health systemic challenges. Walt and Gilson (1994) have argued

that most health policies wrongly focus attention on the content of reform, and neglect the actors involved in policy reform; the processes contingent on developing and implementing change and the context within which policy is developed. Atun and colleagues (2010) have similarly emphasised that new interventions should be viewed with caution or circumspection by multiple potential adopters, affecting the extent, pattern, and rate of their adoption. Thus, when thinking about how to integrate care for patients with HIV and NCDs in South Africa and other LMIC countries, we suggest that PHC clinics and providers must be considered as key actors of implementation for ICDM models. Without addressing major issues of detection, diagnosis, and integrated care at the PHC level, higher levels of care such as secondary or tertiary hospitals will continue to face enormous patient burden in the everyday management of multiple conditions that can and should be relegated to the PHC. There is need to invest more in PHC clinics in terms of equipment, medication and human resources who can deliver the consistent, careful, integrated, and patient-centred care patients deserve.

The MOPD is the first and centralised clinic through which patients initiate care at a tertiary hospital in Soweto. We also recommend that the MOPD requires strengthening to offer integrated and collaborative care to patients with T2DM and other chronic comorbidities, and especially HIV.

Moreover, a key feature of collaborative care is a team-based approach to care – where specialists at tertiary hospital must engage and communicate with providers at PHC clinics to enhance patient's improved outcomes.(Shaw et al., 2019) In context of this study, clinicians at tertiary hospital rarely communicated with providers in different clinics at the tertiary hospital and with PHC clinics – largely due to staff shortages, limited time for meetings and poor communication. Strengthening MOPD and enhancing a proper collaborative care requires training and increasing the number of staff and also, implementing a centralized electronic data capture system at tertiary

hospital that will ease communication and collaboration amongst providers and patients across different levels of care. Further, addressing key systemic issues especially at PHC clinics will enable early screening, detection and management of comorbidities, ease workload at tertiary levels of care, and create a patient-centred as opposed to disease-specific approach.

Findings reported from our study have implications to other LMICs, which are poorly prepared to manage comorbidity or multi-morbidity – partly due to inadequacies in the health system infrastructure (shortages of trained healthcare providers, equipment and medication) (ASSAf, 2020; Beaglehole et al., 2008). For proper and sustainable implementation of the integrated care models, countries must adapt integrated care models to fit their context. This calls for research into how countries are operationalizing and implementing integrated care, challenges and opportunities – which may facilitate coming up with context specific interventions or strategies that would enhance successful implementation of integrated care models. This may include assessing issues of human resource for health, equipment and medication, sustained decision support, developing comorbidity guidelines and checklists etc. (Ku, 2015).

Moreover, healthcare providers working with chronic care patients in LMICs must align chronic care to meet the needs of the patients and population at large. This demands a proper functioning of patient information system, to facilitate care coordination and effective communication between providers and patients. Establishing community linkages in care is one of the key tenets of integrated and collaborative care. Thus, there is need to develop stronger links with communities to promote awareness on chronic comorbidity or multi-morbidity prevention strategies, e.g. via outreach programs, early screening, self-management and care.

Lastly, the Covid-19 pandemic has illustrated the need to understand how multi-morbidities create vulnerabilities and interact with new infections (for example HIV and TB and immunosuppressed population groups). Thus, there is need for more research to understand the complexities around comorbidities or multi-morbidities and health systems to be better prepared to provide more effective care.

Limitations

This study did not involve PHC facilities in Soweto and thus excises what happens in these settings. Yet, our ethnographic interviews encompass observations and informal conversations with different actors in the health care system that inform what challenges and opportunities exist within these settings. This is especially relevant among patients who had been referred from PHC to tertiary hospital, together provided insightful findings about their experience with PHC. Further, findings from this study concur with other qualitative studies (Ameh et al., 2017; Mahomed, Asmall & Anna, 2016; Matima et al., 2018) that have focused on care provisions for patients with T2DM, HIV/AIDS and other comorbidities in PHC in South Africa.

Conclusions

Challenges experienced by patients with T2DM, HIV, and other chronic comorbidities in Soweto calls for new ways to improve patient care by thinking and acting among policy-makers, healthcare organizations, and healthcare professionals—as well as patients and caregivers. In addition to investing in and strengthening PHC level detection, diagnosis, and care, we recommend strengthening the MOPD at the tertiary hospital to offer integrated and collaborative care to patients with T2DM and other comorbidities. The MOPD should also work with PHC to ensure that patients can receive reliable care closer to their homes and families. To achieve this, health

policy makers must address health system challenges such as lack of medical supplies, staff shortages, and a centralised patient information system in the public health care system. Improving the information healthcare providers have from the level of the PHC to the MOPD and specialty clinics is imperative not only to improve the implementation of policies aimed at strengthening the health care system in South Africa but also in sustainability of such policies.

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Table 1: Socio-Demographic characteristics of participants

Gender	N=30 (%)
Male	12(40)
Female	18(60)
Age	
25-35	9 (30)
36-45	10(33)
46-55	8 (27)
>56	3(10)
Profession	
Administrators	3(10)
Data Managers	3(10)
Dieticians	4(13)
General Doctor	6(20)
Endocrinologist	3(20)
Nurses (professional nurses and diabetes educators)	6(20)
Podiatrists	3(10)
Social workers	2(6)
Years of service	
< 5	5 (17)
6-10	6(20)
11-20	9(30)
>20	10(33)

Table 2: Challenges to collaborative and integrated chronic care in Soweto.

Theme	Excerpts
Poor communication	*"There is no consistent communication between a tertiary hospital and these community clinics. Sometimes, if they [patients] see that medication is running out, they will walk to the nearest clinics, some of the clinics give them medication even without any down referral letter."* ***(Provider 4, nurse)*** *"This is something that happened last week [...] at respiratory the doctor prescribed medication for her respiratory problem and diabetes as well. She went to the pharmacy and collected medication for diabetes twice in a day"* ***(Provider 6, nurse)***
Non-centralised patient's information	*"It's frustrating for them, isn't it? the files get lost every now and then. Patients have to queue for opening of new files, they have to figure out what medication they were on to tell the doctor…"* **(*Provider 22, endocrinologist)*** *"Look, honestly until we have an electronic record keeping system in the whole hospital, record keeping is going to be in shambles and working as a team will only be a dream. Look, I only see diabetes patients twice a month which means I only use the Intellovate system twice a month, the rest of the other time I am using manual paper recording in other departments."* ***(Provider 23, doctor)***
Staff shortage, workload and unavailability of doctors	*"It is difficult because doctors have a lot on their hands [...] they are expected to see a number of patients here [diabetes clinic], expected to do this and that and by the time they come back here, the queue has build up again. They will not have time for collaboration with others"* ***(Provider 1, nurse)*** *"A podiatrist is not exactly authorised to prescribe antibiotics. When the doctor is not around maybe once they've left the clinic when they finish, you find that it becomes a challenge […]".* ***(Provider 14, Podiatrist)***
Lack of resources such as medication	*"The problem is not the model [ICDM] but lack of resources. […] I treated the patient and when he got well, I designed a chronic medication plan, I referred the patient to the local clinic but the patient came back and said there are no medication there".* ***(Provider 2, doctor)***
Proximity of clinics	*"Collaboration is difficult. All these clinics are Isolated from each other. So now, we have Inter-professionals communication where I write my own recommendations, you write your own recommendations, somebody writes their own without involving the patient"* ***(Provider 26, endocrinologist)***
Inter-professional conflicts	*"Most of the time, surgeons will override anyone's decision, I don't know why it's like that, but sometimes they do. So […] we will screen the patient and find a wound, write our notes and say that we want to manage this patient with wound care. Then the following day when you go, the surgeons have taken over the patient and maybe the patient is already prepared for theatre, this makes me feel they think we don't know our work".* ***(Provider 21, podiatrist)***

Table 3: Key themes to care for patients with T2DM and HIV/AIDS comorbidities.

Theme	Expectations	Working	Not working
Organizational-Referral system, collaborative & Integrated care	Team of multidisciplinary working together to manage patients with comorbidities	Most patients are referred to a tertiary hospital. Most go through MOPD before they are referred to specialty clinics.	Limited collaboration amongst providers due to poor communication, staff shortage, lack of resources etc.
Functional-Communication and Patients records/information	Efficient communication, electronic health record system for patient information	Communication is mostly done manually through patient's file. Diabetes/endocrine clinic has implemented electronic system that captures patient's biometric data	Due to workload and staff shortage, rarely do health providers communicate with colleagues especially when they are in different buildings. Most other clinics use manual data capture in patient's files. Non-centralised patient's records further challenges proper communication
Patient support	Fully involve patients and their family/caregivers in care or decision making.	Mostly, patients are supported in group forums, such as during diabetes education sessions. Social workers visited patient's at home	Doctors rarely involved patients or caregivers care. Patient supported in groups rather than individually. Some caregivers failed to collaborate with social workers during home visits.

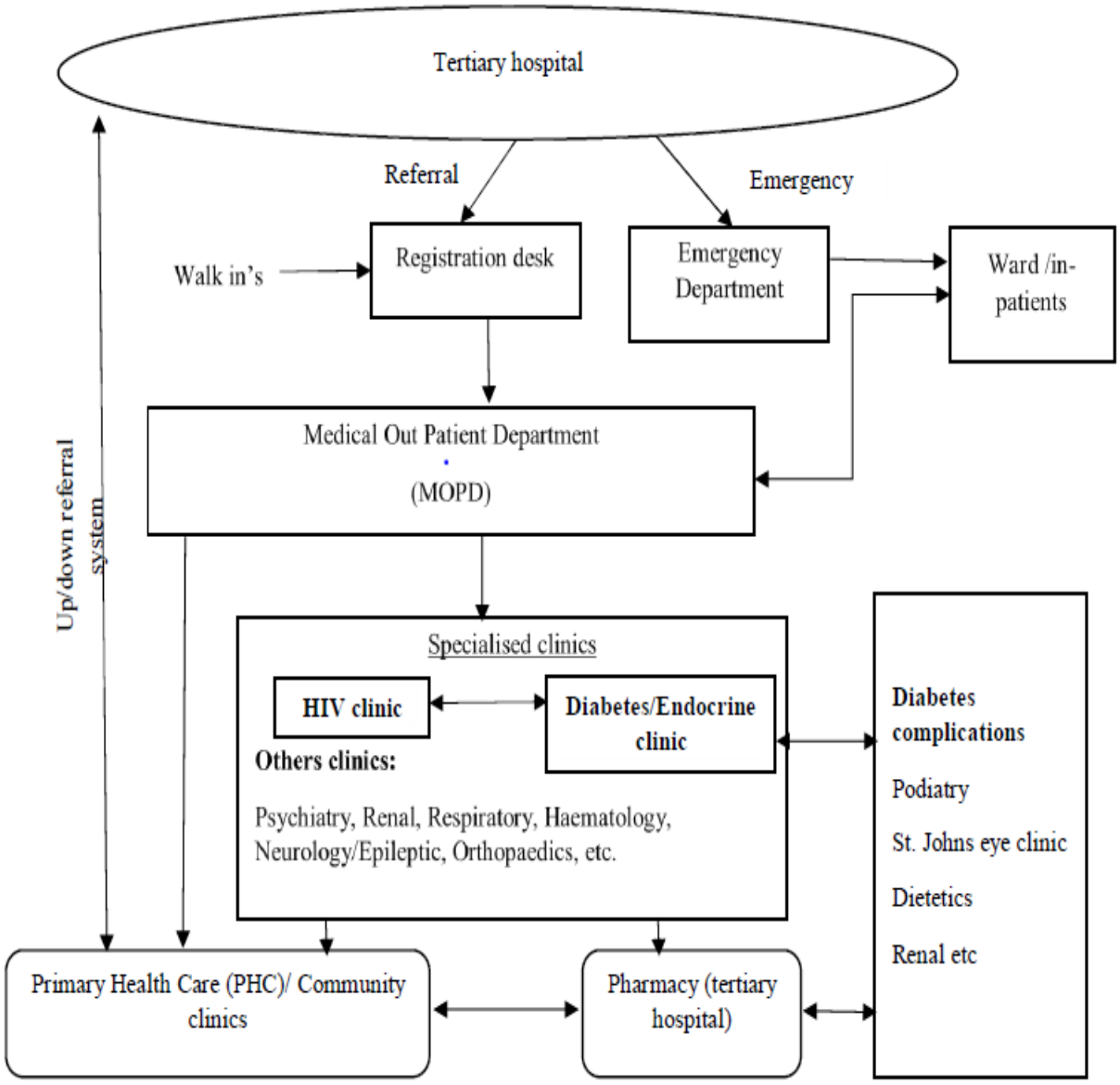

Figure 1: Up and down referral system from PHC to a tertiary hospital in Soweto.

