



**UNIVERSITY OF CAPE TOWN**  
IYUNIVESITHI YASEKAPA • UNIVERSITEIT VAN KAAPSTAD

**A qualitative study on the experiences and perspectives of public sector patients in Cape Town in managing the workload of demands of HIV and type 2 diabetes co-morbidity**

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I, **Rangarirai Matima**, Student Number **MZTRAN001** declare that this mini-dissertation is my own work. Each contribution to, and quotation in this mini-dissertation from the work(s) of other people has been attributed, and has been cited and referenced.

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15 February 2016

# **Section 0: PREAMBLE**

## **ABSTRACT**

Health systems' strengthening is essential in South Africa in an era of the convergence of communicable and non-communicable diseases. Whilst TB is ranked first in all-cause mortality, non-communicable diseases which include cerebrovascular disease and diabetes mellitus follow; with HIV/AIDS in fourth place. In the Western Cape, diabetes mellitus and HIV are the top two causes of death accounting for 6.8% and 5.8% respectively (StatsSA, 2015b). As the burden of non-communicable disease continues to increase significantly due to more South Africans presenting these co-morbid conditions, the complexity of managing these chronic conditions has increased. The reorganisation of primary health services to better cater for patients with multiple chronic conditions has become an imperative in South Africa but still in its infancy. However, how chronic patients with multi-morbidities experience the current services and what their perceived needs are in order to enhance the management of their conditions both at point of healthcare and in their daily lives is not widely understood.

Below, is an outline of the three parts presented in this dissertation. Part A is the study protocol, which gives a background of the intersection of communicable and non-communicable diseases in South Africa, focusing on HIV and type two diabetes (hereafter HIV/T2D) co-morbidity. A qualitative design was employed. In-depth interviews were conducted with ten patients living with HIV/T2D co-morbidity and six health workers who interacted with these patients. Ethical considerations such as potential risks and benefits; confidentiality, autonomy and informed consent are also highlighted in the protocol.

Part B is the structured literature review on chronic care in low and middle-income countries (LMICs). Two sub-sections are presented with the first focusing on LMICs excluding South Africa; and the second for South Africa only. Theoretical frameworks, which were applied to managing chronic conditions and empirical studies on HIV/T2D in these LMICs, are reviewed. Reference to the Cumulative Complexity Model (CCM), will also provide an in-depth understanding of the prospects of strengthening the primary healthcare system in South Africa to address chronic conditions more effectively.

Part C is the journal-ready manuscript of the data collected in the qualitative study. It consists of the background, methods, results, discussion and conclusions. Findings describe patients' experiences of the primary healthcare services and the daily challenges of living with and managing HIV and T2D among a sample of ten patients attending a clinic in Cape Town. Health worker perspectives on managing HIV/T2D co-morbidity are also presented. Both patients and healthworkers also shared strategies on how health interventions could be more responsive to HIV/T2D co-morbidity. Hence, further contributions are made in the knowledge base of strengthening chronic conditions. However, further research with different subsets of patients living with not only HIV/T2D but also other co-morbid or multi-morbid conditions is important for improvements in health policy-making in South Africa.

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**ABBREVIATIONS AND ACRONYMS**

ART	anti-retroviral treatment
ARV	anti-retroviral
CDs	communicable diseases
CHWs	community health workers
CNP	clinical nurse practitioner
DoH	Department of Health
HIV	human immuno-deficiency virus
ICCC	Innovative Care for Chronic Conditions
ICDM	Integrated Chronic Disease Management
LMICs	low and middle-income countries
NCDs	non-communicable diseases
NSP	National Strategic Plan
PHC	primary health care
SSA	sub-Saharan Africa
T2D	type II diabetes
WHO	World Health Organisation

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**STRUCTURE OF MINI DISSERTATION**

**Part 0: Preamble**

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# **Part A: Research Protocol**

## **Introduction**

Health systems are made up of the global and national contexts (macro); local health system contexts (meso level); and the individual context (micro level). Interaction with the citizens is reiterated across the three levels such as provision of health services that are responsive to the needs of the local health system context (Gilson, 2012) and inclusion of citizens in policy planning (Green, 2007). Most low and middle-income countries (LMICs) are experiencing the convergence of non-communicable diseases (NCDs) and communicable diseases (CDs) especially due to decreased mortality and the ageing of the HIV infected (Rabkin et al., 2012, Remais et al., 2013).

The South African health system consists of the public and private sectors and is largely inequitable due to the racial, gender, socio-economic and socio-political factors dating back from the apartheid era (Coovadia et al., 2009, McIntyre et al., 2007). The public sector is State-run where in each of the nine provinces; there is free primary healthcare at primary health centre (PHC) level and a referral system for curative services from the PHC to the district, regional and tertiary hospitals (Coovadia et al., 2009). 30% of the doctors in the country provide services to more than 84% of the population who are public patients. The private sector consists of for-profit general hospitals and private specialists. Private sector patients are approximately 16% of the population; with approximately 75% of private patients affiliated to medical aid schemes. Approximately 25% of private patients paying out-of-pocket (Mayosi et al., 2009) are dependent on the public sector for hospital care (Coovadia et al., 2009).

While the epidemiological transition of the convergence of NCDs and CDs has been acknowledged in the South African public health facilities through strategic plans at national level (DoH, 2013) the implementation is less forthcoming towards public sector patients. Interventions are often designed to improve health and evaluated against local or national health system goals, but patients' experiences in managing these chronic conditions on a daily basis is often overlooked. This is evident in the challenges of large chronic programmes where patient outcomes may become sub-optimal (Cornell et al., 2010).

The proposed study intends to investigate patient workload and capacity for managing HIV and type 2 diabetes (hereafter HIV/T2D) co-morbidity in the Western Cape Province, South Africa. The objective is to explore the patient and health provider perspectives related to workload, which accompanies co-morbidity and how this affects the patient's capacity to manage these conditions effectively. This will provide fresh insights into how health systems may be strengthened for chronic care. For this study, HIV/T2D co-morbidity is the selected co-morbid condition due to the increasing T2D prevalence in sub-Saharan Africa (SSA) (Levitt et al., 2011, Oni et al., 2015) as well as the heavy workload needed for optimal T2D (Haque et al., 2005) and HIV management. Shippee's Cumulative Complexity Model (CCM) (Shippee et al., 2012) will be used to guide the investigation. This is a patient-centred framework that emphasises that the imbalance where workload exceeds capacity is the primary driver of disruptions in care, self-care, and outcomes. The model also incorporates treatment and illness burden. There has been no other research in South Africa to date that has investigated this issue.

## **Background**

### **Epidemiology of HIV and T2D**

HIV is classified as an infectious disease where the cells of the immune system are impaired of their functioning or destroyed. This results in various opportunistic infections and there is high risk of advanced to severe symptoms as it progresses to AIDS (WHO, 2015). Though the condition is managed through antiretroviral therapy (ART); non-adherence to treatment and the high prevalence rate have also contributed to the high burden of the disease on the health system in LMICs (Bangsberg et al., 2001, Nachega et al., 2010). The burden of HIV on the health system is further compounded by presentation of one or more chronic diseases, such as cardiovascular disease (Vance et al., 2011), hypertension (Maduagwu et al., 2012) TB and type 2 diabetes (Faurholt-Jepsen et al., 2012). Particularly, women who are receiving ART such as stavudine are at risk of acquiring T2D as the body composition can be altered to having central fat accumulation and peripheral fat wasting (Dave et al., 2011) and other NCDs especially as they grow older (Rabkin et al., 2012).

On the other hand, Type 2 diabetes (T2D) consists of metabolic diseases which result from defects in insulin secretion, insulin action, or both because of raised glucose levels in the blood (hyperglycemia) (American Diabetes Association, 2010) which makes it the most difficult NCD to manage (Kerr et al., 2007). The complexity of treating T2D is unique to each patient and is further aggravated by the severity of the metabolic abnormality which can progress, regress, or stay the same (American Diabetes Association, 2010) leading to a wide array of health complications. These range from

metabolic abnormalities such as chronic kidney disease (Kalra and Agrawal, 2013) and impaired cognitive functioning (Vance et al., 2011).

The prevalence and incidence rates of HIV/T2D co-morbidity are not published aggregate. Globally, there were approximately 35 million people living with HIV; with 24.7 million coming from SSA (WHO, 2014b). Global estimates for the prevalence of diabetes (both Type 1 and Type 2) was 9% in 2014 (WHO, 2014a); with a global increase specifically for type 2 diabetes (Aguiree et al., 2013); (Hall et al., 2011). HIV continues to be ranked as the leading cause of mortality (WHO, 2014b) and diabetes is projected to be the 7th leading cause of death by 2030 (Wild et al., 2004).

In South Africa, the incidence rate of HIV has dropped from 12.2% in 2012 (Shisana and Onoya, 2014) to 11.2% in 2015 (StatsSA, 2015a). However, HIV is still ranked fourth in all-cause mortality, accounting for 4.8% of deaths in 2014 after TB (8.4%), cerebrovascular disease (5.1%) and diabetes mellitus (5.0%). In the Western Cape, diabetes mellitus and HIV are the top two causes of death accounting for 6.8% and 5.8% respectively (StatsSA, 2015b). A cross sectional study in the Western Cape Province on multi-morbidity (HIV, TB, T2D and hypertension) showed the highest prevalence of multi-morbidity in the 36-45 and 46-55 age group; with T2D patients and HIV patients both having hypertension as the major co-morbid condition (Oni et al., 2015).

### **Interventions to manage co-morbidity of HIV and T2D**

The myriad of interactions between HIV and T2D (Oni and Unwin, 2015) as a co-morbid condition reinforce the idea that health systems strengthening must come first (WHO,

2007) to "prevent mortality and morbidity and improve patient outcome" (Kalra and Agrawal, 2013). The Innovative Care for Chronic Conditions (ICCC) model developed by the World Health Organisation (WHO) recommends a systems approach to chronic care where a patient is seen to be in an environment that is made up of family, community, health providers and policy makers. It is these systems that have to support the patient in managing the chronic conditions (WHO, 2002).

In other developed regions such as Australia, HIV care programs have been adapted to include the screening for multi- morbid chronic conditions (Foster et al., 2011). Progress has also been made in Latin America where governments are not only focusing on HIV care programs, but also working towards the establishment of the infrastructure necessary for NCD prevention and management (Crabtree-Ramirez et al., 2014). However, in low-resource settings of SSA, the adaptation of HIV programs for the management of other chronic conditions such as T2D have only been suggested and integration has not yet taken place widely (Rabkin et al., 2012); with the exception of a few regions (Pastakia et al., 2013, Aantjes et al., 2014, Wroe et al., 2015). Though there is improved availability of HIV care in SSA, there is an absence of horizontal care services for NCDs, which gives rise to preventable, premature morbidity and death (Narayan et al., 2014).

In South Africa, improved chronic care is a priority objective of the Department of Health (DoH) in the provision of healthcare services (DoH, 2013). In this regard, the adaptation of the ICCC model is embodied in the three National Strategic Plans (NSPs) formulated by the state's Department of Health: the NSP on HIV, STIs and TB 2007-

2011; NSP on HIV, STIs and TB 2012-2016; and the NSP for the Prevention and Control of NCDs 2013-2017.

The NSP on HIV, STIs and TB 2007-2011 prioritised scaling up of HIV treatment as many people were dying due to lack of universal coverage of anti-retroviral treatment (ART) (DoH, 2006). In addition, the NSP on HIV, STIs and TB 2012-2016 aims to reduce the HIV incidence rate through HIV prevention programmes such as medical male circumcision (MMC) and free condom distribution in all public facilities (DoH, 2011). Although the scale-up of ART consequently led to increasing prevalence of HIV in ageing populations (Rabkin et al., 2012), the two aforementioned NSPs are noteworthy for prolonging of life and reducing mortality.

The NSP for the Prevention and Control of NCDs 2013-2017 aims to strengthen the health system response to NCDs, TB and HIV due to their convergence with other NCDs; which was not the case with the previous NSPs. It also adopts a novel framework, the Integrated Chronic Disease Management (ICDM) model that is modification of the ICCM framework to the South African context. The three strategic objectives of the ICDM are to create a positive policy environment for managing chronic conditions, enhancing and mobilising community resources for chronic conditions and to re-orientate the health service delivery for improved chronic patient outcomes (DoH, 2013); which acknowledge the new wave of multi-morbidity in the South African population. Hence, the weakness of the ICCM model which does not account for multi morbidity (Oni et al., 2014) is addressed by the ICDM.

However, in the ICCC, ICDM and national programs presented above; patients' workload and capacity issues to deal with their co-morbid conditions is not addressed as a consideration. An examination of the feasibility of effectively managing co-morbid conditions can be done using the Cumulative Complexity Model (CCM.) The CCM posits that as the burden of disease and resulting workload increases, the patient capacity to respond to it diminishes. *'Patient workload'* is defined as the patient's daily tasks and responsibilities such as self-monitoring, self-care, treatment/medicines management and clinic visits expected by healthcare providers. *'Patient capacity'* includes the patient's abilities, personal and social resources that they can bring to bear to meet these expectations, for instance physical and mental functioning, socioeconomic resources, social support, literacy, and attitudes/ beliefs. The extent of the burden and its effects on capacity can negatively affect both health care and health outcomes, generating a spiral of deterioration (Shippee et al., 2012).

### **Research question**

What are the experiences and perspectives of public sector patients in Cape Town in managing the workload and demands of multi morbidity (HIV and T2D) and how does this impact on their capacity for effective self-management?

### **Primary objectives:**

- To identify and describe workload/capacity issues and their inter-relationships as associated with multiple morbidities from the patient perspective
- To identify the health worker and middle health managers perspectives on patient workload/capacity issues and their inter-relationships as associated with multiple morbidities

**Secondary objectives:**

- How are demands of treatment, self-care and life in general experienced and prioritised by the patients?
- How do health workers delegate work to patients with HIV and T2D?
- What resources do the patients have which enable performing the delegated work?
- How are poor patient outcomes diagnosed and addressed?
- What programmes are in place to encourage balance between treatment demands and wellbeing of patients with HIV and T2D?
- What platforms exist in which patients can contribute to a positive health care experience and are patients aware of them?

**Study setting**

The study will be conducted at Site B Ubuntu ART clinic (Site B) in Khayelitsha, Cape Town. Ubuntu is the longest standing site in Western Cape to provide ART in the public health sector (Médecins Sans Frontières, 2010) and is thus well established. A study conducted in a similar setting in Khayelitsha reported that 19% of ART patients visiting the clinic have more than one morbidity; among them hypertension, diabetes and TB (Oni et al., 2015). One site will be used as this is a pilot project testing the feasibility of incorporating the CCM in chronic care across all urban public health settings in the country.

## **Methodology**

### **Study design**

A qualitative study design will be used to explore how patients with HIV and T2D manage the workload and capacity issues inherent in chronic conditions and the role played by health workers in ensuring patients achieve effective self-management. Qualitative research is intended to approach the world “out there” and to understand, describe and sometimes explain social phenomena “from the inside perspective” (Flick, 2013). The implication is that qualitative researchers focus on the meaning research participants attach to their day-to-day experiences and aim to understand the participants' context (Taylor et al., 2015).