CHAPTER 6: INTEGRATED DISCUSSION AND CONCLUSION

'We need new ways of thinking and of working in order to accommodate the complexity of the challenges in and urgent need for health system innovation and change.'

(Herbert and Best, 2011[6])

This is the last chapter of this thesis, and it presents an integrated discussion and conclusion. First, I will revisit the overall aim and objectives of the thesis against what I found. This is summarised in a table – providing the answers for each specific objective. I then present an integrated narrative of key cross-cutting themes from this thesis in the following order: Chronic care in the Clinic and self-management at Home; Reflecting on current study with study conducted in Kenya; Alternative medical care; Individuals versus structures in chronic care; Revisiting the conceptual frameworks used in this thesis. I conclude this chapter by discussing study limitations, future directions, recommendations and conclusion.

[6] Herbert C & Best A. (2011). It's a matter of values: partnership for innovative change, Healthcare Papers, , vol. 2 (pg. 31-7)

6.1 Answering study objectives

The main aim of this thesis was to investigate health and healthcare challenges, as well as opportunities among patients with comorbid HIV and diabetes, and healthcare workers providing care for them in Soweto, South Africa. The research focused on those seeking care and providing care at Chris Hani Baragwanath Academic Hospital (CHBAH), the largest public tertiary hospital in Soweto, South Africa.

Table 3: Research objectives and answers from research

Research Objectives	Reference	Key findings that answers the objective
Objective 1: To understand patients' perceptions and experiences in care seeking for comorbid diabetes and HIV at CHBAH in Soweto and self-management practices.	Chapter (s) 3 & 5	Findings show that structural issues such as poverty and unemployment exacerbated the problems people experience managing comorbidities. These problems led to other compounding issues e.g. unaffordability of transport to the hospital and inability to meet dietary requirements. Living in deprived settings placed both patients and other family members at risks of developing chronic illnesses due to the shared socio-economic context. Thus, most households had more than one individual with chronic conditions. The interdependency of social and medical problems is consistent with syndemics theory. Patients' lived experiences with chronic illnesses entailed pill burden, visiting multiple fragmented clinics and disability (which hindered most from engaging in daily routine activities). Both physical and mental health were found to be reinforced by social or contextual factors which rendered individuals vulnerable to other bodily or affective conditions. Ultimately, family and caregiver support were found to be important in self-management; yet, majority of the participants cited lacking this support.

Objective 2: To understand health care providers' experience in administering care to patients with comorbid diabetes-HIV at CHBAH in Soweto, and to investigate their perceptions on integrated chronic care and patient-centred care (PCC) in Soweto	Chapter (s) 3 & 4	Providers believed that integrated care would be more appropriately practiced at PHC level rather than at tertiary hospital. Providers conceptualised patient-centred care in different ways: relating it to the "***Batho-pele***" principles; placing the patient at the centre of care; and empathising with the patients. Although some providers displayed or understood the key tenets of PCC, the practice of PCC was challenged by both providers and health systemic issues (such as language barrier, staff shortage, lack of multimorbidity guidelines, etc.) and patient related issues (such as poverty, language barrier, lack of transport to hospital, missed clinic appointment, etc.). Providers delivered partial PCC (e.g. during diabetes school) with no individualised care.
Objective 3: To understand the factors that facilitate or impede patients' ability to achieve good health and healthcare providers' ability to provide good health care in Soweto	Chapter (s) 3, 4 & 5	Health systems issues at PHC in Soweto – including lack of doctors, drug stock-outs, lack of equipment led to patients being referred to tertiary hospital. The referral system through care pathways was not properly functional – some patients walked into the tertiary hospital without referral letters. This created clogs and long queues experienced at a tertiary hospital. At the tertiary hospital, patients' care was found to be fragmented, in part due to the structure of the tertiary hospital which offers specialised care. In addition, patients with diabetes were first managed at the MOPD clinic and only referred to specialty clinic when experiencing complications. Health systems challenges such as non-centralised record keeping system, poor communication, etc. hindered integrated and collaborative care at a tertiary hospital. Further, professional barriers including inter-professional conflicts, lack of cultural and structural competence skills also hindered integrated and patient-centred care (see page 143 & 159). There was limited clinical support system for patients – patients were not fully involved in the care for their illnesses (see pages 146, 159).

6.2 Integrated Discussion

In this discussion, findings from the three manuscripts are not repeated. Rather, I will present cross cutting themes that emerged from the whole study; the methodological approach, conceptual framework and any other empirical findings that emerged from this research, which may inform future research on this topic.

6.2.1 Theme 1: Chronic care in the Clinic and self-management at Home

I used a mixed ethnographic design – which entailed observations and multiple interviews with different actors in the health care system and at patients' homes, to explore health and healthcare for patients with comorbid diabetes and HIV in Soweto, South Africa. The use of ethnographic methods provided insights on how health and healthcare materialised both inside and outside the clinic (see Yates-Doerr, 2017). Clinic and home spaces displayed different cultures, roles and power differences, which helped me to shape and construct meanings and realities about how health and healthcare was conceived and designed.

Firstly, I found that patients experienced tension of a choice between self-care for the sake of their health and caregiving roles, for the sake of other family members. In addition, observations revealed how patients desired to continue leading normal lives or act as one 'should' in the face of debilitating symptoms (see more in chapter 3). As described in 'Talcott Parsons, the Sick Role and Chronic Illness' (see, Varul 2010, p. 10), patients abound with dual citizenship in the world of illness and the world of health. Accordingly, Parsons (1958) views sickness as a 'deviance' which threatens individuals' autonomy as it incapacitates or disables his/her social contributions in the society. In this context, the chronically ill are confronted with the competing expectations of an ongoing sick role and of normal everyday roles. As such, individuals would strive hard to perform

the social roles (despite their ill bodies) in order to conform to society demands. In this thesis, I have reported how balancing between self-care while caring for others seemed problematic because, some patients prioritised managing others while neglecting their own health (see chapter 3). This was also compounded by other socio-economic challenges including poverty and food insecurity. These findings may provide useful insights to health interventions that seek to improve chronic care. Patients must be trained and supported with information on how to self-manage at home while also attending to other social or family issues.

Secondly, despite the numerous challenges experienced by patients, observations at the clinic and in patients' home revealed that some patients used the little power they had to make positive changes in their lives. For example, some were more committed to ensuring they followed the recommended diet from the clinic, others ensured they attended clinic regularly, while some demonstrated interest in joining diabetes programmes e.g. weight loss programme at the diabetes clinic (see chapter 4, page 120). During home visits, patients like Bongani (chapter 3) strove to ensure he attended gym to keep his body healthy and fit. These examples offer limited but critical insights into how individuals' agency is manifested within the clinics and at home, regarding decision making. Thus, patients should not be viewed as being vulnerable but must be supported and actively engaged in care and management of their illnesses.

Thirdly, I found that some healthcare providers e.g. dieticians and nurses tried to provide patient-centred care by identifying with the patients' cultures and socio-economic status. However, provision of PCC, integrated or collaborative care was not always easy because, providers experienced an array of health systemic challenges such as staff shortages, inadequate equipment, lack of multimorbid guidelines and drug stock out (refer to chapters 4 & 5). Concurrently, patient related factors such as poverty, education, and language barrier, were materialised within clinical

spaces and impended provision of quality care (refer to chapters 3 & 4). Findings reported in this thesis are in line with other studies conducted in both LMIC and high-income countries (HICs). For example, a qualitative study that sought to explore care provision for cross-border immigrants in South Africa showed that many immigrants experienced challenges to speak local South African languages (e.g. IsiXhosa), and this gave rise to labelling and stereotyping by healthcare staff (Hunter-Adams & Rother, 2017). In addition, language barrier played a key role in immigrant patients undergoing some medical procedures, including tubal ligation, without their consent (Benjamin, Swartz, Chiliza, & Hering, 2016; Hunter-Adams & Rother, 2017).

This thesis also highlights the fact that not only patients and their communities have cultures, but that there is also a 'culture of medicine' (Kleinman, 1981). Studies have elucidated that provider culture and behaviour, which is largely influenced by biomedical paradigms, may contribute to health care disparities by shaping physician behaviour and producing differences in medical treatment along the lines of race, ethnicity, gender or other characteristics (Chapman & Kaatz, 2013). A study conducted in Hong Kong, China revealed how doctors withheld important information pertaining to treatment efficacy, as a way of protecting patient's trust in biomedicine (Siu, 2015). In particular, doctors were reluctant to provide patients with information, as a way of not disclosing their limitations to their patients. Training healthcare providers on how to deal with such cross-cultural issues may reducing disparities in care provision.

Lastly, participant observations facilitated the collection of data in natural settings and the inductive interpretation of behaviours that reflected participants' real-life experiences. Data collection and analysis involved a process that exposed all phases of research activities through continuous questioning and re-evaluation of the researcher (see Attia & Edge, 2017). The key challenge that I experienced during data collection was language barrier. Being a Kenyan, I did

not understand any of the South African local languages, thus, I relied on a research assistant as well as observations which may not have reflected true meaning of events as they occurred. Despite this, the different cases provided in this thesis highlight the fact that the use of ethnographic methods was powerful because, the methods allowed me to transverse medical and mundane spaces – moving in and outside of clinics – thus leading to unique contributions to scholarship on chronic care in South Africa.

As Van der Geest and Finkler (2004) posit, hospitals are often cultures within themselves that are largely influenced by the communities they serve. Consequently, the care provided in one hospital may vary considerably from another hospital based on the context. Thus, context holds a major place, mediating the conceptual and the empirical in ethnographic work. This brings me to another section which looks at chronic care across contexts:

6.2.2 Theme 2: Reflecting on research conducted in Kenya and South Africa

> *"My HIV/AIDs care is provided free of charge but other diseases such as diabetes I pay for*." [Sarah, 55-year-old woman, HIV, Diabetes, Kibera informal settlements, Nairobi].

> "*Travelling to Bara [CHBAH] is so difficult, I have to pay R100 every clinic visit. This is why I default my clinic appointments."* [Mpho, 46-year-old woman, HIV, Diabetes, Hypertension, Soweto]

In 2014, I was involved in a research that explored social experiences and mental health among primary care patients with and without diabetes in Nairobi, Kenya. The research was conducted at Mbagathi District Hospital – which is one of the largest feeder hospital clinics for

Kenyatta National Hospital (the biggest referral hospital in Kenya). Although Mbagathi served people from both within and outside Nairobi, majority of its population came from Kibera informal settlements, because of its accessibility and proximity. We conducted 100 extensive life history narratives with patients seeking care at Mbagathi, in addition to observations at the hospital. Conclusions drawn from this study stem from the emergent themes around living with diabetes, HIV, depression, tuberculosis, malaria, and other co-occurring conditions; with a focus on the complexities of health care seeking (see Bosire et al., 2018; Mendenhall et al., 2015)

Similarities between research in Kenya and South Africa

Research in both contexts were conducted amongst the low-income populations in urban settings – Kibera informal settlements in Nairobi, Kenya and Soweto in Johannesburg, South Africa. Research has shown that, both contexts are experiencing colliding epidemics of HIV and NCDs including diabetes, cancers, hypertension among others (Githinji et al., 2018; Oni et al., 2015). This is largely due to similar socio-economic, environmental and political factors that promote individual risk for diseases and also, exacerbate the severity of these diseases (Mendenhall et al., 2017). These factors not only serve as a driving force for disease clustering but also, influence access to care. Importantly, the increase in number of people with comorbidities or multimorbidity is overburdening the already overstretched public healthcare system in Kenya and South Africa.

Differences in chronic care for comorbid HIV and Diabetes

South Africa has a robust public health sector which covers a large population of underinsured citizens (84% of the population) (Naidoo, 2012, p. 149). In addition, the South

African constitution guarantees every citizen access to health services (section 27 of the Bill of Rights) – this includes the right to health care for both chronic infections and NCDs (NDoH, 2016). Yet, the public healthcare system is challenged with managing the quadruple burden of diseases due to health systemic challenges (Mayosi et al., 2012). In this thesis, I have reported how the public health system in South Africa is challenged in terms of staff shortages, drug stock-out, lack of equipment, and multimorbidity guidelines. These factors hindered provision of integrated care. Another key finding reported in this thesis is that despite the implementation of integrated chronic disease management in most PHC clinics in South Africa, Soweto is yet to benefit from such policies. Patients continue to attend separate clinics for their chronic comorbidities, and this is a finding that has been reported in other contexts in South Africa (Matima et al., 2018). Specifically, at CHBAH (Bara), patients with comorbidities or multimorbidity were required to attend separate specialised clinics – a factor that required some patients to make multiple travels to the clinics. Majority who could not afford transport to the hospital defaulted their clinic appointments. For many, the social costs involved – such as losing daily wages by making multiple trips to the hospital – led to many patients defaulting their clinic appointments. Ultimately, patient related factors such as poverty, unaffordability of recommended diet and language barrier also led to poor drug adherence and self-management.

In Kenya, although patients from Kibera informal settlements experienced similar socio-economic challenges as those in Soweto (e.g. poverty, lack of transport or recommended diet), the narrative about non-adherence to medication and poor self-management for their diabetes was different: Patients with diabetes could not attain good health largely due to unaffordability of diabetes medication. In Kenya, HIV care is comprehensive and free of charge, due to donor funding; yet, access to care for most NCDs including diabetes, requires patients to pay out of

pocket (Okungu et al., 2017). Although patients are encouraged to register for the National Hospital Insurance Fund (NHIF), the fund largely takes care of in-patients or infectious diseases that are prioritised by the international donor community (Nguhiu et al., 2017). As a result, patients with diabetes and other NCDs who could not afford consultation fees and medication for their diseases defaulted their clinic appointments and were non-adherent to their treatment. Many patients with comorbid HIV and diabetes would always attend the HIV clinic (because it was free of charge) and only showed up for their diabetes appointments whenever they could afford the care and services. This is what I have described elsewhere as "Biological Sub-citizenship at a Public Hospital in Nairobi, Kenya" (Bosire et al., 2018) – arguing that prioritising diseases (largely attributed to donor funding) has resulted in creating new members of sub-citizens in Kenya. Individuals are denied their citizenship rights based on their diagnosis.

Syndemic interventions in Kenya and South Africa

Given the above context specific issues to chronic care, there is need for urgent interventions – policy, social and clinical interventions. Achieving health equity and ensuring that the patients receive quality care demands an efficient and just healthcare system that can look at social and medical challenges in tandem. The Kenyan case provides a robust understanding on how regressive user fees hinder patients from accessing care and creates a system of "deservingness". It is paramount for the Kenyan government, through the Ministry of Health (MOH) to look critically into improving health financing to public health facilities. This will not only improve treatment or medications for NCDs like diabetes but also, aim at improving screening and early diagnosis of NCDs. Moreover, there is a need to integrate care for infectious diseases and NCDs e.g. by ensuring that patients with HIV are screened for blood sugar, blood pressure

and other illnesses when attending HIV clinics. This would enhance early diagnosis and timely care for patients with comorbidities or multimorbidity.

In South Africa, there is a need to decentralise chronic care from tertiary or secondary levels to primary healthcare levels. Specifically, diabetes care needs to be managed at PHC, and only patients with complications should be referred to a tertiary hospital. This can only be feasible through strengthening PHCs – by ensuring adequate equipment as well as the availability of trained and skilled providers to diagnose, treat and manage diabetes at the right time. Training providers on integrated care will also ensure that patients with chronic comorbidities are managed on the same day (including prescribing medications) and this will help reduce the multiple trips that patients must make to hospitals.

However, it is important to note that, ensuring diabetes or other NCDs are fully managed at PHCs in South Africa requires a strong political will and support. A case example can be deduced from HIV/AIDs treatment issues in South Africa during the early 2000 – when ARVs were not affordable or feasible in the public healthcare sector in South Africa (other than for PMTCT) (see Schneider, 2002). This was largely due to the political controversies surrounding the disease (Fassin & Schneider, 2003). Today, South Africa has the largest ART programme in the world and most people have access to medication – which has contributed to increased survival and ageing (SANAC, 2017). The same strategy, especially having political will, drive or support, can help in improving management for diabetes and other NCDs at PHCs and community levels.

6.2.3 Theme 3: Alternative medications and care

> *"I usually try other natural concoctions for my diabetes and hypertension. I mix ginger, cucumber, lemon and cinnamon. One lady at Dis-Chem [local store] advised me that the concoction worked for her. I also used one other drug she prescribed to me."*
>
> (Lucy, 50-year-old from Soweto. Managing HIV, Diabetes and Hypertension).

Just like Lucy, many other patients in this study reported having sought alternative care from the '***sangomas'***- traditional healers, spiritual healers or used over-the-counter drugs, for one or all of their illnesses. Earlier studies in South Africa have revealed that patients with chronic illnesses use plural healing mechanisms such as use traditional healers, prophets and churches (Thorogood et al., 2007), that not only provides physical healing but also social and spiritual healing (Mashabela, 2017). Elsewhere, studies have shown that use of alternative medications, non-prescriptive drugs or over-the-counter drugs is common amongst individuals with comorbidity or multimorbidity and also, amongst the elderly (Dhyani et al., 2015; Moses, 2005).

In the present research, use of alternative medication was largely due to inaccessibility to health facilities or frustrations experienced at the hospital (long queues and waiting times and missed clinic appointments) (see chapter 5). Other studies have also revealed that seeking care from alternative providers is due to easy access to these providers, their ability to speak patient's language(s), spending more time with the patients, and providing wholistic care including social and spiritual care (Mashabela, 2017). Importantly, a common distrust in biomedicine has been largely reported to drive individuals to alternative care providers. For example, in his studies in Northern Nigeria, Tocco (2014) notes distrust in biomedicine where many Muslims were

suspicious of the massive intervention and funding from PEPFAR and the United Nations Global Fund to Fight AIDS, Tuberculosis and Malaria (UNGFAMT). Individuals argued that ART was not a cure to HIV whereas Islamic prophetic medicine held promise of cure – "with every disease, Allah has also sent its cure" (Tocco, 2014, p. 121). Thus, individuals relied on Islamic prophetic medicine, with treatment consisting of reciting passages from the Quran and using "natural vegetal and mineral materia medica" (Tocco, 2014, p. 128). Another case involving distrust or frustrations experienced in healthcare system has also been exemplified by the late 2010 case story in Loliondo, Tanzania, where a 76-year-old retired Lutheran pastor and a self-declared "miracle healer", became an overnight sensation when he began distributing liquid herbal medicine that he claimed will heal virtually any chronic illness including HIV/AIDS, diabetes, cancers and hypertension (Mattes, 2014). Given these factors, Mattes (2014) argued that people continue to search for a cure outside of the realm of biomedicine and make pragmatic decisions about where to go and who to see. As such the role of alternative care remain important even in contemporary settings in Africa.

This current research did not fully explore the issue of alternative care and comorbidity or multimorbidity. This limitation warrants further attention by future researchers. For example, based on the challenges experienced by patients in accessing care in hospitals, it may be possible that patients have devised other pluralistic or alternative strategies to manage their illnesses. Yet, it is not clear how healthcare providers handle the issue of patients using both alternative and conventional medications. The question is, are healthcare providers willing to collaborate and work with people who offer traditional or alternative care? Are there plans or resources aimed at training alternative carers in screening and providing patient referral to the hospitals? Findings reported in this thesis exemplify how culture and belief system continue to shape, as well as influence health seeking behaviours even amongst people living in urban informal settlements like

Soweto. In addition, my recommendations concur with earlier studies which have suggested that cultural beliefs, biological perspectives of both providers, patients and the health organisations in management need to be incorporated into the ICCC model (Oni et al., 2014).

6.2.4 Theme 4: Individuals versus structures: Whose responsibility is it?

Quite often, healthcare providers take an active role or "responsibility" in making decisions for patients, based on what they think is for the patients' best interest, without involving patients in care (Ishikawa, 2013). They largely assume that patients will follow the clinical advice provided while managing their illnesses at home. Further, although many clinicians may intuit that "the social" is an arena of great importance in a patient's ability to access care or adhere to medications; addressing the structural impediments to health is, nonetheless, generally considered to lie outside the purview of everyday clinical practice (Farmer, 2006). In previous chapters, I have reported how providers managed patients without involving them in care. This was largely due to patient-provider divide in terms of language barrier, socio-economic factors, or staff shortages and workload.

However, it is recognised that patients with chronic illnesses are their own primary carers (Beaglehole, et al., 2008), hence their needs and preferences must be put into consideration when designing chronic care management plan. Ensuring that a patient is engaged in care is a multifaceted task requiring providers to understand patients' socio-economic factors, beliefs and attitudes towards their illnesses as well as the coping strategies, within the context of their lived experiences. More detailed description on patient-centred care is provided in chapter 4 of this thesis.

I argue that both patients and providers are responsible actors in chronic care. However, both cannot make the required changes in chronic care without structural support. What then can be done to ensure a positive patient-provider relationship in chronic care?

Structural changes: It is expedient to provide a conducive working environment for providers. Ensuring providers have necessary training, skills, and equipment, and reducing their workload through addressing staff shortage issues, will enable providers to establish a good therapeutic relationship with the patients. Moreover, establishing patient-centred care requires that providers must understand the patients. This calls for provider training on cultural competence, cultural humility and structural competence skills (Metzl & Hansen, 2014). Providers need to shift from 'treating diseases in patients' to treating 'the person with the disease' – they can use simple questions like "What really matters to you?" "What are your priorities?" "What motivates you?" "What is making it difficult for you to change?" Asking these questions creates an ambiance environment for patients to discuss their health concerns with providers.

Patients' education about their chronic diseases and treatment plan will perhaps be the first step in ensuring that they understand what disease they have, available treatment options and management plans. In addition, addressing patients' structural vulnerabilities such as enforcing policies that target limiting advertisement and selling of unhealthy foods at the community; subsidised prices for healthy foods; ensuring access to facilities for physical activities; improved housing etc., may help solve some of the key issues that put people at risk of developing chronic diseases in the first place.

Patients' structural vulnerabilities can best be tackled by linking community with clinic through community outreach programmes. This calls for task shifting or task sharing, where

providers work closely with trained community health workers (CHWs) or lay healthcare workers – operating at the interface between health systems and communities to improve chronic care. CHWs can help in conducting patient follow-ups, distribution of medications or linking patients to support groups at the community, screening and providing referrals to the clinics (Goudge et al., 2018). All these activities may help in alleviating healthcare provider burden and increasing access to care for chronic patients.

Lastly, it could be particularly advantageous for healthcare providers to know about existing community resources – such as churches, group meetings, exercise facilities, or mental health programmes – this may enhance collaborations between community and clinics.

6.3 Revisiting the Conceptual Framework

The conceptual frameworks that guided this thesis were adapted from the chronic care model (CCM) that was developed by Edward Wagner (Wagner et al., 1999) and Collaborative Care Model developed by Craven (2006) (see *Fig.1 & 4*). The CCM presents a structure for organising healthcare for chronic conditions by enhancing patient-provider partnership in chronic care (Wagner et al., 1999). The CCM focuses on six key areas: Health systems organisation, clinical information system, decision support, delivery system design, self-management support and community resources. All these components were retained in the adapted model to help explore health and healthcare for patients with diabetes and HIV comorbidity in Soweto. The collaborative care model adds to the CCM by stating that effective care for patients can be achieved through collaboration of care amongst healthcare providers. Thus, I added a component of collaborative care (at the centre of chronic care) in the adapted model (*Fig. 1*). However, these frameworks are more clinically focused, and they do not show variations in disease management.

For example, care for HIV and diabetes varies remarkably because; while HIV can be well managed by adhering to medication, diabetes care and management goes beyond adhering to medication – it requires a complete overhaul of diet. It also entails constant monitoring blood sugar etc. In addition, the frameworks do not shed light on the social/contextual embeddedness of diseases. I, therefore, added factors linked to structural vulnerability (culture, social-economic, media, gender, education etc.), widely known to influence clustering of chronic illnesses. These factors were perceived not only to be impactful to individual or population level but also at health systemic level. Lastly, although CCM shows what elements should be implemented to support patients with chronic conditions, it does not show how the suggested implementation should work to manage patients with comorbidity or multimorbidity.