Data collection methods will be in-depth, one-on-one semi structured responsive interviews with patients and health providers. Semi-structured questionnaires allow flexibility in data collection such as re-formulating questions if the participant does not understand, or encouraging the participant to expand on a particular response through using follow-up questions (Bryman, 2012). Responsive interviewing is defined as the use of main questions, probes and follow up questions; and it promotes partnership between the participant and the researcher throughout the research process as the participant is not treated as an object of research (Rubin and Rubin, 2011). Individual interviews have also been chosen as the preferred method because discussion of lived experiences of managing chronic conditions with patients may be very personal and patients may prefer confidentiality; and due to their varied work commitments and time constraints focus group discussions cannot be done with health workers.

**In-depth interviews with patients**

Ten (10) semi-structured interviews will be done to elicit the personal experiences, perspectives, attitudes and opinions of patients in managing their HIV/T2D co-morbid condition. A semi-structured questionnaire for patients will be drafted in English and used to guide the interview process. As Xhosa, Afrikaans and English are the main languages spoken in Western Cape, with Xhosa being the dominant language in Khayelitsha, a Xhosa speaking translator will accompany the researcher in conducting the interviews. This will allow the translator to assist in the interviewing if the participant cannot fully articulate or comprehend English in some parts of the interview. It is anticipated that each interview will last for an hour or more. The interviews will be audio taped and transcribed later for analysis. Data collection and analysis will be done over six months. This is because there is a high patient turnover at Site B, which will allow data to be collected over a month, and the remaining five months will be reserved for analysis.

**In-depth interviews with health providers**

Six (6) semi-structured in depth interviews, guided by a semi-structured questionnaire for health workers will also be done with health workers working at Site B who provide care for patients with HIV/T2D co-morbidity. These include doctors, nurses, and lay counsellors. These health workers have frequent contact with the patients and they will give their perspectives on the burden of care for patients with multi-morbidities, the challenges experienced by the patients and health providers, what tasks they assign to the patients and how they try to assist in developing patient capacity. Additionally, they will provide insight on the existing policies that influence them and the patients in managing HIV/T2D co-morbidity.

## **Characteristics of study population**

### **Sample selection and size**

As this is a sub-study of an ongoing study that is screening diabetic patients for TB and HIV (Ethics reference number: HREC Ref: 403/2011), HIV/T2D co-morbid patients will therefore be identified from the parent study and approached for consent (see research procedures and data collection methods below). An equal distribution of both sexes for patients (5 men and 5 women) with T2D/ HIV co-morbidity is anticipated; and six health workers working with chronic patients will be interviewed. In the patients group, the inclusion and exclusion criteria will be cross-checked with the patient files and are as follows:

#### *Inclusion criteria*

- Chronic patients who have both HIV and T2D
- Registered at Ubuntu as part of ongoing study
- Initiated ART and also on treatment for T2D
- Both male and females in the 35 - 65 years category
- Capable and willing to provide informed consent
- Capable and willing to be interviewed in simple English

#### *Exclusion criteria*

- Chronic patients who do not HIV and T2D as some of their co-morbidities
- Not registered at Site B
- Below 35 years as this has a higher chance of being type 1 diabetes
- Above 65 years (as it is the least affected age group in this setting)
- A known history of mental illness

- Clinically diagnosed depression

In the health workers group, the inclusion and exclusion criteria will be as follows:

*Inclusion criteria*

- Health managers
- Health workers who work with adult chronic patients
- Capable and willing to communicate in simple English
- Capable and willing to provide informed consent

*Exclusion criteria*

- Health workers who do not work with adult chronic disease patients

## **Recruitment and Enrollment**

The total number of participants to be enrolled for the study is 10 patients and 6 health workers ( $N=16$ ) as this is a pilot project/ sub-study from an ongoing study with a limited budget. To recruit patients, the researcher will liaise with the research medical officer running the parent study to facilitate identification of eligible patients. The researcher will place a note in the patient's file if they meet the eligibility criteria, so that when the patient is consulting with the doctor or the pharmacy, the patient can be referred to the researcher after consultation. The researcher will then explain the study to the potential participant who is free to decline or be part of the study.

To recruit health workers, the researcher will make initial contact with the Site B facility manager who will assist in identifying staff members to be interviewed who fit with the

inclusion and exclusion criteria for health workers. The potential health worker participants will include both allied health workers and clinicians. The researcher will informally approach the identified individual health workers whenever they are free until a total of 6 has been reached.

Convenience sampling will be used for both patient and health worker participants because the researcher will rely on available participants (Babbie, 2010, Ritchie et al., 2013) at the clinic. Purposive sampling will also be done as the researcher will also draw participants from this population based on the eligibility criteria. Patients have the knowledge on the workload and capacity which come with HIV/T2D morbidity. Health workers have the ability to provide much needed information on the assigning of tasks to patients with HIV/T2D co-morbidity.

### **Research Procedures and Data Collection Methods**

In-depth interviews will be conducted by the researcher with each research participant (both patients and health workers) in order to gain more insight on how HIV/T2D and HIV co-morbidity is managed. In this regard, each interview will be face to face and held in confidence in a private room (Ritchie et al., 2013). This will create a conducive atmosphere for the participant to speak freely and openly about sensitive issues. The researcher will explain the purpose of the study to the participant first, and then obtain both verbal and written consent (Appendices 1 and 2). Interviews will be audio taped and each interview will last for an hour; aided by two separate interview guides.

The interview guide for patients will include questions on: demographic data, workload (the demands on patients time and energy, the demands of treatment, self-care, other co-morbidities, access to care for HIV and T2D treatment and family responsibilities) and capacity to cope with the workload (financial and social resources, health literacy and morbidity as it affects ability to function) (Appendix 3). For the health workers, the interview guide will include questions on: how tasks are assigned to patients with multi-morbidity (how often should patients come for follow ups, how often should medication be taken, number of medicines, how many health workers should the patient see), how poor patient outcomes are diagnosed and addressed, programmes in place to maintain the balance between treatment demands and mental well being/social functioning (such as support groups, counselling service, food gardens), and the possibilities on how to change the decision making processes between the patient and health worker to ease patient workload and improve health outcomes (Appendix 4).

Refreshments will be given during the course of the interview to both patient and provider participants. Interviews' transcriptions will be done verbatim and in English. A Xhosa translator will accompany the researcher to every interview and will be of service when the research participant needs clarity in the vernacular. This translator works for the Chronic Disease Institute of Africa (CDIA) and is fully proficient in both Xhosa and English. At the end of the interview, a food voucher to the value of R100 will be given to patient participants only, which will be redeemable at a local store (Shoprite). They will be encouraged to use it for healthy food.

The researcher has sound experience in conducting qualitative interviews as she is a social worker experienced in psychosocial counselling. The researcher has also previously done qualitative research at an undergraduate and honours levels; and has also done courses on qualitative research methods and qualitative data analysis at Master's level. Further training was also done in a one-day workshop with the qualitative research experts who conceptualised the project.

### **Data Safety and Monitoring Plan**

The eliciting of patients' experiential world of HIV/T2D co-morbidity may trigger unintended consequences such as the need for the researcher's sympathy or support. In this regard, the researcher will have a resource list at hand for referrals such as who the participant can go to for counselling, food relief or employment opportunities. Where the researcher is unsure, she will take the contact number for the participant and inquire with the clinic staff on how such an issue can be addressed and then inform the participant of the outcome. An "Early Stop" sheet will be devised which records "refusals" and "unfinished interviews" (Appendix 5). Refusals will be defined as those potential participants who refused to be part of the study after the purpose is explained to them. "Unfinished interviews" will be the participants who would have declined from continuing with an ongoing interview, and those patient participants requiring emergency medical attention. In this regard, the researcher will stop an interview and resume if possible, after health workers have attended to the participant. If the participant is incapacitated to continue, the researcher will record it on the Early Stop sheet. The reason for each early stop case will be noted on the sheet as well.

## **Data Analysis**

Data analysis will start during the data collection phase. This will enable the researcher to identify questions that need refinement in the interview guide and allow richer responses in later interviews on the management of HIV/T2D co-morbidity. Thematic analysis will be applied to the transcripts which is a comparative process of the various accounts that are gathered and finally grouped into themes (Green and Thorogood, 2013, Bazeley, 2013). To elaborate in thematic analysis, the researcher first familiarises him/herself with the data through reading and re-reading the data. Second, codes or labels are assigned to text with similar meaning through a process of re-analysing the data. A codebook will be developed which comprises of six basic components: the code, a brief definition, a full definition, guidelines for when to use the code, guidelines for when not to use the code, and examples (Hennink et al., 2010). This will be beneficial to both the researcher and the supervisor, as it will allow collaboration between the two to validate the codes and refining these codes. A codebook will also assist in the third step of categorisation where, similar codes are merged into categories; with dissimilar codes also standing as individual categories. Finally categories are arranged into themes which reflect the underlying meaning of all the data analysed (Hennink et al., 2010). Throughout all the four stages the researcher will continuously search for new meaning in the data.

In this study, Nvivo computer software will be used to manage data emerging from the transcriptions and analysis of the interviews. To anonymise data, the participants will be assigned numerical identifiers, from participant 1 to 16. In instances where participants disclose names of people during the interview, a pseudonym will be used instead. In

order to minimise risk of having inaudible interviews and deleting interviews, the researcher will do a voice test before each interview and the recording will be copied to the researcher's computer shortly after the interview. To prevent data from being retrieved easily by anyone, the researcher will only share information with her supervisors, use her personal computer and protect it with a password.

## **Ethical considerations**

### **Potential risks and discomforts and minimising risk**

In this study, potential risks and discomforts may be physical and psychological to the patient participants due to them having multi-morbidities. The research participants may experience fatigue due to the fact that before consultation for T2D, patients may be required to not have eaten in the morning so that pre-meal glucose levels can be tested (Koschinsky et al., 1997). Strength can be regained only after eating and in such cases, if a participant is weak he or she will have the interview after consultation and after he or she would have eaten some food. Psychologically, participants may already be overwhelmed with the workload that comes with their multi-morbid conditions. This may result in triggering emotions of helplessness and hamper the research process. In this regard, if the participant becomes very distracted and cannot respond to the researcher, the researcher will find out before the interview whom she can refer patients to if this situation arises. In an emergency case of a research participant needing urgent medical attention a nurse will be informed before each patient interview to be on stand-by.

**Potential benefits**

There are no direct benefits to the research participants but having the opportunity to ‘tell their stories’ and to have someone to listen to them can be therapeutic and satisfying for them. Since findings will be published, it may strengthen the health system in managing multi morbid conditions. To the health services in Khayelitsha, the health workers will be more aware of the issues that concern multi-morbid patients and they will see how they can revise their current clinical practices. This will also allow future patients to receive better healthcare services that will strike a balance between their treatment and general well-being.

**Privacy and Confidentiality**

To maintain confidentiality, transcriptions and reporting research findings will use unique identifiers so that the identity of the research participants remains unknown. All electronic data will be stored in the researcher's personal computer and will only be accessible to the researcher, supervisors and other members of the larger team. Data will be disposed after publication of the study findings.

**Autonomy**

Autonomy implies to respect the rights of the individual. Respecting the rights of the individual requires the researcher to value the worthiness and dignity of the participant from gathering information and to the time of publishing research findings. In this study, the researcher will ensure that the rights of both the patient and health worker participants are not infringed.

**Informed Consent Process**

The researcher will facilitate the process of obtaining informed consent for the patient participants; with the translator assisting in translations from English to Xhosa where necessary. Verbal and written consent will be sought in the private room where interviews will be held, after the purpose of the study is explained to each research participant. Timing for giving consent by the research participant will be before consultation. However, informed consent will be a continual process during the interview as discomfort may arise at any given time; which may warrant an early stop. As the study will consist of adults who have the capacity to make own decisions, there will be no need to consult with family; but if the participant wants to do so, he or she will be free to do so.

Health workers will give their verbal consent in the first contact they have with the researcher; which is during the recruitment and sampling phase. Written consent will be sought in the private room where interviews will be held before the interview starts.

**Capacity to consent**

Not all adults have the capacity to consent as some may suffer from mental illness or severe depression that impairs their ability to make decisions. As such, in the research project, patients who are clinically diagnosed to be mentally ill or severely depressed at the time for data collection will not be included in the study. Only adults who have the

capacity to make personal decisions reasonably will be part of the study; which applies to both patient and health worker participants.

### **Comprehension of information, consent and assent forms**

To determine whether the participant understands the information provided or not, the researcher will ask the participant if he or she has any questions after the researcher states the purpose of the study. If there is a need, clarification will be done by the researcher if the purpose may have been misunderstood; before continuing with the interview process. As research participants will be drawn from the adult population, adult consent forms will be used. The consent form will be translated into Xhosa if need be; for both patient and health worker participants so that the research participant has a very clear understanding of what the research is about and this will assist in the participant making a well-informed decision into continuing with the research or not.

### **Reimbursement for Participation**

A food voucher to the value of R100 will be given to patient research participants only as a token of appreciation.

### **Dissemination**

At the end of the study, research findings will be publicised to suit different audiences because, "the end product of applied qualitative research on public health should be to give public voice or visibility to private or hidden issues, cast new light on puzzling questions, make invisible problems clear and make health problems more understandable" (Ulin et al., 2005). Formal presentations will be done to the Western Cape Department of Health to discuss the applicability of the CCM in multi-morbidity

management; and integrating it with the current ICDM. Presentations will also be done to health workers at the clinic. A mini thesis will be submitted to the university, which after being assessed may be open to others in academia for study purposes. A journal manuscript will also be written and submitted to publicise the findings among other researchers globally.

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## **Part B: Structured Literature Review**

## **Introduction**

A health system consists of building blocks (WHO, 2007) that have health workers, patients and other stakeholders at the centre to influence health care service delivery (De Savigny and Adam, 2009). In chronic disease management, a call for integration of care for communicable diseases (CDs) and non-communicable diseases (NCDs) was proposed through the conceptualisation of the Innovative Care for Chronic Conditions (ICCC) model (WHO, 2002). Theoretical studies that echo health systems strengthening in low and middle-income countries (LMICs) with a shift from vertical disease programs to joint management approaches that account for NCDs and CDs convergence (Marais et al., 2013, Bates et al., 2015); and acknowledge the ICCC model (van Olmen et al., 2012, Oni and Unwin, 2015) have been widely publicised. However, few empirical studies have reported on how health systems of different LMICs have fully integrated chronic diseases' health services to their current clinical practices (Amuna and Zotor, 2008, Pastakia et al., 2013, Aantjes et al., 2014, Wroe et al., 2015). Instead, most report on co-morbidity in non-communicable diseases (Bhojani et al., 2013), communicable diseases (Rich et al., 2012, Legido-Quigley et al., 2013) or a combination of a non-communicable disease and a communicable disease (Kirui et al., 2012).