There is need to come up with chronic care strategies that address the negative feedback loop between structural and social problems. Using a syndemic approach, this study suggests that integrated care should be redesigned to incorporate the social embeddedness of disease, its interactive nature, and the importance for prevention and early intervention (see Mendenhall et al., 2017). Efforts to reduce clustering of chronic conditions must therefore take cognisance of the various levels (clinical interventions, community interventions, upstream and downstream interventions) and address these factors in their entirety (*see fig. 11*).

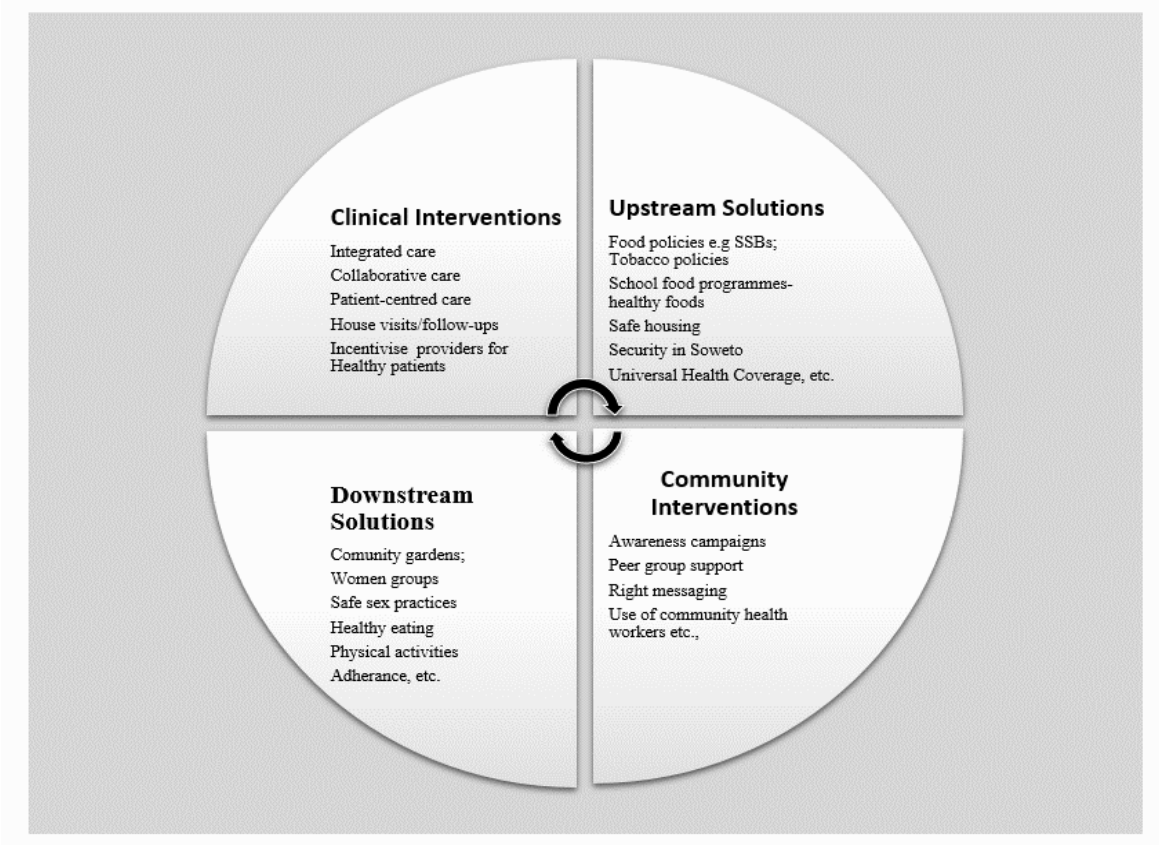

Figure 11: Syndemic Intervention

(Source: Author, 2020)

Elsewhere, studies have shown how the integration of medical and social factors that promote clustering of chronic conditions, have improved patients' health outcome. For example, in 2005, the government of Rwanda, through the Ministry of Health, invited Partners In Health (PIH), a Boston-based non-governmental organisation to support the country's initiative to strengthen rural health services. This effort was financed in part by the Clinton Foundation, and it facilitated building and renovating health infrastructure, supplementing operational budgets and providing staff training (Kidder et al., 2011). This led to the decentralising and integration of chronic care for NCDs and HIV/AIDS, from referral centres to health centres and finally to

community health centres. The partnership also borrowed from the PIH's community-based initiative of addressing structural and social problems, such as poverty, poor nutrition, gender inequality or racism as factors that promote marginalisation, largely contributing to clustering of chronic illnesses (Farmer et al., 2006). According to Farmer, clinical and community barriers to care are removed as diagnosis, and treatment are declared a public good and made available free of charge to patients living in poverty (Farmer et al., 2006).

Other partnership models, such as the Academic Model Providing Access to Healthcare (AMPATH), between the Indiana University School of Medicine in Indianapolis, Indiana and the Moi University School of Medicine, Eldoret Kenya, have shown immense improvement in morbidity and mortality outcomes through an integrated care that concurrently looks at physical, social and psychological problems in care (Quigley, 2009). AMPATH's focus is on the patient as opposed to treating the disease. Partners in this model argue that, if a patient is poor, hungry, or unemployed, or is the victim of racism or abuse, AMPATH will respond in providing holistic care (Quigley, 2009).

Such models are needed in the management of chronic illnesses especially in a context like Soweto where individuals' structural vulnerability continue to shape the narrative around health and healthcare. Following the syndemic framework and a syndemic intervention proposed in this thesis, I argue that chronic care must extend beyond the clinic to include families, households, and social or economic conditions that shape the course of illness(es).This can also incorporate other community institutions such as churches where knowledge, counselling and group support can be offered.

6.4 Limitations

This study did not involve PHC facilities in Soweto and thus, excises what happens in these settings. For example, the researcher could not confirm if all patients referred to a tertiary hospital were experiencing complications – which is a requirement for referring patients to secondary or tertiary care. This was a key limitation for this study. Future studies should aim at understanding diabetes and HIV comorbid care from PHC to secondary or tertiary levels.

Although the use of ethnographic approaches was important in understanding health and healthcare for patients with comorbid diabetes and HIV, the method was found to be time consuming. This greatly limited the scope of the study – including inability to extend the study to PHCs and researcher not able to explore other important aspects such as alternative care. Future researchers who may want to conduct ethnographic studies should consider the time it takes- especially combining clinic and home observations.

Language barrier was another limitation in this research. The researcher engaged a multi-lingual South African as a research assistant who also helped with translations. The use of an interpreter may have distorted the original meanings given to words or ideas (Temple & Young, 2004). However, use of multiple methods of data collection helped to triangulate study results and validate the findings.

Findings reported in thesis are limited to the clinic where data was collected (diabetes/endocrine and MOPD clinics), thus excises what happened in other clinics/departments within the hospital. This makes it difficult to generalise the findings. However, qualitative research does not aim at having representative samples or producing generalisable findings. Instead, the intention is to generate an in-depth understanding of a phenomenon and explore 'transferability'

to other contexts (Ritchie, 2003). In addition, findings reported in this thesis provide important insights for those managing patients with comorbidity or multimorbidity because even in one of the best public hospitals, care is not integrated across conditions that people encounter.

6.5 Recommendations

6.5.1 Health system organisation and functioning

Findings from this thesis offer insights to explore how best integrated chronic care can be designed: Is it for instance a 'bottom-up' (clinical), 'top-down' (system) or two-sided (bottom-up and top-down) approach? While most policies that aim at strengthening health systems focus on health system organisation, a syndemic approach elucidates the complexities through which social, psychological, and biological factors come together to shape emergent and pervasive global health problems (Singer, 2003). Thus, the integration of chronic care has to be pursued at different levels, within and outside the health system, to facilitate the continuous, comprehensive, and coordinated delivery of services to individuals and populations (Kruk et al., 2018). As such, integrated care should be designed in a way that people get proper care for all their conditions together (or are able to see multiple clinicians in one clinic visit) – including comprehensive counselling that is patient-centred.

Perhaps, the first step to achieve this would be by ensuring PHCs in Soweto are strengthened to offer care for diabetes and other NCDs – Primary care is the cornerstone of a high-quality health system, serving as the main entry point for most concerns and playing a crucial role in coordinating care and ensuring continuity across health system platforms. Strengthening PHC in Soweto, and in other similar contexts will facilitate management of chronic patients at

community level and reduce clogs experienced at tertiary levels; and only the most severe cases should be referred up to the tertiary level. However, strengthening PHCs and ensuring successful implementation of integrated care models can only be feasible when the following issues are addressed:

***Human resource training and empowerment*:** There is need to address issues of staff shortage and workload. Importantly, the issue of staff shortage can be partly addressed through task shifting or task sharing – involving working closely with community health workers (CHWs). When trained, CHWs may be useful in undertaking surveillance and treatment for communicable or non-communicable diseases because they usually come from the communities that they serve, thus providing a potential bridge to community engagement efforts (Goudge et al., 2018). In addition, CHWs can reach places where healthcare providers cannot reach, or when providers are not available. They can also overcome cultural and linguistic barriers, whilst expanding access to care and providing new forms of employment.

Healthcare systems should also invest in the development of care professionals' knowledge and competences to manage diabetes care at PHC levels, provide integrated, collaborative and patient-centred care. This calls for training providers, especially nurses, on diagnosis and treatment, as well as, equipping health care professionals (especially in medical schools) with structural competence skills that can promote the change that is required to accomplish patient-centred care. Multi-lingual South Africans should also be encouraged to apply for medical courses in order to work in hospitals in Soweto; this may partly address issues of language barriers.

***Medication, equipment and space*:** There is need to provide necessary equipment and medicine supplies that would facilitate provision of quality care to patients through a patient-centred

approach. Specifically, provision of basic hospital equipment will facilitate timely detection, diagnosis, and treatment of non-communicable diseases alongside and in tandem with HIV care at the PHC level. In addition, to bolster integration of chronic care, there is a need to ensure availability of conducive spaces (at clinic and in patient's home) where integrated chronic care is offered.

Centralised record keeping: There is need to implement a centralised electronic data capture system in public hospitals in South Africa. This will facilitate easy access to patient's information, reduce drug duplications, and, most importantly, reduce the waiting times for patients at facilities. This may enhance integrated and collaborative care. Further, decision support systems need to be integrated into information systems to be used by multiple care professionals in order to enhance collaboration and care coordination.

6.5.2 Clinical recommendations

A cornerstone in successful provision of integrated, patient-centred and collaborative care to patients with comorbidities or multimorbidities is effective communication. Atun and colleagues (2010) describe concern for how communication break-down influences the rate at which an intervention is integrated into the general health system. There is need to address communication barriers identified in this thesis (see chapter 5) – for example, ensure effective communication within and between healthcare facilities in Soweto as well as effective communication between patients and providers. This may enhance the quality of care provided to patients. Recent studies from South Africa have recommended the digitisation of patient's information or records in order to facilitate population surveillance, while also enriching available patient information at clinical consultations (Jacob et al., 2020).

It is paramount for clinicians to be at the heart of integrated care developments, building on the work of the new care models and recognising that the principal benefits of integrated care result from clinical integration rather than organisational integration. If medical settings are too slow to integrate care for patients who present with multiple conditions, then there must be better communication between clinics so that clinicians know when patients visit other clinics, what medicines they are taking, and how competing social and medical demands affect their self-care of one disease or another. This may demand involving patients and caregivers in the design of chronic care – which has been emphasised in this thesis. At the clinical level, this means educating people about their health entitlements, using targeted quality reporting, social networks, and mobile technologies to empower people, enabling patients to partner in their care and in clinical decisions, and to actively manage their health (Kruk et al., 2018). In other words, when engaging patients in decisions pertaining to care, a patient becomes a co-creator in the care process; with shared responsibility between the provider and patient, which may facilitate coming into a consensus/ common ground on clinical management (Barlow et al., 2002; Lorig & Holman, 2003).