As hypotheses (hereafter, theory) and conceptual diagrams (hereafter, theoretical frameworks) can be formulated from research findings and be used to further shape future research and a country's healthcare interventions or programmes (hereafter, healthcare models) (Eccles et al., 2005, Campbell et al., 2007); the aforementioned empirical studies may or may not have been shaped by certain theory or theoretical

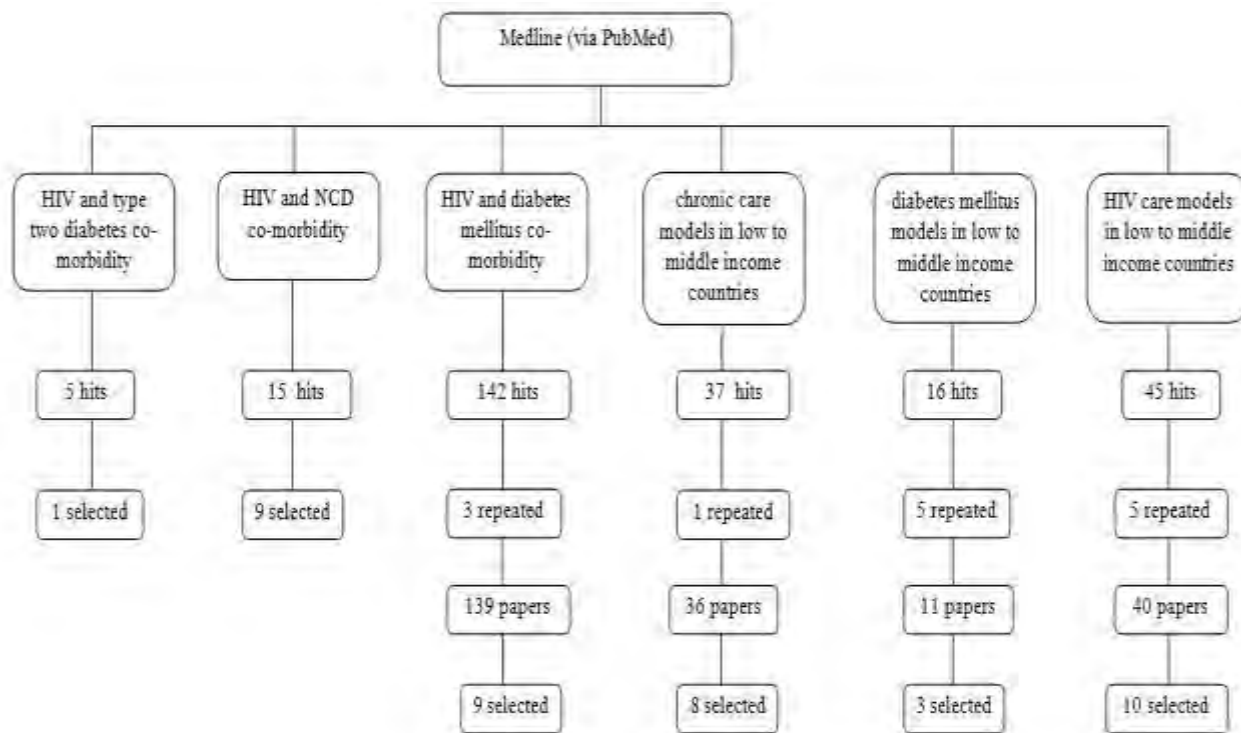
frameworks. A further analysis of the use and non-use of theory and theoretical frameworks is imperative to understand how healthcare models for chronic diseases in LMICs may be more responsive to local contexts. In this scoping review, with reference to HIV and type two diabetes (T2D) services the organisation and management of chronic services including patients' experiences in the organisation of these chronic services for LMICs will be described.

HIV and type two diabetes co-morbidity (hereafter HIV/T2D) will be used as an example of the convergence of CDs and NCDs due to the complexities which come with management of each condition (Goedecke et al., 2013, Haque et al., 2005). LMICs excluding South Africa and a separate section for South Africa will be presented because South Africa's chronic care system is the focus of the study. Although still in its infancy, chronic care services in the South African health system have been redesigned to integrate chronic care for NCDs and CDs at primary healthcare (PHC) level. The ICCC and the Integrated Chronic Disease Management (ICDM) frameworks that conceptualised this reorganisation will provide the basis of interrogating this phenomenon further. However, across LMICs including South Africa, patients' experiences which entail workload and capacity issues are overlooked amidst the organisation and management of chronic services; which a theoretical framework identified as the Cumulative Complexity Model (CCM) (Shippee et al., 2012) acknowledges.

### **Literature search strategy**

Published literature was searched on Medline via PubMed as depicted in the typology below (Fig B1). Six key search terms were "HIV and type two diabetes co-morbidity", "HIV and NCD co-morbidity", "HIV and diabetes mellitus co-morbidity", "chronic care models in low to middle income countries", "diabetes mellitus models in low to middle income countries" and "HIV care models in low to middle income countries". Articles included for the review had to have an abstract, published in the last ten years, human species and in English. Repeated papers from the previous search term were removed before reviewing literature on the following search term.

A total of 246 papers were initially identified and 40 papers were finally selected. Excluded literature was on papers that just gave a description of risk factors for chronic conditions or were mainly epidemiologic in nature, papers which did not describe either HIV or T2D as one of chronic conditions under investigation, papers which were not focused on LMICs; and economic evaluations. The search was refined further by reviewing references from key papers; reviewing relevant methodological papers on health systems and reviewing publications by the Department of Health on chronic services, with special focus on HIV/T2D.



*Fig B1: PubMed search strategy*

## **Models of Chronic Care in LMICs and South Africa**

### **Definition of chronic conditions and co-morbidity**

The term "chronic" has numerous definitions which include, a long-term health related state, illness which lasts for three to six months or longer (Porta et al., 2014); or which may result in permanent residual disability (Modeste and Tamayose, 2004). A further description of chronic conditions encompasses non-communicable conditions, persistent communicable conditions, long-term mental disorders and ongoing physical impairments (WHO, 2002). Co-morbidity is defined as a disease that coexists in a study participant in addition to the index condition that is the subject of the study (Porta et al., 2014). However, as the focus of the review is on healthcare provision of chronic conditions,

using HIV/T2D as an example, the co-existence of these two conditions will not be viewed as one condition more central than the other (Boyd and Fortin, 2010).

### **Chronic care in low to middle income countries**

The first category of models of chronic care identified in LMICs describe the organisation and management of health services within health facilities and they all had the weakness of not acknowledging patient workload and capacity in managing these morbidities. The Indian AIDS Initiative, Avahan, between the government and an international agency; was a population level intervention of HIV prevention strategies across six states in India to reduce HIV transmission especially among pregnant women. Programme evaluation after five years showed that the rate of new infections across the six states benefitting from the programme had dropped (Ng et al., 2011). Although health outcomes were improved, the interactions were mainly at macro (national) and meso (local health system) levels of the health system and the experiences at the micro level (individual), in this intervention are unknown. In Kenya, the organisation and management of chronic services is done vertically as noted in a study on HIV/T2D co-morbidity in rural Western Kenya. The descriptive study provided data on HIV/T2D co-morbidity and also TB/T2D co-morbidity (Kirui et al., 2012). Similarly, with the Indian initiative, how patients experience living with co-morbidities on a daily basis was unreported.

A second category of models of chronic care identified in LMICs were patient-centred. Patient-centred interventions focused on how involvement of the home environment can influence health outcomes and highlighted on the patients' workload and capacity issues

that come with chronic care; but missed the interaction of patients with the organisation and management of services at health facility level. In India, empirical studies (Weaver et al., 2015, Bhojani et al., 2013) investigated patients' experiences for living with T2D; and T2D and hypertension respectively. These studies presented evidence on the need to employ biocultural frameworks in improving health outcomes for women living with T2D and improving chronic care for the urban poor especially in government facilities. However, the biocultural frameworks referred solely to social pathways as the only form of workload; yet issues such as physical and mental functioning, socioeconomic resources and literacy can also influence health outcomes.

The use of patient narratives to understand how people experience and understand T2D across income groups in Delhi, brings to the fore issues of self-care, access and utilisation of healthcare services in this region. Findings revealed that lower-income T2D patients not only had higher rates of depression compared to higher-income T2D patients, but were more likely to delay healthcare and therefore develop diabetes complications due to poor access to medical care (Mendenhall et al., 2012). A balance was hence, maintained on how socio-economic status and how the organisation of chronic care services at PHC level influenced self-management of T2D. However, depression was the only outcome of measure and the plurality and complexity of health outcomes that come with living with T2D is not validated.

Conclusions drawn from systematic reviews on HIV programmes in LMICs indicated redressing of healthcare provision at facility level. The first review was on HIV

programmes for vulnerable groups such as female sex workers which recommended interventions that not only focused on preventive care for HIV and STIs but other women's health issues such as screening for cancer and gender based violence (Dhana et al., 2014). Another review was on the integration of TB and HIV services where referrals within health facilities was key to optimal health outcomes for patients with HIV/TB co-morbidity (Legido-Quigley et al., 2013). HIV voluntary counselling and testing (VCT) programmes also revealed that different modalities of VCT were implemented in LMICs, which was not only facility based (clinic testing and counselling) but extended to the micro level of the health system (home-based testing and counselling) resulting in reduction in risky sexual behaviours (Fonner et al., 2012). However, in all these reviews patients' workload and capacity to engage in these interventions were unexplored.

A third category of chronic care models included both organisation and management of services at health facility level and were patient-centred but the models had different shortcomings to address holistically patients' capacity to manage their chronic conditions. In Rwanda, a partnership of NGOs and Ministry of Health was pivotal in providing community based ART programmes in rural health centres that were largely driven by community health workers (CHWs). In this study, HIV patients were supported through free provision of ART, TB screening and treatment; nutritional and social support; and transport allowances for clinic visits (Rich et al., 2012) which resulted in a high retention rate of adults enrolled in the ART programme. In Kenya, diabetes and hypertension care in rural areas entailed in one programme, concerted efforts between the private sector and Ministry of Health to offer home based care programmes for HIV and

NCDs; and in another programme, community based screening. In the former, HIV counsellors were equipped to undertake door-to door diabetes and hypertension screening; whilst in the latter, the district hospital staff did screening at the health facility and provided treatment for people diagnosed with these two conditions (Pastakia et al., 2013). In these two experiences, goals were set at meso level of the health system, and the intervention was successful; but how the villagers experienced these interventions was unreported.

A systematic review indicated how collaboration between private partnerships; and between private partnerships and governments of various LMICs were successful in implementing various T2D interventions. Some interventions appealed to improving health workers' provision of care for T2D through further training; and others were patient centred programs such as support and education groups relevant to certain settings (rural or urban) and people of similar age-groups and socioeconomic status (Esterson et al., 2014). Whilst health education and literacy have been seen to be important especially in T2D care, the patients' abilities to fully understand their engagement in the intervention are unknown.

In the Philippines, the adapted diabetes self-management education and support (DSME/S) framework was designed for diabetes reorganisation at PHC level. The roles of health workers were enlarged (Dubois and Singh, 2009); to improve chronic care through the support programmes to patients at the PHC and at home. This entailed health workers engaging both stable and unstable patients in self-management health education;

and offering screening and support services for diabetes (Ku and Kegels, 2014). Though this experiment went beyond testing organisation and management of health services at facility by giving patients a platform to share their experiences of chronic management, there was no control group to test the effectiveness of the model. The "context-adapted chronic care model-based service delivery model" (Ku and Kegels, 2015) conceptualised PHC re-organisation and "assisted" self-management of both stable and unstable chronic patients in low income countries but there are no clear linkages in the model of clinical management support and system support and strengthening across the three levels within the health system.

A decentralised model in the provision of ART in some LMICs was noted where treatment could be initiated and maintained at any point of care (hospital and PHC) and at home. However, partial decentralisation was not seen as ideal as it sometimes contributed to loss to follow up (Kredo et al., 2013). Further insight is also needed on knowing how patients experienced the workload and capacity issues that contributed to variations in loss to follow up.

Conceptual work also shows that reorganisation of chronic services was underway in the Pacific. A strategic framework consisting of four phases was proposed as a response to the increasing chronic conditions in the region (Robinson and Hort, 2012). Also, through expanding coverage of "Vital Registration" to account for cause of death statistics for NCDs, health information systems were to be strengthened to provide statistical data of

NCDs (Amuna and Zotor, 2008). This transition also reflects little understanding on how people experience health services reorganisation.

A unique case of Zambia (Aantjes et al., 2014) reveals that general understanding of patients' workload and capacity issues may have been understood by inclusion of the patients in policy formulation. Agenda setting which entails identifying a problem and prioritising it (Buse et al., 2012) was undertaken, to address the convergence of CDs and NCDs in the Zambian health system; and interaction of stakeholders was at the meso and micro levels of the health system. These stakeholders included the government at national and PHC level; non-governmental organisations (NGOs) which largely drive CD and NCD services at community level through programmes such as Community and Home Based Care and patients.

### **Chronic care in South Africa**

In South Africa, chronic care is guided by two theoretical frameworks- the Innovative Care for Chronic Conditions (ICCC) model and the Integrated Chronic Disease Management (ICDM) framework (DoH, 2013). The ICCC model is built on the previously widely used Chronic Care Model; which largely gave a clinical perspective in managing chronic conditions (Wagner et al., 1996, Wagner, 1997). The ICCC hypothesises that optimal health outcomes for chronic conditions are realised by people within an enabling health system environment. Role players are patients and families, health care teams, and community supporters who form functional interrelationships within the health facility, community and policy environment. Each role player is seen to

be informed, motivated and prepared to manage chronic conditions; and communication and collaboration are maintained among all levels of care (WHO, 2002).

The ICCC further posits that current health systems prioritise acute care instead of chronic care that creates challenges that cut across micro, meso and macro levels of the health system. To address the limitations envisaged in the micro, meso and macro levels of the health system; the ICCC model has, six guiding principles which are: evidence based decision making by health workers, focus on public health as opposed to individual care, implementation of chronic conditions prevention strategies, offering quality healthcare services, integration of chronic conditions services and adaptability to changes in burden of disease. These innovations may only be exhibited by decision-makers taking strategies which support a paradigm shift, managing the political environment, building integrated health care, aligning sectoral policies for health; using health care personnel more effectively; patient-centred and family centred care; supporting patients in their communities and emphasising prevention (WHO, 2002).

The ICCC has been adapted to fit the South African context through formulation of the Integrated Chronic Disease Management (ICDM) framework which is aligned with objectives of the national strategic plans on the organisation and management of NCD and CD health services (DoH, 2011, DoH, 2013). The ICDM is a model of managed care for both communicable and non-communicable diseases that promotes optimal clinical outcomes for people living with single to multi-morbid conditions at primary healthcare (PHC) level through four phases of PHC re-organisation, clinical management support,

"assisted" self-management and system support and strengthening. Pilot projects were set up in 42 selected PHCs in three provinces (North West, Mpumalanga and Gauteng) in 2011 and are suggested to be the model of care for NCDs.

The components of PHC re-organisation address operational efficiency such as improving patient process flow and integrated care for patients with CDs and NCDs. From the search strategy used, no empirical studies could be traced which reported on the integrated care for NCDs and CDs within the PHCs in South Africa except for two studies that gave prevalence data on both CDs and NCDs (Mash et al., 2012, Oni et al., 2015). The lack of data on the convergence of CDs and NCDs may be ascribed to the reorganisation still in its' infancy and how separate national strategic plans on the organisation and management of NCD and CD health services (DoH, 2011, DoH, 2013) are translated at the point of care.

At the level of the health workers, devolution of authority and responsibility as a form of decentralisation (Bossert, 1998) is evident as the PHC operational manager leads and controls change in service delivery within the PHC and the community. From the nurses and medical practitioners job descriptions, role substitution and role delegation is evident (Dubois and Singh, 2009) as PHCs are largely nurse-driven with medical practitioners only meant to consult referred patients and mentor professional nurses. Clinic committees stand as PHC representatives for the community leaders and community members; but they face challenges as promoters of community participation in health services mainly due to an unclear mandate (Haricharan, 2012).

Clinical management support are individuals who foster teamwork and collaboration among health workers at PHC, district and sub-district levels to ensure quality of care and realisation of optimal clinical outcomes for chronic conditions. The ICDM champion is a key figure among clinical management support staff as he or she is the trainer of clinical practice guidelines (PC101) for chronic conditions. Stable chronic patients benefit from "assisted" self-management driven by ward-based outreach team of community health workers (CHWs). Health workers provide health promotion services at chronic patients' homes and at the PHCs. This may be alluded to successes such as CHW's effective management of hypertension and T2D (Ndou et al., 2013), HIV/ TB and for other priority diseases in South Africa; but challenges which come with change in organisational culture have to be addressed first (Schneider et al., 2015). Services will also be extended at population level with adolescents by school health teams.

System support and strengthening for the PHC will consist of human resources, health information, medicine supply, equipment, leadership and advocacy which are the other five building blocks of action viewed to strengthen health systems (Gilson, 2012). Innovations in health information systems have already been identified where a simple offline electronic version of the paper register is used for monitoring antiretroviral therapy in high HIV burden settings (Osler et al., 2014).

### **Towards a working framework to understand patient workload and capacity: the Cumulative Complexity Model**

The ICCC model has been subject to scrutiny for not accounting for patient workload and capacity that come with multi morbidity and modifications to the framework have been proposed (Oni et al., 2014). In addition, in the ICDM, the emphasis is on job descriptions, networking, and support services but very little is known about how patients experience this reorganisation. The CCM becomes unique in that it was developed for health workers to assess patients' experiences in living with chronic conditions and encourage health interventions that are responsive to the complexities of managing these chronic conditions (Shippee et al., 2012). Patients are viewed to have workload of demands that come with living with co-morbid conditions. These include patient and non-patient tasks and responsibilities faced daily such as self-care, job and family. Their capacity to meet this workload of demands is determined by a number of factors such as physical or mental functioning, socioeconomic resources, social support, literacy, and attitudes or beliefs. The interaction of workload and capacity affect patients' access and utilisation of healthcare services and self-care; which influence health outcomes. Health outcomes are also influenced by the burden of treatment and burden of illness that continue to be feedback loops.

### **Conclusion**

The literature reviewed reflected that chronic care in LMICs is based on service delivery plans that may or may not be guided by specific theory or theoretical frameworks. Three forms of models for chronic care services identified for LMICs focused on the organisation and management of health services at health facility level; patient-centred

interventions; and chronic care services that include both organisation and management of services at health facility level and the patients' experiences. These models were centralised to certain geographical locations, with some being the standard of practice across similar settings in the same country.

In South Africa, as the integration of chronic conditions in the health system is still in early stages, scant data were available to reflect patients' experiences in the reorganisation. From the shortcomings of the chronic care models for LMICs including South Africa in incorporating patient experiences, measurement of workload and demands of multi morbidity (HIV and T2D) using the Cumulative Complex Model was identified as a potential tool to guide development of interventions to improve care in the context of multi morbidity.

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# **Part C: Journal Article**

**Selected Journal: BMC - Health Research Policy and Systems**

**A qualitative study on the experiences and perspectives of public sector patients in Cape Town in managing the workload of demands of HIV and type 2 diabetes co-morbidity<sup>1</sup>**

**Abstract**

**Background:** The South African health system is experiencing a convergence of communicable and non-communicable diseases. As the incidence rates of co-morbidity continue to rise, the Integrated Chronic Disease Model (ICDM) which is a modification of the Innovative Care for Chronic Conditions (ICCC) to fit the South African health system; proposes health services that are oriented towards integration of chronic services. Little is known about how chronic patients with multi-morbidities currently experience the (re)-organisation of health services and what their perceived needs are in order to enhance the management of their conditions both at point of healthcare and in their daily lives.

**Methods:** Qualitative methods were applied in the study. Individual interviews were done with a purposive sample of 10 adult patients who have HIV and type two diabetes co-morbidity (HIV/T2D) and 6 health workers who provided health services to this group of patients at a primary health care facility in Cape Town. Interviews were recorded and transcribed. Analysis was aided by the NVivo computer program and thematic content analysis methods were applied.

**Results:** Shippe's Cumulative Complexity Model (CCM) was used as a testing tool to explore patient workload and capacity to manage chronic conditions whose linkages are

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not clear in the ICCC model and ICDM. Despite the burden of illness and burden of treatment, which come with living with multi-morbidities, patients were well adjusted with self-care. However, health workers' experiences from practice indicated that patients HIV/T2D management varied as not all patients were well-adjusted. Both patients and health workers also shared strategies, which were supportive and less enabling of integrated care for chronic conditions.

**Conclusion:** The CCM, largely is a suitable framework to explore multi-morbidity as it captures most of the themes around "patient workload" and "patient capacity". In this setting, the meaning attached to the themes under these two concepts suggested that what may be classified as patient workload or capacity in the CCM; would not be viewed by other participants as patient workload or capacity. More country examples are necessary to show the effectiveness of integrated chronic care health services in improving patient workload and patient capacity that comes with living with multi-morbidity. This would entail not only reorganisation of health services at the health facility; but taking into account patients' lived experiences and feedback in this reorganisation.

**Keywords:** integration, Type two diabetes, HIV, multi-morbidity, workload of demands, capacity,

## **Background**

An ideal health system is built on six blocks which include: governance, information systems, finance, service delivery, human resources and; medicines and technologies [1]. The ultimate goals include being responsive to the health needs of the people, promoting fairness in distribution of health services, protection of families from catastrophic health

expenditure and respecting people. Health systems in low and middle-income countries (LMICs) are burdened by the increasing prevalence of multi-morbidity, with growing numbers of people living with both communicable diseases (CDs) such as HIV and TB and non-communicable diseases (NCDs), such as hypertension and diabetes. In response to the need for strengthening health systems for chronic care, the Innovative Care for Chronic Conditions (ICCC) model was conceptualised by WHO in 2002, which emphasises the importance of offering quality healthcare services, the integration of chronic conditions services and adaptability to changes in burden of disease [2].

Literature on LMICs gives evidence of repeated calls for a shift from vertical disease programs to joint management in order to reduce the burden of CDs and NCDs on both the individual patient and the health system [3-8]. In South Africa (SA), the integration of CDs and NCDs is guided by the Integrated Chronic Disease Management (ICDM) framework [9] which is an adaptation of the ICCC model to the local context. The ICDM is aligned with the objectives of the national strategic plan on the organisation and management of health services for CDs and NCDs [9, 10]. It is argued that optimal clinical outcomes for people living with single or multi-morbid conditions can be achieved through primary healthcare (PHC) re-organisation involving improved clinical management support, clinical practice guidelines for integrated care and the use of community health workers to assist patients with self-management (ICDM Manual). However just as in Zambia, Malawi and the Pacific, [3, 11, 12] PHC re-organisation in South Africa is still in its initial stages and limited empirical work exists on the convergence of the CD and NCD epidemics.

HIV and type two diabetes (T2D) co-morbidity is an illustration of CD/NCD convergence in the South African health system due to the complexities faced in effective management of the conditions by both health workers and patients [13] [14, 15] and in the Western Cape, are ranked to be the top two causes of mortality [16]. Only two local studies have reported on the prevalence of HIV/T2D co-morbidity. A cross sectional study in the Western Cape Province on multi-morbidity (HIV, TB, T2D and hypertension) showed the highest prevalence of multi- morbidity in the 36-45 and 46-55 age group; with T2D patients and HIV patients both having hypertension as the major co-morbid condition [17]. Nationally, Mash et al (2012) reported on morbidity in primary healthcare across all age groups and reflected that HIV/AIDS and T2D were both ranked third for reasons of primary care diagnoses [18].

However, healthcare interventions or programmes (hereafter, identified as models for chronic care) proposed in LMICs fail to address the organisation and management of HIV/T2D services in totality. Health facility oriented models [19, 20], which are conceptualised and implemented within health facilities, do not take into adequate consideration patients' lived experiences in the organisation of chronic healthcare services. Patient-centred interventions [21-23], which focus on the how the patient's home environment influences self- management of chronic conditions, miss the interaction of patients with the organisation and management of services at health facility level. Health facility-patient centred models [24-28], which are meant to be a collaboration of health workers and patients in managing chronic conditions, have limitations in fully addressing patients' capacity to manage their chronic conditions.

These factors are largely a lack of feedback from patients on how they experienced these interventions such as patients' capacity to understand fully their involvement or non-involvement in the intervention and reasons for loss to follow up.

The Cumulative Complex Model (CCM) [29] attempts to address these constraints as it is a "patient-centered model intended to guide improvements in the analysis and evaluation of patient complexity and promote innovative care delivery for complex patients". Patients are viewed as having a workload of demands that come with living with co-morbid conditions. These include daily tasks and responsibilities related to self-care, job and family. Their capacity to meet the workload of demands is determined by their physical or mental functioning, socioeconomic resources, access to social support, level of literacy, and attitudes or beliefs. The interaction of workload and capacity, affect patients' access and utilisation of healthcare services and ability for self-care; which ultimately influence health outcomes. Health outcomes are also influenced by the burden of treatment and burden of illness that continue to be feedback loops (See Figure C1 under Results).

## **Methods**

The purpose of this study was to explore the experiences and perspectives of public sector patients in Cape Town in managing the workload of demands of HIV /T2D co-morbidity; and how this influenced their capacity for effective self-management. The study was conducted in Khayelitsha, a peri-urban, largely informal township of predominantly black South Africans in Cape Town. It is one of the eight sub-districts in

the Cape Metropole and although 62% of the labour force is employed, 74% of household income is less than R3 200 per month. 45% of households live in formal houses; 62% of households have access to piped water in their yard and 81% of households use electricity for lighting [30].

Patient participants were drawn from Ubuntu Clinic and the general clinic, which provide HIV and TB services; and primary health care for all other diseases such as T2D management, respectively. These two clinics are situated at Site B PHC facility. Health providers were drawn from Ubuntu Clinic and the general clinic. At Ubuntu Clinic, the prevalence rates of hypertension, HIV, T2D and TB, indicate that HIV and T2D are ranked second and third respectively with respect to co-morbid chronic conditions. Also, HIV accounts for 38.4% and T2D 18.3% of the total adult cases. [17].

Ethical approval for the study was granted by the Western Cape Department of Health and the Human Research Ethics Committee of the University of Cape Town (HREC Ref: 314/2015). A qualitative, cross sectional study design was used. For participants who verbally accepted to be part of the study, written consent was obtained (Appendices 1 and 2). Convenience sampling was used for both patient and health worker participants because the researcher had to rely on available participants at the health facility. Purposive sampling was also done as the researcher drew participants from the health facility based on the eligibility criteria.

Inclusion criteria for patients included: having both HIV and T2D co-morbidity; having initiated antiretroviral therapy (ART) and also be on treatment for T2D; be between 35 - 65 years old; capable and willing to provide informed consent, and be interviewed in

simple English. As Xhosa is the dominant language in Khayelitsha, a translator was present in each patient interview to provide translation assistance if the research participant needed to ask or answer questions in the vernacular. Equal numbers of male and female patients were recruited. Six health workers were also recruited in the study which included two doctors, two clinical nurse practitioners (CNPs) and two HIV counsellors. All health workers were from the general clinic, except one CNP from Ubuntu clinic. The inclusion criteria included had to be working with adult chronic patients; willing to communicate in simple English and capable and willing to provide informed consent.

In-depth, one-on-one, semi structured interviews were conducted with ten patients to elicit lived experiences of managing chronic co-morbidities; and six health workers to elicit descriptions of the role they played in ensuring effective self-management among their patients. Patients were asked what they had to do to care for their health, the challenges they faced in meeting these demands and the factors that helped them. Health workers were asked how they provided care for HIV/T2D patients, the challenges experienced in this interaction and how they assisted in developing patient capacity. Interviews were guided by two separate semi-structured questionnaires for patients and health workers (Appendices 3 and 4). The questionnaires were based on the themes of the CCM; together with two other empirical studies that explored the concepts of "patient workload" and "patient capacity" (May et al 2014; Eton et al, 2015). Each interview was face to face, held in confidence in a private room, audio taped and lasted for approximately an hour.

Demographic data were recorded for all participants at the beginning of the interview (Table 1). Interviews' transcriptions were done verbatim and in English. At the end of each interview, a food voucher to the value of R100 was given to patient participants as a token of appreciation. Data analysis commenced during the data collection phase which enabled further probing of certain issues based on previous participants' responses. Thematic content analysis was applied to the transcripts [31, 32]. This involves the researcher becoming familiar with the data through reading the data, reflecting, coding and refining codes. Data from participants are then described and compared. Lastly, data are extracted and explained by agreeing with, defending or extending existing literature. A codebook was also developed [33] and Nvivo computer software was used to manage the data.