Achieving patient-centredness requires a cultural adjustment both within the individual provider and at the health system level. First, provider attitudes and behaviours can accelerate or thwart PCC. Providers must therefore be willing to learn cultural and structural competence skills that will enable them to offer clinical messaging that fits particular patient's context. Second, learning institutions must broadly review the curriculum used for teaching medical students to ensure that aspects of culture are covered. This may facilitate the enabling of medical students to deal with cross-cultural issues when managing patients. Healthcare systems also need to reflect on organisational cultures or medical hierarchy at the hospitals as well as issues to do with the commercialization and the commodification of medical care. Lastly, providers must also be willing

to adopt an incentive structure that encourages spending adequate time with patients with complex needs and consistently encouraging patients who want to be actively engaged in the management of their own health.

6.5.3 Policy recommendations

Policy-makers can foster both integrated, collaborative and PCC by aligning policy, regulatory and financial environment so that they are supportive of integrated care and help make effective care for people with multimorbidity sustainable.

Chronic care policies must also have context specific treatment interventions; this may include establishing multimorbidity guidelines. This will give directions on how comorbid conditions (especially those that cluster together) should be managed, as co-existing conditions compared to single occurring conditions. Furthermore, policy makers must ensure that chronic care models and frameworks from developed countries are adapted to fit the local context and match up with people's conceptualisation of diseases and care.

There is a need for policy interventions that would address the social-economic factors that place individuals at vulnerable positions to development of these chronic conditions. To achieve health promotion and the prevention of disease, comprehensive integrated health promotion strategies that address individual factors (such as lifestyle behaviour and health literacy) and socio-economic factors (such as education, poverty, and housing) together with improved health services, are required for improved patient outcomes and increased wellness.

Examples of key policy interventions at the population level may include to subsidise prices for healthy foods, limit the number of fast-foods outlets (Igumbor et al., 2012), restrict

marketing and advertisements of unhealthy foods, mandatory labelling of front pack of foods (Reyes et al., 2019) or taxation of unhealthy foods. The idea of taxation of unhealthy foods has already been implemented with the South Africa Health Promotion Levy (a sugary beverage tax) enacted in 2018 (National Treasury, 2016). All these strategies can assist in reversing the environmental drivers of NCDs. However, without formal structures and a broad array of mandatory legislation and regulation similar to those used to quell the tobacco epidemic, the food and beverage industry will continue to shape and manipulate the polices, and the negative trajectory of fast-food expansion will continue to cause health complications. Thus, all these strategies require the political will to stand up to powerful international corporations — something that many find difficult within the global neoliberal economy (Nakhimovsky et al., 2016). Other policies may include healthy feeding programs in schools and health education or literacy both at schools and in the community and proper housing.

6.5.4 Research Implications and Future Directions

In sub-Saharan African countries, little is known about the epidemiology of comorbidity or multimorbidity (especially linking this topic to healthcare system); clinical guidelines are not always designed to take care of this population, and financing as well as delivery systems have not evolved to adequately manage comorbidities or multimorbidity. More studies should be conducted to provide empirical evidence on comorbidities or multimorbidity and how the healthcare system needs to be organised to address the existing gaps in care. Researchers should also embrace multi-disciplinary approaches to understanding comorbidities or multimorbidity. This may include partnerships between anthropologists, sociologists, public health, physicians, or even health economists who may give more insights on economic aspects of chronic illnesses.

Future Directions:

1. Future researchers should consider studying the whole healthcare system from PHC to secondary and tertiary levels of care. This would provide a comprehensive picture of how the system functions, gaps on each level and which interventions best suits a specific level of care.
2. Healthcare financing remains a key issue in chronic care management. As global funders are moving away from funding chronic illnesses in most LMICs, future researchers should look into innovative approaches or strategies that governments in LMICs are putting in place to finance their own health systems, so as to manage comorbidity or multimorbidity.
3. There is a need to look into alternative care practices for comorbidities or multimorbidity – this is especially true as patients get frustrated in the current overburdened healthcare systems, which may drive them to alternative care and treatments. Importantly, future researchers should look at how actors in conventional medicine are embracing or partnering with individuals practicing alternative care.
4. Future researchers should also explore issues around space in chronic care. So far, there is minimal (if any) research that specifically addresses the issue of space when managing comorbidity or multimorbidity – yet, this is a key area of facility reorganization e.g. in the ICDM model in South Africa.
5. Lastly, I have argued in this thesis that thinking *syndemically* requires social and clinical policies to be addressed in tandem. Hence, there is need to explore the role of the social or policy environments such as taxation of tobacco, sugar sweetened beverages in contexts like South Africa, and its impact on comorbidity or multimorbidity.

6.6 Conclusion

A rapid increase in number of people living with comorbidities or multimorbidity in SSA is alarming. This calls for new approaches that aim at strengthening PHC, to integrate care for chronic diseases, management and reduce the strain experienced at tertiary levels of care. In South Africa, policies aimed at strengthening PHC such as the ICDM have not been implemented across the whole country. In Soweto, patients continue to experience fragmented care for their comorbidities or multimorbidity. Successful implementation of integrated, collaborative and patient-centred care in South Africa, and in other parts of SSA, may only be feasible if the aforementioned health system challenges are adequately addressed. In addition, integrated care models need to be redesigned so as to address social and medical problems in tandem. Lastly, there is need for more research on comorbidity or multimorbidity, especially investigating the existing gaps in treatment and care, prevention strategies or recommendations on best ways to organise the healthcare system to manage patients with multimorbidity.

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APPENDICES

Appendix 1: Contribution to science during My PhD Program

1) **Edna N Bosire,** Emily Mendenhall, Lesley Jo Weaver (2020) Comorbid Suffering: Breast Cancer Survivors in South Africa. Journal- Qualitative Health Research. http://doi: 10.1177/1049732320911365
2) **Edna N Bosire,** Emmanuel Cohen, Agnes Erzse, Aviva Tugendhaft, Karen Hofman, Shane A Norris (2020). "I'd say I'm fat, I'm not obese": Obesity normalisation in urban-poor South Africa." Journal- Public Health Nutrition. doi:10.1017/S1368980019004440
3) **Edna N Bosire,** Nicholas Stacey, Gudani Mukoma, Aviva Tugendhaft, Karen Hofman, Shane A Norris. 2020. "Attitudes and perceptions amongst urban South Africans towards sugar-sweetened beverages and taxation". Journal of Public Health Nutrition https://doi.org/10.1017/S1368980019001356
4) Igumbor JO, **Bosire EN**, Basera TJ, et al (2020). CARTA fellows' scientific contribution to the African public and population Health Research agenda (2011 to 2018). *BMC Public Health*. 20(1):1030. doi:10.1186/s12889-020-09147-w
5) Molete M, Stewart A, **Bosire E,** Igumbor J. The policy implementation gap of school oral health programmes in Tshwane, South Africa: a qualitative case study. *BMC Health Serv Res*. 2020;20(1):338. doi:10.1186/s12913-020-05122-8
6) Rose Clarke Nanyonga, **Edna N. Bosire**, David J. Heller, Elizabeth Bradley, Nancy R. Reynolds (2020). Predictors of Nursing Leadership in Uganda: A Cross-Sectional Study. Journal Health policy and Planning (Accepted, in press)
7) Emily Mendenhall, **Edna N Bosire**, Andrew Wooyoung Kim, Shane A Norris 2019. Cancer, chemotherapy, and HIV: Living with cancer amidst comorbidity in a South African township. Social Science and Medicine. DOI: 10.1016/j.socscimed.2019.112461
8) Stephanie V. Wrottesley, **Edna N Bosire,** Gudani Mukoma, Molebogeng Motlhatlhedi, Gugulethu Mabena, Mary Barker , Polly Hardy-Johnson, Caroline Fall, Shane A. Norris. (2019) Age and gender influence healthy eating and physical activity behaviours in South African adolescents and their caregivers: Transforming Adolescent Lives through Nutrition Initiative (TALENT). DOI: https://doi.org/10.1017/S1368980019002829
9) Cathrine Drapper, **Edna Bosire,** Alessandra Prioreschi, Lisa J Ware, Emmanuel Cohen, Stephen J Lye, Shane A Norris. 2019. Urban young women's preferences for intervention strategies to promote physical and mental health preconception: A Healthy Life Trajectories Initiative (HeLTI). Journal of Preventive Medicine *https://www.sciencedirect.com/science/article/pii/S2211335518302419*
10) Emmanuel Cohen, Lisa Ware, **Edna Bosire**, Alessandra Prioreschi, Catherine Draper, Shane A. Norris (2019). "Material and relational difficulties: The impact of the household environment on the emotional wellbeing of young black women living in Soweto, South Africa". Journal of Family Issues. DOI: 10.1177/0192513X19887524

11) Andrew Wooyoung Kim, Bonnie Kaiser, **Edna Bosire,** Katelyn Shahbazian, Emily Mendenhall 2019. Idioms of Resilience among Cancer Patients in Urban South Africa: An Anthropological Heuristic for the Study of Culture and Resilience. Transcultural Psychiatry (56(4):136346151985879 https://www.ncbi.nlm.nih.gov/pubmed/31299876

12) Emily Mendenhall, Abednego Musau, **Edna Bosire**, Victoria Mutiso, David Ndetei & Melanie Rock (2019) What drives distress? Rethinking the roles of emotion and diagnosis among people with diabetes in Nairobi, Kenya, Anthropology & Medicine, DOI: 10.1080/13648470.2019.1650243

13) Alessandra Prioreschi, Lisa J Ware, **Edna Bosire**, Emmanuel Cohen, Stephen J Lye, Shane A Norris. 2019. Environmental, Social, and Structural Constraints for Health Behavior: Perceptions of Young Urban Black Women During the Preconception Period-A Healthy Life Trajectories Initiative. Journal of Nutritional Health Behaviour https://www.ncbi.nlm.nih.gov/pubmed/31101479

14) Emily Mendenhall, Rebecca Rinehart, Christine Musyimi, **Edna Bosire,** Victoria Mutiso, David Ndetei: 2019. An Ethnopsychology of Idioms of Distress in Urban Kenya. Journal of Transcultural Psychiatry. https://journals.sagepub.com/doi/full/10.1177/1363461518824431

15) **Edna N. Bosire** & Onyango-Ouma W. 2019. "Women's Three Bodies: An Anthropological perspective on barriers to safe abortion services in Kibera Informal Settlements, Nairobi, Kenya. Journal of Maternal and Child Health, 4(2): 97-109 https://doi.org/10.26911/thejmch.2019.04.02.05

16) **Edna Bosire,** Emily Mendenhall, Gregory Barnabas Omondi, David Ndetei .2018. When Diabetes Confronts HIV: Biological Sub-Citizenship at a Public Hospital in Nairobi, Kenya. Medical Anthropology Quarterly. https://anthrosource.onlinelibrary.wiley.com/doi/10.1111/maq.12476

Oral Presentations

March 2020	Oral Presentation: "An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the case of Soweto, South Africa." Georgetown University, Washington DC, USA.
October 2019	Oral Presentation: "Provider perspectives on Integrated & patient-centred care for patients with HIV and diabetes at a public tertiary hospital in South Africa." University of the Witwatersrand, School of Clinical Medicine Biennial Research Day. Johannesburg, South Africa.
2018 October	Panel Presentation: Health Systems Research (HSR) 5th Global Symposium. The Politics of Health policy and systems at the global and National levels: Overcoming systemic barriers to improve health in marginalized communities. Liverpool, United Kingdom.

2018 February	Qualitative Trainer: Global Challenges Research Fund – Network for Adolescent Nutrition, BKL Walawalkar Hospital, Dervan, near Chiplun, India (Talent Study)
2017 November	Oral Presentation: "Diabetes Confronting HIV in Nairobi, Kenya." Ethnographic Perspectives on Health Systems in Sub-Saharan Africa, Georgetown University, Washington DC, USA.

Poster presentations

August 2019	"Pathways to care for patients with comorbid Type 2 Diabetes and HIV/AIDS in Soweto: A Health System's Perspective". University of the Witwatersrand, School of Public Health Biennial Research Day. Johannesburg, South Africa.
September 2018	"Every day before I sleep, I need to have a coke: Attitudes and perceptions amongst urban South Africans towards Sugar sweetened Beverages and taxation." University of the Witwatersrand, Faculty of Health Sciences Research day. Johannesburg, South Africa.