**Table 1: Demographic data of participants (N = 16)**

	Patient profiles (n=10)	Health worker profiles (n=6)
<b>Age</b> Median (range)	43 (39-62)	41 (27-60)
<b>Gender</b> Female Male	5 5	5 1
<b>Highest education level</b> Primary school (Grades 1 - 7) Secondary School (Grades 8 - 12) Tertiary qualifications: Diploma Degree §Masters	1 8 1	1 1 2 2
<b>°Employment status</b> Unemployed Employed Retired	5 4 1	6
<b>°Housing</b> Type: * Formal * Informal  Ownership: Self Relative  Water supply: Self Communal  Energy supply: Electricity °Other	3 7  5 5  6 4  8 2	

<b>■Number of patients who specified their household members</b>		
Partner	7	
Child(ren): Minors ( 0 -18years)	3	
Adults (>18years)	3	
Grandchildren (0-18years)	3	
Relatives(>18years)	2	
Sibling (>18years)	1	
<b>■Other self-reported co-morbidities</b>		
Hypertension	6	
<b>■Years on treatment</b> (Median, range)		
T2D	7 (3-23)	
HIV	8.5 (0.5-16)	
<b>*Position held in health service</b>		
HIV Counsellors		2
Clinical Nurse Practitioners		2
Medical Officers (Doctor)		2
<b>*Ratio of years of experience</b>		
HIV Counsellors		0.33:3
Clinical Nurse Practitioners		3:20
Medical Officers (Doctors)		6:30

§ongoing or completed

□ all employed patients jobs were classified as unskilled labour and all health workers were skilled labour

■ patient data only

◆ Formal housing is made of permanent material such as bricks

● Informal housing is made of temporary material such as steel sheets and plastic

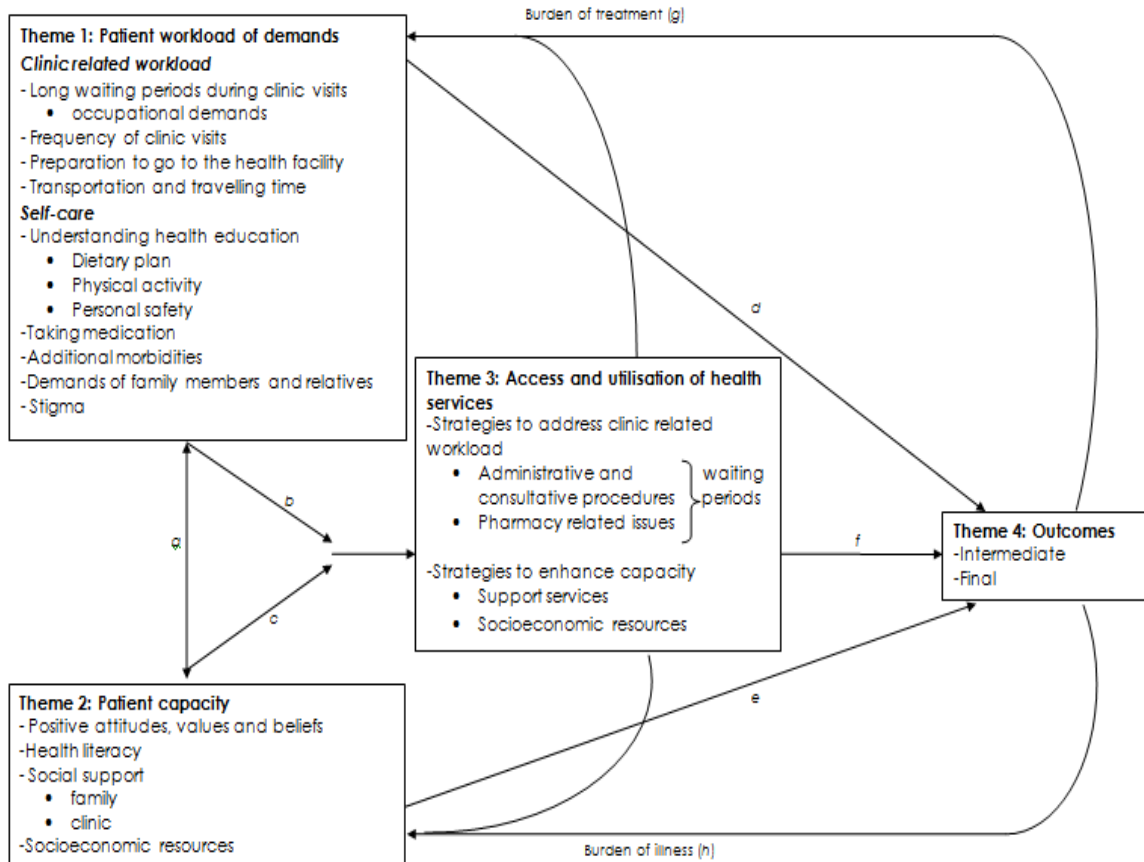
▮ solar, wood, paraffin

★ health worker data only

## Results

The CCM as applied to HIV/T2D co-morbidity in this study is presented below (Fig C1); and findings of each theme are described below. All themes are tabulated (Tables 4- 8) with an example drawn from the participants' interviews given. Further explanation of these tabulated themes is given in-text. (Whilst submission to a journal requires tables and figures as separate files, for the purposes of the thesis and to improve readability, I have inserted these in-text).

**Figure C1: Cumulative Complexity Model for HIV/T2D co-morbidity**



## Theme 1: Perceived patient workload

### 1.1 Health care

Patient and health worker participants reported that at the time of interview, there was no integration of care for patients with HIV/T2D multi-morbidity and that the administrative and consultative functions for HIV/T2D clinic visits were done in two separate clinics on separate days. Of importance, all T2D patients had “club day visits” whilst HIV patients were stratified into two distinct groups – “club members” and “non-club members” as presented in Table 2. In PHC, the club system was devised for patients with a chronic disease who are considered stable that aims to streamline their clinic visits and improve waiting times, disease management, and adherence.

Table 2: Comparison of scheduled clinic visits for T2D and HIV

	Diabetes Clinic	HIV Clinic		
<b>Type of affiliation</b>	Club patients	Antiretroviral (ARV) adherence club patients	Non-ARV adherence club patients	
<b>Enrolment/ Membership</b>	Open	Fixed	Open	
<b>Eligibility criteria</b>	All patients with type two diabetes (T2D)	Antiretroviral treatment (ART) for more than a year -Virally suppressed	-Antiretroviral treatment (ART) for less than a year -Not virally suppressed - Defaulters from ARV adherence club -Eligible members on waiting list	
<b>Types of visits and consultative procedures</b>	<p><b><u>Non- club day</u></b> Collection of medication at the pharmacy</p> <p><b><u>Club day</u></b> <b>Waiting in the club room for:</b></p> <p>Matching of patient appointment cards to folders by the administrative clerk ↓ Patients' triage processes (urine test; weight and height; blood pressure checks PLUS blood sugar test) ↓ consultation with a clinic nurse practitioner (CNP) -prescription and proceed to pharmacy if all the tests' results were optimal ↓ <b>referral to doctor for:</b> -raised blood sugar level (&gt;12 or 15mmol/l ) and proceed to Trauma unit to be placed on a drip - raised blood pressure</p> <p><b>referral to other health professionals such as:</b> health educators/ dieticians/ social worker/ psychiatrist : for further guidance, support and treatment -proceed to pharmacy</p>	<p><b><u>Medication visit</u></b> <b>Collection of medication at the club room</b></p>	<p><b><u>Health check visit</u></b> <b>Observations at the club room</b></p>	<p><b><u>Medication and health check visit</u></b> <b>Queuing in different waiting areas for:</b></p> <p>Matching of patient appointment cards to folders by the administrative clerk (reception) ↓ Patients' triage processes (urine test; weight and height; and blood pressure checks) ↓ consultation with a clinic nurse practitioner (CNP) -prescription and proceed to pharmacy ↓ <b>referral to doctor for:</b> persistent side effects and proceed to pharmacy ↓ <b>referral to other health professionals such as:</b> HIV counsellors - for further guidance and support Dieticians: nutrition plans.</p>

At the HIV Clinic, the adherence club patients have fixed membership, meaning each club consists of the same patients who are approximately 35 per club, and when a patient is lost to follow-up, the doctor or CNP assigns another patient who is not in an adherence club yet to fill the position. However, the diabetes club system operated on an open membership where patients had to show up on a club day based on the appointment that the doctor assigned. This often resulted in overcrowding in the club room and an unbalanced allocation of patients for each club day:

*"There are a couple of issues with the booking system...some Monday's we'll get two hundred people and then on some Mondays we get eighty people in the club. And the reason this happens is because those giving out the dates to come back don't have access to the numbers that are coming back on that day."- Participant H2, doctor*

The stratification of HIV patients into "ARV adherence club members" and "non-club members" was further advantageous for adherence club members than non-club members as viewed by both health workers and patients. With this arrangement, club members avoided queuing for their folders and for the pharmacy as they went directly to the club room on their scheduled days. At the HIV adherence club, patients collected their medication and/or consulted with a clinical nurse practitioner (CNP), who would have pre-prepared access to each patient's folder. According to health workers, because of these merits there were many patients who wanted to gain access to the club, but membership of the club was strictly controlled: patients are only eligible if they have been on ART for more than a year and are virally suppressed.

The separate HIV/T2D clinics necessitated patients to routinely attend both the HIV and T2D clinics once a month and more frequently depending on whether either disease was not optimally managed, if adherence levels were low, or if treatment was recently initiated (Table 3).

*Table 3: Self-reported waiting periods and frequency of visits at T2D and HIV clinics by patients*

	Diabetes Clinic	HIV Clinic
<b>Waiting times</b>	<p><b>Whole consultation: +/- 7 hours (n=10)</b></p> <p>Reception : &gt;1 hour (n=2) ↓ Triage: &gt; 1/2 an hour (n=2) ↓ Consultation with the doctor: &gt;3hours (n=3) (for follow up or rebooking) ↓ Health worker's lunch break&gt;1 hour (n=1) ↓ Pharmacy: &gt; 2 1/2 hours (n=4)</p>	<p><b>Whole consultation: &gt;2 hours (n=10)</b></p>
<b>Frequency of visits</b>	<p><b>All patients</b></p> <p><b>Collection of medication:</b> =1 visit per month (n=10)</p> <p><b>Consultation with the doctor:</b> &gt;1 visit per month (n=3)</p> <p><b>Club visit:</b> =1 visit per four months (n=2)</p> <p><b>§Retinal screening and foot screening:</b> once annually (n=1)</p>	<p><b>§Newly diagnosed: &lt;1 year on ART</b></p> <p><b>Collection of medication:</b> = 1 visit per month for the first four months THEN = 1 visit per two months</p> <p><b>Short term HIV counselling:</b> =3 visits in a week OR over 3weeks</p> <p><b>Long term counselling:</b> 6 - 12 months</p> <p><b>§Adherence: &gt;1 year on ART</b></p> <p><b>Collection of medication:</b> =1 visit per two months (n=3)</p> <p><b>Consultation with the doctor:</b> &gt;1 visit per month (n=6)</p> <p><b>CD4 count tests</b> once annually (n=4)</p>

§ health worker data

All patient participants, except for one, were frustrated with the long waiting periods at the diabetes clinic. When patients were referred to a doctor they were required to wait for a further 3-5 hours and when referred to the pharmacy, an average of 2.5 hours. They would also wait for an additional hour while the health workers had their lunch break, which could be add up to 7 hours. Sometimes, additional appointments were given for another day to see the doctor, counsellor or dietician. Patients described the waiting as exhausting, frustrating, jeopardy to remunerative work security and a waste of their time (Table 4). The situation was worsened particularly when they would either arrive at the pharmacy too late to get their medication or to be told that none was available due to a stock-out:

*“...Sometimes we don't even receive our medication on that day that you came for the clinic. They will give you a letter that tells you, you have an appointment tomorrow morning.” – Participant P3, female*

**Table 4: Patients' clinic-related workload of demands**

<p><b>Long waiting periods during T2D clinic visits were:</b></p> <p><b>(i) exhausting</b> (n=9)          "At the pharmacy, the pharmacists are problematic. It causes stress. There, you can even sleep there and have dreams."  <i>-Participant P5, male, HIV treatment: 6 years, T2D treatment: 15years</i></p> <p><b>(ii) incomplete consultations</b> (n=3)          "Sometimes I didn't get my pills because of, they say, "No, the pharmacy is closing at five o'clock because today it's busy."  <i>-Participant P10, male, HIV treatment: 6 months, diabetes treatment (Type I and II): 23 years</i></p> <p><b>(iii) wasted time for remunerative work</b> (n=2)          "If I'm coming here, I'm coming to do the club. I do not feel right because it takes a long time and I am supposed to go to work. Every time I must ask for the paper for a doctor. At work, they're sick and tired (of it) because of every other day I'm coming to produce the paper (sick note)"  <i>- Participant P7, male, HIV treatment: 9 years, T2D treatment: 5 years</i></p>
<p><b>Frequency of HIV/T2D clinic visits</b> (n=10)          "Like this month, I was here on the 27th in the day hospital on the day for the diabetes. Now I will be here at Ubuntu (for HIV treatment) on 6th August....It would be better if there was just one date for both. That would make it very much easier for us to manage."  <i>-Participant P9, female, HIV treatment: 14 years, T2D treatment: 8years</i></p>

**Preparation to go to HIV/T2D clinic** (n=10)**(i) Assisting children before leaving for health facility** (n=1)

"I wake up my little children that need to go to school, and I get things fixed for them so that they get ready, and then once I'm finished, 6.30 am, I leave the house come to the clinic 6.45am"

*-Participant P6, female, HIV treatment: 9 years, T2D treatment: 6years*

**(ii) Early arrival at the health facility: between 06.30 and 07.00 hours** (n=10)

"(For) the diabetes clinic...I wake up at 5am... ( at the HIV Clinic) I wake up, at around 8am"

*-Participant P9, female, HIV treatment: 14 years, T2D treatment: 8years*

**Transportation** (n=8) **and travelling time** (n=9) **to HIV/T2D clinic**

"I use the train. The train it can take up to two hours in bad times. In good times it can take more or less thirty minutes.... In Cape Town, I don't know other places; the train is the cheapest transport. Because the taxi is expensive, the bus is also expensive."

*-Participant P8, male, HIV treatment: 12 years, T2D treatment: 3years*

Diabetes health workers were aware of the burden attending the clinic placed on patients and estimated the waiting times at the diabetic clinic to be between 4-6 hours in total. On the contrary, one newly diagnosed HIV patient (ART>1year); together with the rest of the patient participants who were adherence patients (ART<1year) found the average wait of two hours to visit the HIV clinic acceptable.

All of the patients prepared and left their homes for either clinic very early in order to queue before the clinic opened at 8am. Most patients reported waking up between 5 and 6 am. Some patients had to wake children up earlier than usual to prepare them for school. Those at some distance from either clinic obviously had to consider travelling time. Travelling time ranged from fifteen minutes to an hour. Patients used different modes of transport to get to the health facility, depending on affordability that ranged from travelling by foot (20%), taxi (40%), train (10%), private car (10%) and unreported (20%). Train commuting was the cheapest mode of transport, but most unreliable.