Conference/Workshops attended

March 2020	Supervisor's Course: Supervision and Examination of Post graduate students, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, South Africa.
August 2019	Supervisor's workshop: Nitty Gritty of Examination (Masters and PhD students), School of Public Health, University of the Witwatersrand, Johannesburg, South Africa.
July 2019	National Research Fund (NRF) training workshop on communicating science and engagement initiatives to both researchers and the general public, NRF offices, Pretoria, South Africa
November 2018	South Africa-Kenya Diaspora Colloquium- Academies of Science of South Africa in collaboration with the Kenya National Commission of Science and Technology (NACOSTI), held at Pretoria, South Africa.
December 2017	Health Threats and Opportunities in Urban Vulnerable Geographies held at Georgetown University, School of Nursing and Health Sciences, USA.
November 2017	American Anthropological Association (AAA) Annual Meeting. Theme: Anthropology Matters. Washington DC, USA.

Awards, Grants & Fellowship, Appointment

2020 Full scholarship award from the organizing committee, Health System Research 6th Global Symposium, November 2020 in Dubai: Women Mentorship Program

2020 Travel Grant from the Soweto-Syndemics study- Training students on Qualitative Data Analysis using Dedoose software, Developing codebook and coding. Georgetown University, Washington DC.

2019 Best overall poster presentation across disciplines, University of the Witwatersrand, Faculty of Health Sciences, School of Public Health Research Day.

2018 Full scholarship award from the organizing committee, Health System Research 5th Global Symposium in Liverpool to attend and present: Liverpool, UK.

2018 Travel grant from the Global Challenges Research Fund -University of Southampton, England, to participate and train in Qualitative Research Methods on Network for Adolescent Nutrition, BKL Walawalkar Hospital, Dervan, India.

2017 South Africa Medical Research Council -Doctoral Fellowship for 3 years at the Developmental Pathways for Health Research Unit (DPHRU), University of the Witwatersrand, Johannesburg South Africa

Appointment-Health System Global

2019 Appointed as a Mentor for the Health System Global (HSG) Women Mentorship program for early-career women based in Low-Middle-Income countries and working in HPSR, who are interested to publish their research.

Appendix 2: Approval of PhD study Title

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

Private Bag 3 Wits, 2050
Fax: 027117172119
Tel: 02711 7172076

Reference: Mrs Sandra Benn
E-mail: sandra.benn@wits.ac.za

21 June 2018
Person No: 1828411
PAG

Ms EN Bosire
Paradise Park Estate, Athi-river
Athi-river Sda Church, Athiriver
281-00204
Kenya

Dear Ms Bosire

Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled *An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the case of Soweto, South Africa* has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

Appendix 3: Human Research Ethics Committee (Medical) Wits

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Ms EN Bosire

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M171125

NAME: (Principal Investigator)	Ms EN Bosire
DEPARTMENT:	School of Clinical Medicine Department of Paediatrics and Child Health Developmental Pathways for Health Research Unit Chris Hani Baragwanath Academic Hospital
PROJECT TITLE:	An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the case of Soweto, South Africa Change of study title noted on 02/01/2020
DATE CONSIDERED:	24/11/2017
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Professor SA Norris
APPROVED BY:	Dr N Naran, Co-Chairperson, HREC (Medical)
DATE OF APPROVAL:	09/04/2018

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to submit details to the Committee. I agree to submit a yearly progress report. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in November and will therefore reports and re-certification will be due early in the month of November each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Edna N Bosire
Principal Investigator Signature

02 January 2020
Date

PLEASE QUOTE THE CLEARANCE CERTIFICATE NUMBER IN ALL ENQUIRIES

Appendix 4: Permission to conduct research – CHBAH



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE
CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 2 Feb 2018

TITLE OF PROJECT: Culture and comorbidity: a critical look at co-occurring conditions in urban resource-constrained settings; case of Soweto in South Africa

UNIVERSITY: Witwatersrand

Principal Investigator: EN Bosire

Department: DPHRU

Supervisor (If relevant): SA Norris, J Goudge, E Mendenhall

Permission Head Department (where research conducted): Yes

Date of start of proposed study: Feb 2018
Date of completion of data collection: Dec 2021

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and the study is subject to:-

- Permission having been granted by the Human Research Ethics Committee of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.

.....
Recommended
(On behalf of the MAC)
Date: 02 February 2018

.....
Approved/Not Approved
Hospital Management
Date: 06/02/18

Appendix 5: Patients' Information Sheet

Hello, my name is **Edna Nyanchama Bosire,** a PhD student and Principal Investigator for this study, under the Departmental Pathways for Health Research Unit (DPHRU), Department of Pediatrics at the University of Witwatersrand. I will be conducting a study entitled "**An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the case of Soweto, South Africa".** The main aim of this study is to investigate health and healthcare challenges and opportunities among patients with comorbid diabetes and HIV and health care workers providing care for them in Soweto, South Africa. The study will look at the health system at CHBAH to find out how health care providers manage patients with comorbid diabetes and HIV and Patients' experiences on the care that they receive. Before you decide to participate, I would like you to understand why the research is being done and what it would involve for you.

What is involved in the study? The study will be conducted in DPHRU offices at Chris Hani Baragwanath hospital campus. You will not receive additional benefits for participating in this study. However, some people enjoy participating in this qualitative study because there is opportunity to share personal experiences and perspectives.

If you agree to take part in the study, I will ask you to attend our research unit where I will conduct the interview. I will ask you a series of questions related to your living environment or neighbourhood, your family, and your experiences with health and illness.

Procedures: I am requesting your participation in a one-on-one interview about life experiences and management of your diabetes and HIV conditions. Your feedback will help improve my understanding on the factors that facilitate of impede you in accessing medical care for your conditions in Soweto and your experience with managing these diseases. This will be an In-depth interview and it will take approximately one to two hours of your time. You will have a 10 minutes break to rest in the middle of the interview and we will serve you with a drink. The interview will be tape-recorded with your consent, and the recordings will be safely stored to protect your privacy. Your name will not be used in the recording.

This form is designed to tell you everything you need to understand before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. The decision to join or not join the research study will not cause you to lose any benefits.

Risks and Discomforts: There are no foreseeable risks or discomforts associated with this study. You may stop the study at any time.

Benefits: There are no direct benefits for you. But your feedback from the interview will be used to improve my understanding of people's experiences with care seeking for multiple chronic illnesses in Soweto and also how the health system helps patients manage these illnesses. Your

participation is completely voluntary. No material compensation will be provided for your participation. Your help with this study is greatly appreciated.

Confidentiality: I will assign you a study serial number rather than your name for data collection. The code that links the study number to your name will be kept in a secure place, available only to the Principle Investigator. All research records and recorded interviews will be kept in a secure, password protected computer. Your name and other facts that might identify you will not appear in study results. Any shared data will not include any identifiable information.

Audio-recordings of the interview will be destroyed two years after the research is published, or six years after the study if no publication occurs. People other than those doing the study may look at study records: Agencies and committees that make rules and policy about how research is done have the right to review these records, as well as agencies that pay for the study.

Withdrawal of Participation: Participating in the interview is voluntary, and you may leave the study at any time without penalty. This decision will not affect in any way your current or future care seeking at the hospital.

Voluntary participation in research: You have the right to agree or refuse to participate in this research. If you decide to participate and later change your mind, you are free to stop at any time. Your refusal to participate will not affect you in care seeking at the hospital.

Records of your participation in this research: You have the right to privacy. The principal investigator will keep information about your participation in locked files. Your interview will be labelled with a number to ensure your privacy.

Ethical approval: This study will only kick off after it receives an Ethical clearance from the University of the Witwatersrand, Human Research Ethics Committee (HREC).

Publication of the results of the research: The results of this research may appear in scientific publications without identifying you in any way.

Your questions: The investigator listed on the first page of this form is available to answer your questions about this research. You may contact the investigator at any time on the following numbers **0712153763.** If you require any further information or have any questions/complaints about the study please contact the Human Ethics Committee of Witwatersrand **011 717 71234** or **anisa.keshav@wits.ac.za** .

In case of any distress or discomfort after the interview, or if you should require someone to talk to after the interview, the interviewer will connect you to **Sister Thoko at (011) 717 2701** for counselling services. Sister Thoko is professional nurse who is based at DPHRU as a resident trained nurse counsellor and has served in that capacity for over 15 years. YOU WILL HAVE A COPY OF THIS INFORMATION SHEET TO KEEP. Your signature on the consent forms certifies the following: You have read the information provided in this consent form. You have received answers to all of your questions. You have freely decided to participate in this research. You understand that you are not giving up any of your legal rights.

If you are happy to take part in the study please read and sign the attached consent form.

Appendix 6: Consent form for participation for patients

I agree to myself being a participant in the study.

The goals and methods of the study are clear to me.

I understand that the study will involve an interview. All the details and purposes of this study have been explained to me. I understand that I have the right to refuse to participate in the study.

I agree to participation in the study on the condition that:

1. I can withdraw from the study at any time voluntarily and that no adverse consequences will follow on withdrawal from the study.

2. I have the right not to answer any or all questions posed in the interviews.

3. The University of the Witwatersrand Human Ethics committee must approve this study before it starts.

4. All results will be treated with the strictest confidentiality.

5. My name will not be published in scientific journals and in the media.

6. The study scientific team are committed to treating participants with respect and privacy through interviews conducted in private and follow-up counselling available on request.

7. In case of any distress or discomfort after the interview, or if I require someone to talk to after the interview, the interviewer will connect me to **Sister Thoko at (011) 717 2701** for counselling services. Sister Thoko is professional nurse who has been working earlier at CHBAH as a nurse for over 20 years and now is based at DPHRU as a resident trained nurse counsellor and has served in that capacity for over 15 years.

will receive a referral note to a health service if I show symptoms of mental distress

PARTICIPANT

Printed Name…… Signature ……....Date……

RESEARCHER:

Printed Name…… Signature…….. Date…….

Appendix 7: Consent form for audio recording for patients

I agree to myself being a participant in the study and I agree that this interview will be audio-recorded.

The goals and methods of the study are clear to me.

I understand that the study will involve an interview and that this interview will be audio-recorded. All the details and purposes of this study have been explained to me. I understand that I have the right to refuse to participate in the study.

I agree to participation in the study on the condition that:

1. I can withdraw from the study at any time voluntarily and that no adverse consequences will follow on withdrawal from the study.

2. I have the right not to answer any or all questions posed in the interviews.

3. The University of the Witwatersrand Human Ethics committee has approved the study protocol and procedures.

4. All results will be treated with the strictest confidentiality.

5. My name will not be published in scientific journals and in the media.

PARTICIPANT

Printed Name…… Signature ……Date……

RESEARCHER:

Printed Name…… Signature…… Date…….

Appendix 8: In-depth interview guide for patients

Opening Questions

1. Where do you come from? For example, were you born?
    a. Soweto: _____
    b. Johannesburg; name area of city: _____
    c. City in South Africa (not Johannesburg); name: _____
    d. Rural area in South Africa; name: _____
    e. Outside of South Africa; name: _____
2. Where do you live now?
    a. Soweto; name area of city: _____
    b. Other: _____
3. How long have you lived there? _____ months/years (circle one)
4. How old are you? _____ years
5. Gender of respondent: a. Female b. Male c. Other
6. Marital Status
    a. Married
    b. Single (never married)
    c. Widowed
    d. Divorced/separated
7. Who lives in your house?
    a. Spouse/partner
    b. parents
    c. c. children
    d. grandchildren
8. How many children do you have? _____
    a. How many are biological children? _____
    b. How many adopted from other family or friends? _____

c. Why were they adopted? _____

d. How many are living? _____

e. Where do your children live? _____

f. Who pays their school fees? _____

9. How many grandchildren do you have? _____

a. Do they live near you? _____

b. Do they live with you? _____

c. Do you support them financially? _____

d. Where do your grandchildren live? _____

e. Who pays their school fees? _____

10. What is the highest level of education you completed?

a. No School

b. Primary; last year completed: _____

c. Secondary; last year completed: _____

d. Completed Secondary

e. Technical School; what in? _____

f. University

g. Who paid your school fees? _____

11. How many Rand does your household earn per month? _____ _____

12. Who earns money for your household?

a. Self

b. Spouse/Partner

c. Both

d. State Grant

e. Other _____

13. What is your type of employment? How do you get money?

a. Self b. Casual Labor c. Permanent with Pension d. Contract e. Unemployed

14. What is your type of residence? Where do you live?

a. Tenant b. Own house c. RDP house d. Stay with family with no rent contribution

15. What type of door do you have on your house?

a. Steel b. Iron sheet c. Wooden

16. What type of walling materials are on your house?

a. Bricks b. Plastered mud c. Iron sheets d. wood

17. How many rooms are in your house? _____ rooms

18. How many people live in your house? _____ people

19. Do you have indoor lighting?

a. Electric bulbs b. Solar bulbs c. Kerosene lanterns or lamps

20. What type of toilet do you have access to?

a. Private flush toilet b. Communal flush toilet c. Private pit latrine d. communal pit latrine

21. How do you access water for domestic use most of the time?

a. Tap water b. Buy from vender c. Borrow from neighbour well/borehole?