However, some of the patients noted that they visited the HIV Clinic in the morning as well but not very early as there were shorter waiting periods. A health worker described how she felt sympathy for a patient with multiple morbidities:

*"She has got about ten medications to take every day. She is taking ARVs and now she is coming with a blood pressure of over two hundred (mg/dl) and her blood sugar is uncontrolled. So, she is seen here in our clinic (diabetic clinic), she is seen in the psychiatric clinic and she is seen at Ubuntu (HIV clinic)" - Participant H1, doctor*

### **1.2 Self-care**

Health education provided at the two clinics was central in shaping patients' knowledge for HIV/T2D management; but adherence to recommendations was often challenging (Table 5). Patients spoke of T2D nutrition as they regarded the dietary recommendations given by health workers at the two clinics to be the same for managing HIV. This included: drinking water instead of fizzy drinks, eating less carbohydrates, using less salt, substituting sugar with diabetes sweeteners, having less fatty meat and eating more fruit and vegetables. The importance of ideal portion size and frequency of meals on a given day were also mentioned:

*"I must eat five times a day. Not like three times a day and making six slices. I must make like small portions. But I must make sure my starch is less and less, because according to her that is causing my weight to rise." -Participant P8, male*

All patients, except for one, reported that they struggled to afford the recommended foods:

*"...your rice is not right, potatoes are not right, mealies are not right and that is the only food that we eat. So we can't afford that stuff."- Participant P2, female*

Health workers from both clinics were conscious that many patients could not afford buying the required foods and so made an effort to recommend affordable options and to explain to patients that often the problem was the way food was prepared:

*"I tell them that you can get these things at the umababela (the street vendor) because you get them cheap there; spinach, cabbage. It is also how to cook them at home, because they like to fry, they like the beef stock, they like the Aromat...."* – Participant H5, CNP

Adherence to physical activity recommendations appeared to be relatively easier: three patients mentioned that they had developed a daily routine of walking in order to manage T2D. Two other patients said that they danced or jogged to lose weight:

*"There was a time that my weight used to be hundred and ten, but now, ever since I started exercising it's gone down to ninety four, so exercising helps. Even if you don't have to walk around the place - just being at home and dancing is exercise."* - Participant P3, female

Patients highlighted on the need of ensuring personal safety for both HIV and T2D. For HIV patients spoke about safer sexual practices and the need to protect open wounds whilst for T2D, one patient mentioned the need for proper foot care, which included washing and drying feet properly; and wearing the right shoes "to be safe".

Taking medication constituted a major task for patients in order for them to maintain optimum health outcomes. HIV medication was a 3-in-1 combination pill that was taken

orally once a day by nine of the participants; yet one patient reported to have one tablet in the morning and two pills in the evening. Seven patients were on insulin for T2D; with two of the seven patients; and another two taking three and four extra tablets, respectively; orally everyday. Three of the remaining patients took one to three pills per day for T2D. Six patient participants had to take medication also for hypertension. Patients noted that T2D management required more attention than HIV management as high sugar levels could easily impair physical functioning. However, despite the quantity of medication, patients did not feel overburdened to manage their health:

*"Managing diabetes; it comes naturally to me. I do it effortlessly, because I find trusting my treatment is the key to help me to manage it." - Participant P4, male*

**Table 5: Self-care by HIV/T2D patients**

<p><b>Health education:</b></p> <p><b>(i) Dietary options for T2D management</b></p> <p><b>- Knowledge of dietary plan (T2D)</b> (n=9)          "We use veggies, fruit; and we don't mix starch with starch. We eat a balanced meal. And if you use milk, you use low fat milk; and don't use sugar and don't use fish oil...you eat half a banana and you only eat green apples."  <i>-Participant P3, female, HIV treatment: 6 years, T2D treatment: 5years</i></p> <p><b>-Challenges with affordability of required food</b> (n=3)          There's times where there are no carrots so you end up cooking rice and potatoes which is what they don't want. And sometimes maybe I ha*ve - there's no food and I have five rand, so I buy <i>vetkoek</i>."  <i>-Participant P3, female, HIV treatment: 6 years, T2D treatment: 5years</i></p> <p><b>(ii) Need to engage in physical activity for T2D management</b>(n=3)          "I like to jog very much even at my house."  <i>- Participant P10, male, HIV treatment: 6 months, diabetes treatment (Type I and II): 23 years</i></p> <p><b>(iii) HIV/T2D personal safety</b> (n=10)          It is just me that is focused about not having a cut for their (family) safety, that's it."  <i>- Participant P5, male, HIV treatment:6 years, T2D treatment: 15 years</i></p>
<p><b>Taking HIV/T2D medication</b> (n=10)          "Nothing interferes with taking my medication...If I forgot the time; the alarm is going to remind me it's nine 'o clock - I need to take my medication."  <i>- Participant P2, female , HIV treatment:16 years, T2D treatment: 6years</i></p>
<p><b>Additional morbidities: hypertension</b>(n=6)          "I'm having a problem with diabetic and high blood pressure. So I need to come to the clinic on a monthly basis, once a month"  <i>- Participant P10, male, HIV treatment: 6 months, diabetes treatment (Type I and II): 23 years</i></p>

**Family pressures****(i) Pressures from relatives** (n=1)

"(When having family functions) I will have one drink, even the meat, normal meat. Since I've been diabetic, I used to like meat too much. But now one or two pieces for me is enough."

*-Participant P8, male, HIV treatment: 12 years, T2D treatment: 3years*

**(ii) Pressures from spouses** (n=3)

"(The) problem is my wife makes my sugar go up. (She) sometimes shouts at me. I try to tell her the doctor said you mustn't shout at me; you must talk so that I must understand."

*- Participant P7, male, HIV treatment: 9 years, T2D treatment: 5 years*

**Stigma** (n=9)**(i) Disclosure of HIV status resulted in stigma from:****-Spouses** (n=2)

He didn't even want to see me; didn't even want wind coming from me towards him. He had me stay at the back of the house."

*- Participant P9, HIV-related stigma*

**-Relatives** (n=1)

"my sister...phoned me and say listen, there's one of the ladies within the family she is being going around spreading that I'm HIV positive. I say to her that is nothing. I've got better things to worry than to worry about people saying I'm so and so. Everybody's sick. They may be sick in a different way, but everybody's sick."

*-Participant P8, male, HIV treatment: 12 years, T2D treatment: 3years*

**(ii) Disclosure of T2D status resulted in stigma from:****-Relatives** (n=2)

"You see the family is not alright. If you have an argument, they say, "This guy has something." But they know I've got diabetes. But I hear the way they're talking, you see. They crush me you know. "Where are you getting diabetes but you are small?"

*- Participant P7, male, HIV treatment: 9 years, T2D*

**(iii) Disclosure of HIV/T2D must be restricted to the family unit due to fear of being stigmatised** (n=4)

"When one receives such information, you only tell your family. That's the basic. After that, because going and telling everyone that you are sick, that's not going to do anything for you. Because in the end, you are the one who is sick, so you have to accept the fact that now, I have got this and I now I have to take my life in this way."

*- Participant P5, male, HIV treatment: 6 years, T2D treatment: 15 years*

At an emotional level, some patients reported that they felt burdened by the difficulties their chronic conditions interposed in their relationships with their family members (n=1) or spouses (n=3). Spousal challenges included one patient being scolded by his wife; another patient could not talk about his HIV status to his partner because she became too distressed, fearing that he would die; and a third patient was expected by his partner to eat the same food as everyone else in the household, which was not ideal for T2D.

Both patients and health workers raised the issue of HIV/T2D stigma as an additional emotional burden. Whilst it was acknowledged that the community was more accepting

of HIV than in the past, two patients said that they had not disclosed their HIV and T2D status to people outside the immediate family because they feared stigmatisation. Health workers also mentioned that it was difficult for men to discuss sexual health problems such as impotence due to T2D treatment:

*"I had a newly diagnosed, family man (with T2D) and he asked me, "Sister, what is going to happen to me now. I know there is the loss of libido; because I have heard from so and so that he has a problem and now is that going to happen to me?" – Participant H5, CNP*

## **Theme 2: Perceived patient capacity**

### **2.1. Positive attitudes**

All patient participants believed positive attitudes were essential to accepting and coping with living with HIV/T2D (Table 6). Patients reported to have faith in medical treatment; support from family and believed in religious or cultural practices, which helped them psychologically to come to terms with their morbidities. The positive diagnoses of HIV and T2D were difficult at first, as it affected them physically and mentally, but all of them felt that they had adjusted well over time:

*"That time that I just found out this condition, that I've got these diseases; at that time I felt, at my lowest. I felt very, very low at that time. I felt like I couldn't accept the way that I had to live, but as time went by, I accepted those things and that's what I am now." - Participant P1, female*

Apart from one patient who was uncomfortable taking insulin, further actions mentioned which indicated that patients had incorporated taking medication into their daily routine included setting alarms to remind them to take their medication and taking medication just before meals.

**Table 6: Patients' positive attitudes, values and beliefs**

<p><b>Adherence to treatment</b> (n=5)          "Yah I do cooking, I do laundry, I clean the house.... it doesn't interfere...I set the alarm...so that if I forgot the time, the alarm is going to remind me it's nine 'o clock - I need to take my medication."  <i>-Participant P2, female, HIV treatment: 16years, T2D treatment: 6years</i></p>
<p><b>Family support such as provision of food, encouraging words, companionship and assistance in home upkeep especially from siblings, children, parents and some partners</b> (n=10)          "So I have got my sister that's there to - that makes sure that I take my medication. At times it's hard and even at the hospital she is there for me. She supports me all the way. And if there is a time that I can't make my appointment date on, at the clinic - there's time when she comes from home then she gets my treatment."  <i>-Participant P3, female, HIV treatment: 6 years, T2D treatment: 5years</i></p> <p>"In Cape Town, at least it's easy to get food here especially from my brother. It's very easy to get some money and food."  <i>- Participant P10, male, HIV treatment: 6 months, diabetes treatment (Type I and II):23 years</i></p>
<p><b>God is believed to be a source of strength in managing multi-morbidity</b> (n=4)          "I am a religious person myself, so I always trust in the Creator that He strengthens me and He leads me the right way. That is what I would say my pillar of strength is, my way of life."  <i>-Participant P5, male, HIV treatment: 6 years, T2D treatment: 15years</i></p>
<p><b>Acceptance of positive HIV/T2D and results</b></p> <p><b>(i)All patients accepted their HIV results despite being shocked or dismayed at diagnosis</b> (n=10)          "Since I've started (treatment), there's nothing difficult. The only thing HIV must not involve is tobacco and alcohol because the other doctors told me, the alcohol goes to the liver, its cleansed by the liver, the same tablets are going to the liver. So if you drink too much you are overworking your liver, which can lead to liver failure. So I understand if your liver is not working then that is a problem. So I'm saying, when it comes to HIV, you need to avoid tobacco and alcohol."  <i>- Participant 8, male , HIV treatment:12 years, T2D treatment: 3years</i></p> <p><b>(ii) Patients had varied reactions at initial diagnosis (n=5) and present day (n=9) when diagnosed with T2D</b>          "Before there was a time that I didn't accept that I have diabetes; and things weren't going well for me then. In the space of a month I would be in hospital every month; I'd be in hospital very sick, and I've been to Tygerberg Hospital, I've been to Khayelitsha. Until I accepted the fact that I have diabetes and the only way that I won't return to those hospitals and lay in those hospital beds is if I take my health seriously and take my medicine - follow my treatment the way it's supposed to be taken and exercise."  <i>-Participant P3, female, HIV treatment: 6 years, T2D treatment: 5years</i></p>
<p><b>Acceptance of mental or physical effects of having multiple morbidities</b>  <b>-The acceptance of side effects of having multiple morbidities varied at initial diagnosis (HIV (n=7); T2D (n=8)) and present day (HIV/T2D (n=10)).</b></p> <p>"I was taking d4T (stavudine)... I wasn't feeling right I feel like every, every; my body is painful. So I come to the clinic and I tell them that this d4T is not working for me... I was using that d4T, I changed my shape. It changed my shape...to a very tiny person. I wasn't fat. But my structure, was a good structure.... when I come to the clinic, some people also complain about the same problem that I'm facing so it's like - I told myself that it's - I'm not the only one so I have to accept it; that I look like this now."  <i>- Participant P2, female, HIV treatment: 16 years, T2D treatment:-6years</i></p> <p>Ever since I started treatment for HIV...(when ) I go (to the diabetes clinic) for treatment for diabetes and high blood pressure, then that is causing more problems, because my blood pressure is too high at the time... you know once I sleep during the night maybe I get sometimes terrible dreams or I wake to just go for pee. So my heart is beating too much, so fast. So I have to calm down, because once I panic, I start to have, I have to walk outside around my house; or to drink some water to calm down"  <i>- Participant P10, male, HIV treatment: 6 months, diabetes treatment (Type I and II): 23 years</i></p>

## 2.2. Health literacy

Health workers for both clinics viewed health education essential in helping patients understand HIV/T2D management. They reported using visual aids, written material and group education as health education methods:

*“So they have that pamphlet which they take home. We always tell them, “Put it on your fridge, in your face where you'll be able to see; so that something will pinch (remind) you if you're still doing what you're not supposed to do.” -Participant H5, CNP*

In addition, self-management was discussed with patients individually during consultation and in the case of HIV, external advocacy groups such as Treatment Action Campaign (TAC) and Mothers2Mothers were stationed permanently at the health facility to provide continued HIV education. According to health workers, the level of health literacy depended on the patient's physical and mental functioning, age and education levels.

One patient maintained that no health education materials were available in both clinics. However, the remaining participants recalled seeing posters or pamphlets on both HIV and T2D clinics:

*“There are things that are on the wall, especially in the diabetes club area where they show you that you must take twenty five percent starch, twenty five percent protein and fifty percent veg. And they show you what kind of alternative sugar that you must use...”*  
- Patient P8, male

This patient argued that it was their responsibility to make sure they were well informed:

*“It also depends on your curiousness. If you are not curious enough then the information is going to be far away from you. You have to be inquisitive and ask how HIV works.” -*

*Patient P8, male*

Other quotes are presented in Table 7.

**Table 7: Assessment of patients' health literacy**

**Health literacy** (n=9)

**(i) Patients managed to keep optimal health outcomes by following T2D and HIV education**

“So the diabetes side you always have to follow the law. Otherwise if you don't follow the law the results will show quickly.” - *Participant P6, female, HIV treatment: 9 years, T2D treatment: 6years*

“I know a lot of people that have been diagnosed in the same year as me, they passed away long time ago. Because they didn't come to terms of adjusting like decreasing their alcohol intake, changing their behaviour when it comes to women. Now they didn't like last for long.”

-*Participant P8, male, HIV treatment: 12 years, T2D treatment: 3years*

**(ii) While psychiatry patients were seen to have little understanding of their treatment in practice, in this sample, a patient older in age and low education level struggled in understanding a positive HIV status** (n=1).

“(A psychiatry patient) has got about ten medications to take every day. So now she is coming with a blood pressure of over two hundred (mg/dl) and her blood sugar is uncontrolled. So I ask her how many ARVs are you taking. She says three. So I don't know if it is the combination tablet and the others are vitamins or are it three different drugs, I don't know.” - *Participant H1, doctor*

“HIV I really don't understand. The clinic guys wouldn't be able to tell me about HIV. I was told its just dirty blood, that my blood is dirty... I was given a huge book to read and there were things like signs. I was just told there is no cure. That this is something I have to accept now. There's only medication that can just keep it.” - *Female, 62 years, educated up to Grade 5, HIV treatment: 14 years, T2D treatment: 8years*

### 2.3. Social support

A wide array of needs was identified showing the complexities around provision of support to patients not only at home, but also in the clinic environment. Family support was viewed important by patients. A lack of social support from the family caused distress for some patients and negotiating social support for lifestyle change was seen as an important ‘task’ for patients on diagnosis (as can be seen in Table 5 - family

pressures). However, others spoke warmly of the support they received from family members:

*"There's a unity of strength...I get full support from my children." - Participant P6, female (See Table 6 for related quotes).*

One health worker mentioned that family members were supportive in some areas such as accompanying patients on their clinic visits; but another viewed family members less helpfully when it came to helping patients with their dietary requirements.

Three patients and two health workers viewed clinical support as adequate for HIV/T2D management (Table 8). According to one health worker and one patient, support was more established at the HIV clinic than the diabetes clinic because of the presence of programmes provided by Mothers2Mothers and TAC. Additionally, HIV patients with very low body-mass index (BMI) were referred to a food programme for dietary supplementation. At the T2D clinic, one health worker mentioned that the referral system was very helpful for patients and two patients appreciated the health education they received.

However, four patients were of the view that clinical support was inadequate for multi-morbidity management. Patients articulated a need for: 1) further information and counselling about the implications of having children if one was HIV positive ( $n=1$ ); 2) age-specific, T2D support groups ( $n=1$ ); 3) greater empathy from health workers for their struggles in managing their blood glucose ( $n=2$ ). Support programmes were reported to be more established at the HIV clinic than the diabetes clinic. One health worker noted

that referral of patients to the psychiatrist, dietician or social worker was difficult as these services were under-resourced, infrequent and in high demand. Two patients mentioned that the bread and soup services during clinic visits for T2D were unreliable and not sustained.

**Table 8: Strengths and weaknesses in clinic-related social support**

<b>STRENGTHS</b>
<p><sup>¶§</sup><b>Availability of support programmes at both the HIV/T2D clinics</b> (n=5)</p> <p>"On the HIV side there are people from TAC. They used to come teach us about - like the treatment that we are using and the things that we should know."  <i>-Participant P2, female, HIV treatment: 16years, T2D treatment: 6years</i></p> <p>"We involve every stakeholder here because we have the occupational therapist, we have the physiotherapist, we have the health promoter, we have the social worker, so we involve all (of them) ...we are also trying to involve the community based carers (community health workers)"  <i>-Participant H5</i></p> <p>"We do receive some type of counselling and they (clinical staff at the T2D clinic) make sure that you understand the fact that now your life is going to change."  <i>-Participant P5, male, HIV treatment: 6 years, T2D treatment: 15years</i></p>
<b>WEAKNESSES</b>
<p><sup>¶</sup><b>Need for further information and counselling at HIV/T2D clinics</b> (n=4)</p> <p>"For me, it is this family planning thing that, they must maybe explain in detail. You must have this kind of CD4 count and you must follow this procedure in order for you (to have children)...As far as I'm concerned, in an African culture, the woman that is married she must give birth because that is a continuation of the surname."  <i>-Participant P8, male, HIV treatment: 12 years, T2D treatment: 3years</i></p> <p>"There is a supporting group... the problem is ...I don't know how to put this...like the elders and the youngsters, there's a different scenario, because the elders is so much more stereotyped about certain things."  <i>- Participant P10, male, HIV treatment: 6 months, diabetes treatment (Type I and II):23 years</i></p> <p>"So, you get to the clinic and they don't understand why your sugar levels are up. You try to explain to them and they don't understand - all they tell you is that you have to try and keep it below...."  <i>- Participant P6, female, HIV treatment: 9 years, T2D treatment: 6years</i></p>
<p><sup>§¶</sup><b>Lack of consistent support programmes at theT2D clinic as compared to the HIV clinic</b> (n=3)</p> <p>"(At the general clinic), the psychiatrist comes once a week or once every two weeks for a few hours. So the Sister has to select who sees the psychiatrist."  <i>-Participant H1, doctor</i></p> <p>"The only support we get is from soup kitchens. They come once a week but sometimes there's - they don't come next week and I don't understand why. And then they appear in the other week that's what we're told."  <i>- Participant P1, female , HIV treatment:8 years, T2D treatment: 12years</i></p>
<p><sup>¶</sup><b>Lack of feedback on patients' clinic-related suggestions at T2D clinic</b> (n=1)</p> <p>"As a (patient), if you are not happy just write it down; there's a paper and a pen there. But now we don't know when change will happen. Or maybe it's the Head of the diabetic side, did he get our complaints?"  <i>- Participant P10, male, HIV treatment: 6 months, diabetes treatment (Type I and II):23 years</i></p>

<sup>§</sup> health workers perspectives

<sup>¶</sup> patient perspectives

The health services at both clinics had taken the initiative of making a suggestion box available in order to try to be more responsive to patient complaints and queries. The facility manager at the diabetes clinic was also open to meeting patients:

*“We have the manager’s office that is open to everyone. Should the person be not satisfied, he or she needs something to be done now, we send them to the manager’s office” – Participant H5, CNP*

These opportunities could be considered as mechanisms of support but one patient viewed suggestion boxes as ineffective due to lack of feedback.

#### **2.4. Socio-economic resources**

Some patients were unable to meet their daily needs for HIV/T2D management because of their low socio-economic status. Three patients were in full time employment and were financially self -sufficient. However, two relied on a disability and old grant, respectively; with the rest dependent on family members for survival. Adherence to dietary recommendations was expressed as a major problem especially if the family had to share the same food:

*“You see, I (get paid) end of the month. I (get) the money; I buy the stuff I’m supposed to be eating. I’m not eating alone that stuff. In the middle of the month that food’s finished, and also the money is finished.”- Participant P7, male*

A doctor called for the revision of the eligibility criteria for the disability grant as qualification was easier for people who had physical disabilities as opposed to non-physical disability. Two other health workers and support groups supported the idea as

they viewed provision of disability grants to all patients with chronic conditions would help patients adhere to a healthy diet:

*TAC wrote a letter to our government and we signed in support...The proposal was for everyone who is unemployed and HIV positive, to get a grant - maybe a payment of a R1 000 from Government every month." - Participant H6, CNP.*

However, one health worker disagreed:

*"I don't think it's necessary to provide them with any extra funding or anything like that to eat healthier, because there is food: fruit and vegetables are available and cutting sugar- that doesn't cost a lot of money."-Participant H2, doctor.*

Two patients pointed out that food gardens could be a means of food security yet two other patients perceived this as impossible due to lack of space and the input required in producing food.

*"It's because at the place I'm staying (informal settlement) there are not a lot of yards so that we can have vegetable planting." – Participant P7, male*

### **Theme 3: Access and utilisation of health services**

All participants reported that access to and utilisation of HIV/T2D health care services was shaped by how patients encountered administrative and consultative procedures with health workers; including dispensation of medication at the pharmacy, the presence and absence of support services at the health facility and patients' socioeconomic status. Both health workers and patients were happy with the provision of health education, but

patients would have loved to have comprehensive clinic visits. Such aspects included health workers addressing other health concerns besides HIV/T2D such as minor illnesses and mental health; increasing pharmacy staff and balancing the number of health workers attending to patients during clinical staff lunch break. Three health workers and one patient suggested that the national government addresses health worker shortages so that waiting periods are shortened:

*"And the staff is too little. So I know that our managers and Government are aware of that." - Participant H6, CNP*

One patient appreciated home visits by community health workers (CHWs) to deliver medication to the elderly; yet another suggested having mobile clinics for T2D with referrals to the PHC for complicated cases. The absence of a computer system complicated HIV/T2D management because health workers did not have a holistic picture of patient data such as the illnesses that a patient had; and the history of the patient. One patient noted that sometimes results for annual tests were not communicated. Doctors also felt incapacitated to manage effectively HIV/T2D as each condition was treated separately, since clinical guidelines (PC101 guidelines) were separate; and patients had separate files and prescriptions for the two clinics.

Hence, the need of a computer system that is accessible to health workers and integrated clinical guidelines to manage HIV/T2D were suggested:

*"The only way we can integrate that is if you have a computer system. So if I have a computer here, can you access reports from Ubuntu so that I can see what their CD4*

*count is, what was done last time and so on at least...We got guidelines for diabetes and there are guidelines for HIV, but there is no integrated guidelines. So how do you question management of HIV and diabetes if there is no unique guideline for that? Or HIV, diabetes and MDR when there is no specific guidelines for it?" - Participant H1, doctor*

Doctors also suggested that to promote continuity of care a system could be devised where patients are assigned to one or two doctors or CNPs. Further training was seen as ideal especially for mentoring junior doctors not to over prescribe. Health workers were of the opinion that generally, patients were adequately compliant in terms of medication, but not with diet. They also complained that patients did not attend the clinic at the correct times:

*"Every person who arrives at the clinic for help will be seen... (but if) it is quarter to four and the patient told the receptionist that they came for an HIV test, we have to leave at four o'clock. So we don't have enough time for the results" - Participant H4, HIV counsellor*

#### **Theme 4: Health Outcomes**

Despite the health outcomes experienced by patients (Table 9), all patients maintained that they were managing their health adequately.

**Table 9: Health Outcomes**

<p><b><i>Final health outcomes</i></b></p> <p>*<u>HIV related</u> Permanent small body (n=1)</p> <p>*<u>T2D related</u> Renal failure (n=1) Chronic Obstructive Pulmonary Disease (COPD) (n=1) Hypertension (n=1)</p>
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<p><u>HIV and T2D related</u>  *Frustration/anger (n=1)</p> <p>*Chronic renal failure; Cardiovascular disease; Dementia; Psychosis; <i>Retinitis pigmentosa</i> (loss of vision); Hypertension</p>
<p><b>Intermediate health outcomes</b></p> <p><u>HIV related</u>  *<i>Dizziness</i> (n=1) <i>Night sweats</i> (n=1) <i>Nightmares</i> (n=1) <i>Pneumonia</i> (n=1)</p> <p>*<i>Psoriasis</i></p> <p>*<u>T2D related</u>  *<i>Uncontrolled blood sugar levels</i> (n=5) *<i>Uncontrolled blood pressure</i> (n=1) <i>Blurred vision</i> (n=3)  <i>Temporary disability</i> (n=1) <i>Overweight</i> (n=2)</p> <p><u>HIV and T2D related</u>  *<i>Dizziness</i> (n=3) **<i>Depression</i> (n=1) ** <i>Hospitalisation</i> (n=4) *<i>Fits</i></p>

\* Self-reported experiences by patient participants

• Doctor's diagnoses recalled from consultations at HIV/T2D clinics

From the patient interviews, it was possible to assess the physical and mental functioning of patients as good, average or poor and give an overview of how the HIV/T2D patients in this study appeared to manage their health (Table 10). Improvements were noted in present day physical and mental functioning of both HIV/T2D patients.

**Table 10: Self-reported physical and mental functioning by HIV/T2D patients**

	Physical functioning				Mental functioning			
	HIV		T2D		HIV		T2D	
	Newly diagnosed (n=5)	Current (n=9)	Newly diagnosed (n=6)	Current (n=10)	Newly diagnosed (n=7)	Current (n=10)	Newly diagnosed (n=8)	Current (n=10)
Good	2	9	2	8	2	7	3	6
Average	3	-	3	2	3	3	3	4
Bad	-	-	1	-	2	-	2	-

**Discussion**

The study confirms that there is no integration of care for chronic conditions which is in contrast with the ICDM and also still misaligned with the call to have integrated care for CDs and NCDs. Service delivery as a building block of the health system, must be responsive to the needs of the population [1]. However, patients in this study still experienced parallel health services for chronic conditions. In this study, patient participants identified themselves to fulfill many of the tasks of the CCM [29] which included clinic attendance, taking medication, learning about the conditions and self-management behaviours. A patient's capacity to engage in these tasks determines whether the work is perceived as manageable or not. All the patients interviewed in this study, noted that T2D management was more difficult than HIV care. This may be attributed to the different clinical presentations that T2D may have [34]. However, in South Africa, lived experiences of women who self-reported previous diagnosis of T2D and were also affected by HIV, illustrate the subjective nature of managing of these co-morbid conditions as HIV management was seen to be worse than T2D management [21]; which was not the case among patient participants in this study.

Respondents in this study identified a number of barriers to achieving these tasks. These included a lack of financial resources to meet dietary requirements, pressure from family members not to follow healthy lifestyles and personal attitudes and beliefs. Although difficult to achieve, having control over food options and discussing nutrition with spouses were identified as some of the promoting factors for dietary adherence [35]. In addition to these factors, other challenges in optimal diabetes self-management include knowledge about diabetes and patients' adherence to treatment [36]. However, these

latter tasks did not appear to complicate self-care for patients in this study as depicted in the model. Taking medication was only seen to be difficult at point of diagnosis but patients were at the time of data collection, well-adjusted and had normalised this task into daily routine [37]. Patients valued health education on self-management. Literature gives the benefits of education such as reduction of health costs and improvement in general health outcomes [38] especially among literate patients [39].

One of the patients noted that the inclusion of all adult patients in T2D support groups at PHC level repelled young-adult patients' involvement in health education activities. This characteristic of the current approach to chronic care in Cape Town where patients needs are not fully addressed may translate the same effects of anxiety and frustration of patients in managing their chronic conditions[40]. Reorganisation of support groups to be age-specific may be done; and success stories in managing chronic conditions may be experienced as in the case of other settings that have homogenous support groups [41]. Apart from face to face support groups, different forms of support groups may yield different results. Mobile telephone peer support groups have reminded T2D patients on self-management where although in one study they did not manage to improve blood sugar and pressure levels [42] in another study, blood pressure was controlled [43].

Long waiting periods and health worker shortages were the most frustrating issues raised by participants at the T2D clinic. These have been identified as barriers in seeking health services elsewhere in South Africa [44, 45]. In contrast, HIV waiting periods are shorter mainly because of the ARV adherence club system; which avoids overcrowding and

reduces waiting times at the health facility [46] . Further innovations of organisation and management of chronic care have been suggested to retain patients in care such as workplace programmes for employed patients[47] which can also be applied to alleviate long waiting periods at the health facility particularly for T2D management.

Patient-health worker power divide was evident: it was perceived that health workers taking breaks in-between work left patients unattended. While regulations stipulate on the need of a one hour meal interval after working continuously for five hours [48] a functional system of rotation so that there is a balance between health workers on lunch break and those attending to patients was seen ideal by patients. Health workers perceived suggestion boxes to be a mechanism of demonstrating patient power since patients could use of the suggestion boxes to post compliments and queries. However, patients noted that they did not get feedback making this platform ineffective for communication. Health worker-patient relationship has to be reciprocal such that patients have client power towards health providers and health workers have an obligation to provide service to the people [49].

A multi-sectoral response to public health needs was illustrated by support services from the national and local government such as disability grants and provision of food supplies for specialised group of patients. However, though the intention was to address socioeconomic challenges faced by the patients, these short-term benefits; which become unsustainable. While non-governmental organisations (NGOs) could be tapped as resources for community food gardens thus ensuring food security, challenges in long-

term funding pose as a threat in such a development effort [50]. Stigma was still evident in the community and various interventions have been suggested to diffuse HIV stigma which range from information based, skills building, counselling to contacting the affected people [51].

The role of community health workers (CHWs) in delivering home based services and mobile clinics was also valued; which has also been valued by other groups of patients such as HIV and TB sufferers[52]. However, rolling out of the service to all chronic conditions (in this case HIV and T2D) could be limited by the resources needed in redesigning health services which are already a challenge in the Western Cape [53] and the complex nature of managing T2D that may require consultation with specialists.