22. How do you cook food most of the time?

a. Gas b. charcoal c. electric d. firewood

23. Do you have a fridge that can keep your foods fresh?

    a. I have a fridge that works all of the time
    b. I have a fridge that works most of the time
    c. I have a fridge that works some of the time
    d. I have a fridge, but it doesn't work
    e. I don't have a functioning fridge

24. How often do you buy food? _____

25. Approximately how much do you spend on food on an ordinary day? _____

26. Approximately how much do you spend on food per month? _____

DIRECTIONS: The qualitative interview begins with open-ended questions that point to starting a dialogue. The interviewer should encourage the study participant to do most of the talking but should use the questions listed here as a guide. After you ask each question, wait for the study participant to respond and go on to the next question when you are satisfied with the answer. If it seems as though the study participant did not understand a question, then repeat it or ask it in another way. If the study participant goes on talking without much prompting, then let them guide the conversation. Bold indicates major questions and probes are in parentheses. Mentally check off these questions as they are asked so you do not repeat a question if it has been discussed previously.

Remember to audio record each interview. Use a back-up recorder to prevent technological problems.

Thank you for participating in this interview. This interview will be different than others that you might have participated in the past. I will ask you questions and ask you to talk freely about your experiences with seeking care for your chronic conditions. Please ask me at any time if you do not understand a question, need more clarification, or would prefer to not answer a question. We ask that you provide honest answers that will provide us the best information possible to understand your personal experiences.

General Background Questions

a) Can you tell me about your childhood?

[Probes: Where are you from? Where did you grow up? How long did you live there? With whom did you reside during your childhood (parents or other guardians)? Where did your parents grow up? Do your parents currently reside near you? Do you have siblings? Do you live near/keep in touch with them? Do you share meals with them, communicate, and so on? Did you ever move due to political instability? Has anyone in your family been infected or affected by HIV/AIDS?]

b) Can you tell me about your family and neighbourhood?

[Probes: Have you ever been married? Are you still married? Can you tell me about your spouse? Do you have kids? Can you tell me about your children (age, do they live with you, schooling, etc)?

Where do you live? Who resides with you? What is your house like? What surrounds your house, such as stores, other people, and so on in your neighbourhood?]

c) Can you describe some of the things that you do for your family and for yourself? For example, do you spend a great deal of time caring for family members?

<u>Key questions</u>

Domain 1: Health, Illness and Disease

1a. What does health mean? What does it mean to be healthy?

[Probes: Can you describe for me a time when you felt healthy? Why were you healthy then?]

1b. What does it mean to be sick? Can you share what words you use to describe sickness?

(What makes you sick? Does everyone experience sickness the same way)?

1c. What are some of the things that enable you to get health care whenever you feel like?

1d. What are some of the barriers/difficulties in taking care of your health?

Domain 2: Vulnerability to illnesses and Diseases

2a. Can you describe your neighbourhood? (Probes- Where do you live? Who resides with you? What surrounds your house, such as stores, other people, and so on in your neighbourhood?]

2b. How safe is your neighbourhood?

2c. What challenges do you encounter in your living environment?

2d. How do you think the following factors facilitate or impede health and healthcare for patients with both diabetes and HIV/ other chronic diseases in Soweto?

- Historical events (e.g. apartheid era, Stress from past events, etc)
- Social-Cultural (Cultural beliefs and traditions, religion, etc)
- Economic (Probes- Poverty, economic status, employment status, Number of dependents, etc)
- Political (Probes- How laws and policies influence health care access, distribution of medications, etc)

2e. Has any of these factors affected you before (Probe- historical, social, cultural, economic, political)? Please explain

2f. What do you think can be done to help reduce the challenges brought about by the above factors that makes people vulnerable to illness and disease?

Domain 3: Chronic disease and diagnosis (focus on HIV/AIDS and Diabetes)

3a. One of the reasons you have been invited here today is because you have previously been diagnosed and treated for HIV/AIDs and Diabetes.

- What words do you use to describe HIV/AIDs?
- What words do you use to describe Diabetes?

[Probes: What words do other people use to describe these diseases? (Including friends and family, as well as other people, including people at Church, the market, or on TV)

3b. How do you think about your diseases- HIV/AIDS and Diabetes?

3c. What do you think caused your HIV/AIDs? Diabetes?

3d. Can you tell me when you were diagnosed with HIV/AIDs? please explain what happened? (Probes- when were you diagnosed? which hospital? what motivated you to go to the hospital? Who accompanied you during the diagnosis?)

- How did you feel when you were diagnosed with HIV/AIDs?

3e. Can you tell me when you were diagnosed with Diabetes? please explain what happened? (Probes- when were you diagnosed? which hospital? what motivated you to go to the hospital? Who accompanied you during the diagnosis?)

- How did you feel when you were diagnosed with Diabetes?

3f. Have your health conditions (HIV and Diabetes) altered or changed your life in any way? If yes, is it more in any particular area of your life, such as work, family life, marriage, sexual relationships, social relationships and so on?

[Probes: Can you provide examples of things that have changed since your diabetes diagnosis? Can you tell me about some things that have stayed the same since your diabetes diagnosis that you expected to change?]

3g. Has this health condition (HIV and Diabetes) changed your daily routine? If you have seen a change in your life due to the condition, can you explain the ways in which your daily life has changed?

[Probes: Do you believe that your condition enriches your life? Or you do you find it to be stressful? Or do you feel as though condition has little effect on your life?]

3h. Have you ever felt stress in relation to your HIV or Diabetes?

[Probes: How does/has diabetes affect/ed your feelings? Does it contribute to a low mood? Do you associate any feelings from past experiences with diabetes? Why or why not? What are they? What caused these feelings?

3i. How do you address stress or tension in your life? Do you take medication? Or do you do other things? Can you tell me more about that? (potentially they will answer walk, talk to a friend, doctor, healer, eat, etc).

3j. When/to whom do you disclose your diagnosis/not disclose?

3k. How have people reacted to your having HIV and Diabetes? Have you ever felt discriminated or supported?

(***Instructions: At this point, the participant must be given a 10- minutes break***).

Domain 4: Patient's Experience with care seeking for co- morbidities

4a. Where do you go for your health care and/ get medication for: (a) HIV/AIDs? (b) Diabetes?

(probes- Do you go to the same hospital or different hospitals? Do you have same clinic days or different? Do you experience any challenges when seeking care? What do you think can be done to curb these challenges?)

4b. How many times per month do you attend the clinic for: (a) HIV/AIDs? (b) Diabetes?

4c. Do you get attended by one doctor/health care provider or different people? (Probes- if different health care providers attend to you, how is the experience? What are the challenges that you are facing? What do you think can be done to curb these challenges?)

4d. Do you find having several different health professionals looking after you a good or bad thing? (Do you feel they communicate? How could this be improved?)

4e. Do you understand the roles of different health professionals involved in your care and management of these diseases (HIV/AIDs/ Diabetes)?

4f. Do you understand different tests/investigations and treatments that have been done / given to you for these diseases?

4g. Do you think that health professionals spend adequate time with you in hospital? Do you have any suggestions for how this may be improved?

4h. How do you feel you have been treated by health professionals involved in your care? Do you have confidence in these health professionals?

4i. Is it important to you to see the same health professional i.e. is continuity important to you? What is more important: seeing a health professional quickly or seeing someone that you have seen before?

4j. Are frequent changes made to your medications? How do you feel about this? What would make your life easier?

4k. How do you feel about your treatments for (a) HIV/AIDs (b) Diabetes? Have you ever stopped taking them / doing them against medical advice?

4l. How do you feel about the progress you have made in recovering from illnesses? Is it something that you have achieved on your own or with a team of other people? What could have improved this?

4m. Have you ever done a self-directed research on these diseases and its management (Probe-books / leaflets / internet / media/ friends and family / life experience / people with the same illnesses)

4n. How do you get information on managing these diseases? (Hospital, TV, Radio, internet, Friends, etc)? Is the information enough/helpful?

4o. Have you ever received conflicting information from different sources on how to manage these diseases? If yes, please explain

4p. Can you describe your experience with the health care system where you get your care for your diseases?

- Medication or drugs
- Availability of health care providers
- Waiting time before you see a doctor
- Waiting time before you get the medication
- Costs involved when seeking health care
- Appointments

4q. How does culture and your belief system influence your health seeking behaviour? How about the kind of medication you use and the manner in which you use?

- Do you feel that the health care providers treat and manage your conditions in a culturally appropriate way? (if yes/no, please explain).

Domain 5: General knowledge and experience with the diseases

5a. How has been your general experience with multiple morbidities?

5b. Do you know any other person with Multi-morbidities? Have you ever talked to them? How has been their experience with the diseases?

5b. Have you ever received counselling or psychotherapy for your HIV and Diabetes? Can you describe what type of care you were given? By whom? In a clinic, from a friend, or loved one? Was it helpful?

- If no, do you think counselling is necessary?

5c. Have your family helped you with psychological and practical support such as transport, prescriptions, finances, help with therapies, aiding communication? Were there any areas of difficulty with this? Could health services help with this process in any way?

5d. Has Religion been helpful in managing your illnesses? Do you believe that Religion can help you out/heal these diseases?

5e. Have you ever tried an alternative medication to your illnesses? (Probe- Traditional healers, Faith healers?) If yes, please explain what happened and how was the experience?

5f. Do you have other illnesses to manage along with your HIV/AIDs and Diabetes? Please tell me. If so, do you have any difficulties managing multiple illnesses? What would make your life easier?

5g. Do you feel involved in decisions about your healthcare?

5h. Do you monitor your own health at home in any way? What would make this easier?

5i. Can you describe how your life might differ from having only one of the two chronic conditions that you have? Which one do you think is more difficult to manage? Which one is easier to manage? If you could pick one of the conditions that you have, which one would it be?

Domain 6: Stigmas and beliefs

6a. Do you tell people about your HIV and diabetes? Why or why not? Did people treat you differently before and after you were diagnosed?

[Probe: why do you hide your diagnosis? OR why are you candid about your diseases?]

6b. What diseases are really bad to have? Are there any diseases where you try to stay away from someone who has it?

[Probe: Are there some diseases that people hide because they are afraid people might think differently about them if they knew they had been diagnosed?]

6d. Is AIDS the same as Diabetes? Are either secret?

6e. How do people's beliefs about HIV impact your daily life? Who/what/how/when do you tell people about having HIV, if at all? What do people say?

6f. How does your HIV affect your Diabetes? How does your Diabetes impact your HIV?

[Probe: Can you give an example when your HIV affected your ability to achieve your Diabetes treatment? Or can you give an example of when your Diabetes affected your HIV care?]

6g. If you had advice about someone with HIV and diabetes, what would you tell them?

[Probe: What about someone diagnosed with HIV and cancer? Hypertension?

Thank you very much for participating in this interview. It takes time to participate in qualitative interviews and we very much appreciate your time. END

Appendix 9: In-depth interview guide for healthcare providers

Opening Questions

1. How old are you?
2. What is your training/ profession?
3. Please, describe your currently position and responsibility in the hospital?
4. How long you have you been in this type of work?
5. How long have you been working in this hospital?

DIRECTIONS: The qualitative interview begins with open-ended questions that point to starting a dialogue. The interviewer should encourage the study participant to do most of the talking but should use the questions listed here as a guide. After you ask each question, wait for the study participant to respond and go on to the next question when you are satisfied with the answer. If it seems as though the study participant did not understand a question, then repeat it or ask it in another way. If the study participant goes on talking without much prompting, then let them guide the conversation. Remember to audio record each interview. Use a back-up recorder to prevent technological problems.

Thank you for participating in this interview. This interview will be different from the others that you might have participated in the past. I will ask you questions and ask you to talk freely about your experiences with providing care for patients with chronic conditions. Please ask me at any time if you do not understand a question, need more clarification, or would prefer to not answer a question. We ask that you provide honest answers that will provide us the best information possible to understand your personal experiences.