Information systems are also necessary building blocks of health systems. Weaknesses in administration and consultation procedures where patient had separate files for the two clinics, an inefficient T2D appointment system and incomplete data indicated a need for an integrated system such as a computer network to consolidate patient data. This has been recommended in the literature [54, 55]. Also though the ICDM is guided by the PC101 clinical guidelines, treating a patient by referring to one disease at a time and not understanding all the diseases a patient has may trigger unpleasant side effects which may come with living with multi-morbidity [13, 56-58] and using consolidated guidelines may be helpful. Continuity of care was raised as a strategy to improve HIV/T2D management and it has been associated with improved quality of care for chronic patients [59]. However, retention of health workers may pose as a challenge[60]. The gains

anticipated in continual professional development by health workers in this setting are noted in literature such as trainings offered within and outside the health facility which promote participant active participation [61].

### **Limitations**

Due to resource and time constraints for this mini-thesis, the sample for this study was limited to 10 patients and 6 healthcare workers in one setting. This did not enable the researcher to explore fully all the different dimensions of the CCM model and it remains uncertain as to whether data saturation was achieved: it is possible that more interviews could have yielded further issues of relevance, a greater breadth of information and deeper insight on this topic. Social desirability bias could have resulted in patients offering the researcher a more positive picture of their situation than is really the case. The researcher not being a South African and not being conversant in the local language could also have limited respondent's openness in the discussions.

### **Conclusions**

HIV/T2D services require better integration as the current organisation and management is cumbersome to both health workers and patients. In the short term, education material can be made available in clinics for patients which includes information on HIV, T2D and other chronic conditions and how best to manage these in their singularity and plurality. In addition, the availability of consolidated guidelines may be helpful for PHC facilities to have the capacity to manage co-morbidity. However, this may not be an easy task as health workers may need further training to enlarge their roles. In the long term, a

complete re-organisation of PHC centres may be required were "separate clinics" are phased out and an ideal clinic in which chronic patients may have a single consultation for all their morbidities. This may also assist in addressing the problem of waiting periods.

The CCM was largely an effective model of understanding patients lived experiences of morbidity and it brought out the variations in what may be constituted patient workload and patient capacity in the South African context. In this regard, incorporating its elements with the ICDM may provide a better approach of chronic patients managing their health in their home environment and their utilisation of health services. However, the lack of data of country examples of integrated chronic care health services of CDs and NCDs show that there is still need of more piloting especially of the CCM.

### **Competing interests**

None declared

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### **Authors' contributions**

RM was responsible for the data collection, data analysis and writing up of the report.

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## **Part D: Appendices to dissertation**

## **Appendix 1: Information Sheet and informed consent form for HIV/T2D patients on workload/capacity issues and their inter-relationships as associated with multiple morbidities**

Strengthening Health Systems for Chronic Care: Intersection of Communicable and Non-communicable Diseases Services in South Africa

**Title of study:** A qualitative study on the experiences and perspectives of public sector patients in Cape Town in managing the workload of demands of HIV and type 2 diabetes co-morbidity

**Researcher Name:** R. Matima, University of Cape Town

### **INFORMATION SHEET**

In South Africa, more people are now living with multi morbidities which are two or more chronic health conditions such as HIV, TB, hypertension and type 2 diabetes (T2D). I am inviting you to take part in a study exploring the patient and health provider perspectives related to the tasks and responsibilities which comes with HIV and type 2 diabetes (T2D) co-morbidity and how this impacts on the patient's capacity to effectively manage the condition. This study is being conducted by researchers at the Chronic Disease Institute of Africa and University of Cape Town.

HIV and T2D co-morbidity are the selected two health conditions because more people are living with HIV and T2D and the heavy tasks and responsibilities needed to manage HIV and T2D. HIV is a virus passed from one infected person to another through body fluids which needs continual treatment to live longer. Type 2 diabetes (T2D) is a chronic disease caused by a person not producing enough insulin, a hormone which controls the amount of sugar in the blood.

Individual interviews will be done with a total of 10 people who are both HIV and T2D patients. We would really appreciate if you could be part of these interviews so that we can know more on how improvements can be made in handling these two health conditions.

Your participation in individual interviews will be face-to-face with the researcher and will take one hour approximately; but may extend over an hour if there are still more issues to discuss. The interview will be in a private room in the clinic for confidentiality. The interview will be audio-taped and stored on the researcher's computer. You will not in any way be forced to be part of the interview and you will be able to stop the interview at any time without having to give a reason.

Once the study is complete the recording will be deleted. Your name will not be used in any of the reports written up about this research. After taking part in the study, you will receive a food voucher as a token of appreciation for agreeing to help us in this study.

If you have any concerns about your rights or welfare as a participant in this study please contact the Faculty of Health Sciences Human Research Ethics committee address: Faculty of Health Sciences Human Research Ethics Committee (HREC). Room 52, Old Main Building, Groote Schuur Hospital, Observatory 7925. Tel: [+27 21 406 6338](tel:+27214066338), Fax: [+27 21 406 6411](tel:+27214066411). Alternatively, please feel free to contact either one of the supervisors to this study:

Researcher: Rangarirai Matima 072 492 5562

Supervisors: Dr Tolullah Oni, 021 650 1299

Dr Katherine Murphy, 021 406 6820

**Consent Form**

**By signing this document:**

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

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

I give my permission for the researchers to use the information I give in the interview for the purposes of improving HIV and T2D management; and for the purposes of academic publication.

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

I agree to take part in this research study.

Name of research participant:.....Signature.....Date:.....  
.....

Name of person obtaining consent:.....Signature.....Date:.....

## **Appendix 2: Information Sheet and informed consent form for healthcare providers on workload/capacity issues and their inter-relationships as associated with multiple morbidities**

Strengthening Health Systems for Chronic Care: Intersection of Communicable and Non-communicable Diseases Services in South Africa

**Title of study:** A qualitative study on the experiences and perspectives of public sector patients in Cape Town in managing the workload of demands of HIV and type 2 diabetes co-morbidity

**Researcher Name:** R. Matima, University of Cape Town

### **INFORMATION SHEET**

In South Africa, more people are now living with multi morbidities which are two or more chronic health conditions such as HIV, TB, hypertension and type 2 diabetes (T2D). I am inviting you to take part in a study exploring the patient and health provider perspectives related to the tasks and responsibilities which comes with HIV and type 2 diabetes (T2D) co-morbidity and how this impacts on the patient's capacity to effectively manage the condition. This study is being conducted by researchers at the Chronic Disease Institute of Africa and University of Cape Town.

HIV and T2D co-morbidity are the selected two health conditions because more people are living with HIV and T2D and the heavy tasks and responsibilities needed to manage HIV and T2D. HIV is a virus passed from one infected person to another through body fluids which needs continual treatment to live longer. Type 2 diabetes (T2D) is a chronic disease caused by a person not producing enough insulin, a hormone which controls the amount of sugar in the blood.

Individual interviews will be done with a total of 6 people who are healthcare workers who work with adult chronic patients. We would really appreciate if you could be part of these interviews so that we can know more on how improvements can be made in handling these two health conditions.

Your participation in individual interviews will be face-to-face with the researcher and will take one hour approximately; but may extend over an hour if there are still more issues to discuss. The interview will be in a private room in the clinic for confidentiality. The interview will be audio-taped and stored on the researcher's computer. You will not in any way be forced to be part of the interview and you will be able to stop the interview at any time without having to give a reason.

Once the study is complete the recording will be deleted. Your name will not be used in any of the reports written up about this research..

If you have any concerns about your rights or welfare as a participant in this study please contact the Faculty of Health Sciences Human Research Ethics committee address: Faculty of Health Sciences Human Research Ethics Committee (HREC). Room 52, Old Main Building, Groote Schuur Hospital, Observatory 7925. Tel: [+27 21 406 6338](tel:+27214066338), Fax: [+27 21 406 6411](tel:+27214066411). Alternatively, please feel free to contact either one of the supervisors to this study:

Researcher: Rangarirai Matima 072 492 5562

Supervisors: Dr Tolullah Oni, 021 650 1299

Dr Katherine Murphy, 021 406 6820

### **Consent Form**

#### **By signing this document:**

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

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

I give my permission for the researchers to use the information I give in the interview for the purposes of improving HIV and T2D management; and for the purposes of academic publication.

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

I agree to take part in this research study.

Name of research participant:.....Signature.....Date:.....

Name of person obtaining consent:.....Signature.....Date:.....

**Appendix 3: Interview schedule for patients**

- A. Please tell me a story of what happens on a day you visit the clinic - from the time you wake up until you leave the clinic.
- B. What do you like best; and how can things be done differently for you to be satisfied during your clinic visit?
- C. May you tell me how you are managing/handling your health at home.
- D. What can you think of, that can make it less difficult/easier for you to manage your health?
- E. How well do you think you are doing in managing your health along with the other everyday responsibilities you have? What would you say is working well for you? And what is not working so well? Please explain and give your reasons.
- F. If you have had any side effects to the medication, can you explain one of your experiences? What may have happened and what helped you to pull through? OR If you have had no side effects to the medication, can you explain what may have helped you to stay healthy?
- G. Since having these health problems what would you say to any other person who also has chronic conditions?
- H. Is there anything else you would like to tell me about your health and how you are coping with caring for yourself?

#### **Appendix 4: Interview schedule for health providers**

A. May you please explain to me what usually happens when a patient with HIV/ T2D comes for a clinic visit; from the moment he or she arrives at the facility until he or she leaves the facility?

B. How would you describe your specific role regarding the care of these patients?

C. What do you like best about your current clinical practices for patients with HIV/T2D; and how can things be done differently?

D. In what ways do you think HIV and T2D have impacted on patient's quality of life?

E. Is there anything else you would like to tell me about providing care for these patients?

**Appendix 5: Early Stop Sheet**

Participant	Reason for Early Stop

## Appendix 6: Ethics clearance letter



UNIVERSITY OF CAPE TOWN  
Faculty of Health Sciences  
Human Research Ethics Committee



Room E52-24 Old Main Building  
Groote Schuur Hospital  
Observatory 7925  
Telephone [021] 406 6338 • Facsimile [021] 406 6411  
Email: [nosi.tsama@uct.ac.za](mailto:nosi.tsama@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

13 July 2015

**HREC REF: 314/2015**

**Dr T Oni**  
Public Health & Family Medicine  
Falmouth Building

Dear Dr Oni

**PROJECT TITLE: STRENGTHENING HEALTH SYSTEMS FOR CHRONIC CARE: INTERSECTION OF COMMUNICABLE AND NON-COMMUNICABLE DISEASES SERVICES IN SOUTH AFRICA (Masters-candidate-R Matima) sub-study linked to 403/2011**

Thank you for your response to the Faculty of Health Sciences Human Research Ethics Committee dated 17 June 2015.

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until the 30<sup>th</sup> July 2016.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.  
(Forms can be found on our website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms))

*We acknowledge that the student R Matima will also be involved in this study.*

**Please quote the HREC REF in all your correspondence.**

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Yours sincerely

**PROFESSOR M BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**

Federal Wide Assurance Number: FWA00001637.

Institutional Review Board (IRB) number: IRB00001938

This serves to confirm that the University of Cape Town Human Research Ethics Committee complies to the Ethics Standards for Clinical Research with a new drug in patients, based on the Medical Research Council (MRC-SA), Food and Drug Administration (FDA-USA), International Convention on Harmonisation Good Clinical Practice (ICH GCP), South African Good Clinical Practice Guidelines (DoH

2006), based on the Association of the British Pharmaceutical Industry Guidelines (ABPI), and Declaration of Helsinki guidelines.  
The Human Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

## Appendix 7: Instructions for authors of the journal used



### Research Criteria

Research articles are reports of data from original research.

### Preparing your manuscript

#### Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:
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  - or for non-clinical or non-research studies a description of what the article reports
- list the full names, institutional addresses and email addresses for all authors
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- indicate the corresponding author

### Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the [CONSORT](#) extension for abstracts. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications

- **Trial registration:** If your article is a systematic review or reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be stated in this section. See our [editorial policies](#) for more information on trial registration

### **Keywords**

Three to ten keywords representing the main content of the article.

### **Background**

The Background section should explain the background to the study, its aims, a summary of the existing literature and why this study was necessary or its contribution to the field.

### **Methods**

The methods section should include:

- the aim, design and setting of the study
- the characteristics of participants or description of materials
- a clear description of all processes, interventions and comparisons. Generic drug names should generally be used. When proprietary brands are used in research, include the brand names in parentheses
- the type of statistical analysis used, including a power calculation if appropriate

### **Results**

This should include the findings of the study including, if appropriate, results of statistical analysis which must be included either in the text or as tables and figures.

### **Discussion**

This section should discuss the implications of the findings in context of existing research and highlight limitations of the study.

### **Conclusions**

This should state clearly the main conclusions and provide an explanation of the importance and relevance of the study reported.

### **Declarations**

#### **List of abbreviations**

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

#### **Ethics approval and consent to participate**

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval.

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If your manuscript does not report on or involve the use of any animal or human data or tissue, this section is not applicable to your submission. Please state “Not applicable” in this section.

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### Table of contents

- Preparing main manuscript text
- Preparing figures
- Preparing tables
- Preparing additional files

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#### Online document

Doe J. Title of subordinate document. In: The dictionary of substances and their effects. Royal Society of Chemistry. 1999. [http://www.rsc.org/dose/title of subordinate document](http://www.rsc.org/dose/title%20of%20subordinate%20document). Accessed 15 Jan 1999.

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Healthwise Knowledgebase. US Pharmacopeia, Rockville. 1998. <http://www.healthwise.org>. Accessed 21 Sept 1998.

#### Supplementary material/private homepage

Doe J. Title of supplementary material. 2000. <http://www.privatehomepage.com>. Accessed 22 Feb 2000.

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Doe, J: Title of preprint. <http://www.uni-heidelberg.de/mydata.html> (1999). Accessed 25 Dec 1999.

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Doe, J: Trivial HTTP, RFC2169. <ftp://ftp.isi.edu/in-notes/rfc2169.txt> (1999). Accessed 12 Nov 1999.

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Figure keys should be incorporated into the graphic, not into the legend of the figure.

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PowerPoint (suitable for diagrams and/or images, figures must be a single page)

TIFF (suitable for images)

JPEG (suitable for photographic images, less suitable for graphical images)

PNG (suitable for images)

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#### Figure size and resolution

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width of 600 pixels (standard), 1200 pixels (high resolution).

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width of 85 mm for half page width figure

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maximum height of 225 mm for figure and legend

image resolution of approximately 300 dpi (dots per inch) at the final size

Figures should be designed such that all information, including text, is legible at these dimensions. All lines should be wider than 0.25 pt when constrained to standard figure widths. All fonts must be embedded.

#### Figure file compression

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Tabular data provided as additional files can be uploaded as an Excel spreadsheet (.xls) or comma separated values (.csv). Please use the standard file extensions.

Table titles (max 15 words) should be included above the table, and legends (max 300 words) should be included underneath the table.

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