Vulnerability to illnesses and diseases in Soweto

1. What are some of the factors that contribute to individuals' vulnerability to illness and diseases in Soweto? Probes:
    - Historical events (e.g apartheid era, Stress from past events, etc)
    - Social-Cultural (Cultural beliefs and traditions, religion, etc)
    - Economic (Poverty, economic status, employment status, number of dependents)
    - Political (laws and policies, leadership, distribution of medications, etc)

Experience with administering care for chronic diseases

1. What are some of the common chronic diseases that patients present with in your hospital?
2. At what point do patients present to the hospital for care for their chronic diseases? (Probes- if delays in presentation, why do you think so? Please give reasons)
3. Can you describe to me how you care for patients with chronic diseases?
4. Do you have enough resources to care/manage patients with chronic diseases? Probe: if yes, how do they help your normal working? If no, what is missing/not enough?
5. Have you ever felt uncomfortable when offering care to patients with chronic diseases? If yes what was the situation, please explain? (e.g. due to workload, when patients start narrating about their life histories, when you meet a patient that you already knew from your neighbourhood?)
6. Do you offer counselling services for patients with chronic diseases?
7. Have you encountered any event or a situation which affected your normal service delivery in the hospital? If yes please describe the event
8. What are some of the challenges that you experience while administering care for patients with chronic diseases?
9. What are some of the suggested solutions to these problems?
10. What do you recommend to the health care policy to improve the way care is given to patients with chronic diseases?
11. Who finances treatment and care for patients with chronic illnesses?

Experience with caring for multiple chronic illnesses

1. How do you administer care for patients with multiple chronic illnesses? (Probe – prescription of medications, tests, appointments, etc.)
2. Do you have separate clinics for patients with diabetes and HIV? (separate spaces where they are seen by a nurse/physician)
3. How are treatment for patients with diabetes and HIV offered? Is it administered by same health care provider or different? Please explain
4. Approximately how much time do the patients spend waiting in the queue before they see a health care provider? Do you think this is a challenge to the patients? What do you think can be done to curb this?
5. Approximately how much time do you spend with a patient when they get into your room? (Probes- do you think the time is enough, are patients satisfied, what do you think can be done to improve this)?
6. At what point are referrals made to Bara for a patient with a) Diabetes (b) HIV/AIDs

7. How do you communicate to patients with multiple morbidities on any news or information related to their illnesses and care?
8. Do you offer counselling services for (a) Diabetes (b) HIV/AIDs?
9. What are some of the factors that facilitate of impede delivery of health care services to patients with comorbid diabetes and HIV in CHBAH? What about for other chronic conditions? (Probe- equipment's, technology, workload, defaulting, etc)
10. Generally, how has been your experience in managing patients with multiple chronic illnesses?

Integrated and Collaborative care

1. What is your understanding of integrated chronic care? What about collaborative care?
2. Do you have Integrated or collaborative care in diabetes clinics at Bara? If yes, how does it work?
3. What do you think about the integrated chronic care? Is it a good or a bad thing? Please explain
4. Is it important to have integrated chronic care for management of chronic diseases in hospitals in Soweto? Why or why not?
5. Why do you think integrated chronic care has not been implemented in most hospitals in Soweto?
6. Generally, based on my interview today, is there anything else that you may want to add?

Thank you for participating in the Interview.

Appendix 10: Information sheet for Healthcare Providers

Hello, my name is **Edna Nyanchama Bosire,** a PhD student and Principal Investigator (PI) for this study, under the Departmental Pathways for Health Research Unit (DPHRU), Department of Paediatrics at the University of Witwatersrand. I will be conducting a study entitled "**An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the case of Soweto, South Africa."** The main aim of the study is to investigate health and healthcare challenges and opportunities among patients with comorbid diabetes and HIV and health care workers providing care for them the concept of vulnerability for people residing in Soweto, South Africa., with multiple health conditions. The study will look at the health system at CHBAH in Soweto to find out how health care providers manage patients with diabetes and HIV and any other chronic conditions. Before you decide to participate, we would like you to understand why the research is being done and what it would involve for you.

What is involved in the study? The study will be conducted at our offices in of MRC/Wits Developmental Pathways for Health Research Unit at Chris Hani Baragwanath hospital campus. You will not receive additional benefits for participating in this study. However, some people enjoy participating in this qualitative study because there is opportunity to share personal experiences and perspectives.

If you agree to take part in the study, I will ask you to attend our research unit where I will conduct the interview. I will ask you a series of questions related to your experience with administering care for patients with chronic illnesses.

Procedures: I am requesting your participation in the In-depth interview about your experiences in administering care for patients with chronic/multiple chronic conditions. I will start by asking about your perceptions on the factors that facilitator or impede health and healthcare for patients with comorbid diabetes and HIV. I will also ask questions on your experience in offering medical services to such patients. This interview will take approximately one hour of your time. The interview will be tape-recorded with your consent, and the recordings will be safely stored to protect your privacy. Your name will not be used in the recording.

This form is designed to tell you everything you need to understand before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study. The decision to join or not join the research study will not affect your work at the hospital.

Risks and Discomforts: There are no foreseeable risks or discomforts associated with this study. You may stop the study at any time.

Benefits: There are no direct benefits for you. But your feedback from the interview will be used to improve my understanding on health care providers' experiences in administering care for patients with chronic/multiple chronic illnesses in Soweto. Your participation is completely voluntary.

Voluntary Participation. Participation in this study is voluntary. No material compensation will be provided for your participation. You have the right to agree or refuse to participate in this research. If you decide to participate and later change your mind, you are free to stop at any time. Your refusal to participate will not result in any penalty or loss of your job at the hospital.

Confidentiality: All the information that you give to me will be kept confidential. Your name and other facts that might identify you will not appear in study results. All the information that you will provide will be kept in a secure place, in a lock and key cupboard at DPHRU office and will only be available to the Principal Investigator. Any shared data will not include any identifiable information.

Audio-recordings of the interview will be destroyed two years after the research is published, or six years after the study if no publication occurs. People other than those doing the study may look at study records: Agencies and committees that make rules and policy about how research is done have the right to review these records, as well as agencies that pay for the study.

Withdrawal of Participation: Participating in the interview is voluntary, and you may leave the study at any time without penalty. This decision will not affect in any way your current work at the hospital. You may also refuse to answer any questions that you do not want to during the interview.

Records of your participation in this research: You have the right to privacy. The principal investigator will keep information about your participation in locked files. Your interview will be labelled with a number to ensure your privacy.

Ethical approval: This study will only kick off after it receives an Ethical clearance from the University of the Witwatersrand, Human Research Ethics Committee (HREC).

Publication of the results of the research: The results of this research may appear in scientific publications without identifying you in any way.

Your questions: If you require any further information or have any questions/complaints about the study please contact the Human Ethics Committee of Witwatersrand **011 717 71234** or **anisa.keshav@wits.ac.za**. The investigator listed on the first page of this form is available to answer your questions about this research. You may contact the investigator at any time on the following numbers **0712153763.** In case of any distress or discomfort after the interview, or if I require someone to talk to after the interview, the interviewer will connect me to **Sister Thoko at (011) 717 2701** for counselling services. Sister Thoko is professional nurse who has been working earlier at CHBAH as a nurse for over 20 years and now is based at DPHRU as a resident trained nurse counsellor and has served in that capacity for over 15 years.

YOU WILL HAVE A COPY OF THIS INFORMATION SHEET TO KEEP. Your signature on the consent forms certifies the following: · You have read the information provided in this consent form· You have received answers to all of your questions. You have freely decided to participate in this research. You understand that you are not giving up any of your legal rights.

If you are happy to take part in the study please read and sign the attached consent form.

Appendix 11: Consent form for participation for HealthCare Providers

I agree to myself being a participant in the study.

The goals and methods of the study are clear to me.

I understand that the study will involve an interview. All the details and purposes of this study have been explained to me. I understand that I have the right to refuse to participate in the study.

I agree to participation in the study on the condition that:

1. I can withdraw from the study at any time voluntarily and that no adverse consequences will follow on withdrawal from the study.

2. I have the right not to answer any or all questions posed in the interviews.

3. The University of the Witwatersrand Human Ethics committee must approve this study before it starts.

4. All results will be treated with the strictest confidentiality.

5. My name will not be published in scientific journals and in the media.

6. The study scientific team are committed to treating participants with respect and privacy through interviews conducted in private and follow-up counselling available on request.

7. In case of any distress or discomfort after the interview, or if I require someone to talk to after the interview, the interviewer will connect me to **Sister Thoko at (011) 717 2701** for counselling services. Sister Thoko is professional nurse who has been working earlier at CHBAH as a nurse for over 20 years and now is based at DPHRU as a resident trained nurse counsellor and has served in that capacity for over 15 years.

PARTICIPANT

Printed Name…… Signature……....Date……

RESEARCHER:

Printed Name…… Signature…….. Date…….

Appendix 12: Consent Form for audio-recording for Healthcare Providers.

I agree to myself being a participant in the study and I agree that this interview will be audio-recorded.

The goals and methods of the study are clear to me.

I understand that the study will involve an interview and that this interview will be audio-recorded. All the details and purposes of this study have been explained to me. I understand that I have the right to refuse to participate in the study.

I agree to participation in the study on the condition that:

1. I can withdraw from the study at any time voluntarily and that no adverse consequences will follow on withdrawal from the study.

2. I have the right not to answer any or all questions posed in the interviews.

3. The University of the Witwatersrand Human Ethics committee has approved the study protocol and procedures.

4. All results will be treated with the strictest confidentiality.

5. My name will not be published in scientific journals and in the media.

PARTICIPANT

Printed Name…… Signature ……. Date……

RESEARCHER:

Printed Name…… Signature…… Date…….

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

DPHRU
MRC/Wits Developmental Pathways for Health Research Unit

Appendix 13: Screening Questionnaire

Study Title: "An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the case of Soweto, South Africa

Place of screening: Diabetes/endocrine clinic, CHBAH

Screening ID:					

Research assistant Name:		Research Assistant Signature:	
Time		Date:	D D M M Y Y

For Office Use:					
Eligible:	Yes		No		Comment:
Enrolled:	Yes		No		

1. Do you verbally consent to me asking you questions for possible enrolment in a research study?

No		If No, thank him/her for their time and move on.
Yes		If Yes, continue to next question.

2. Are you older than 18 years of age?

No		If No, thank him/her for their time and move on.
Yes		If Yes, continue to next question.

5. Have you been diagnosed with Type II diabetes and currently on treatment?

No		**If No, thank her/him for their time and move on.**
Yes		**If yes, continue to next question.**

6. Have you ever been diagnosed or currently on treatment for HIV?

No		**If No, thank her/him for their time and move on.**
Yes		**If yes, continue to next question.**

7. Which other condition have you ever been diagnosed with or currently on treatment?

b. Hypertensions Yes: _____ No: _____

c. Obesity Yes: _____ No: _____

d. Other _____

Note: The participant must have both diabetes and HIV. (if yes for diabetes and no for HIV, thank him/her for their time and end the screening process. If yes for both diabetes and HIV, continue to screen for other conditions that they may have. If they have/don't have other conditions, recruit the participant and make appointments for the interview).

Appendix 14: Confidentiality Agreement Form

DEVELOPMENTAL PATHWAYS FOR HEALTH RESEARCH UNIT

DEPARTMENT OF PAEDIATRICS, SCHOOL OF CLINICAL MEDICINE, FACULTY OF HEALTH SCIENCES, UNIVERSITY OF THE WITWATERSRAND

Study Title: An anthropological perspective on health and healthcare for patients with both diabetes and HIV: the Case of Soweto, South Africa

CONFIDENTIALITY AGREEMENT

I……. (staff number…….), am a……..

I hereby declare the following:

- I fully understand the patient's right to confidentiality with regards to identity, health status and any other personal information,
- Therefore, I will adhere to the principles of confidentiality as a staff member /research assistant under Developmental Pathways for Health Research Unit at all times.
- I will not remove or tamper with any data files and questionnaires.
- I will not disclose or discuss participant results outside of the research unit.

DATE: _____

SIGNATURE: _____

WITNESS: _____

DATE:_____

SIGNATURE:_____

Appendix 15: Plagiarism Declaration form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Edna Nyanchama Bosire (Student number: 1828411) am a student registered for the degree of Doctor of Philosophy in the academic year 2020.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: _____ Date: 20 August 2020

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