

Improving Self-management for Type 2 diabetes and hypertension patients in Peri-urban townships in the Western Cape, South Africa

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Key Words

Self-management

Diabetes complications

Hypertension

Illness perception

Chronic disease management programmes

Risk factor monitoring

Self-management support

Stealth interventions

Patient-derived solutions

Chronic disease care



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Abstract

Improving self-management for Type 2 diabetes and hypertension patients in Peri Urban townships in the Western Cape, South Africa

Background: The rising burden of Type 2 diabetes mellitus (T2D) and hypertension (HTN) and the impact of non-communicable diseases (NCDs) in general on weak public health systems in low- and middle-income countries (LMICs) require innovative approaches for disease prevention and management. T2D and HTN are major preventable NCDs through early risk factor detection. Once diagnosed with these conditions, patients' monitoring and control is done to reduce the occurrence of disease complications. We hypothesized that optimized contextual patient self-management plays a critical role in risk factor control, disease management and prevention of complications.

Aim: To design and recommend a patient informed, contextualised T2D/HTN self-management care package for patients receiving healthcare services from the Chronic Disease Management Programmes (CDMPs) in Peri-Urban Townships in the Western Cape, South Africa. The work is guided by the SMART2D framework, which describes self-management and determinants, actors and contextual issues required for optimal self-management support.

Study Design:

This is a multistage mixed methods study consisting of three (3) studies looking at different aspects of self-management as follows:

Study 1 -published-Masupe TK, Ndayi K, Tsolekile L, Delobelle P, Puoane T. Redefining diabetes and the concept of self-management from a patient's perspective: implications for disease risk factor management. Health Educ Res. 2018 Feb 1;33(1):40-54. doi: 10.1093/her/cyx077. PMID: 29315392; PMCID: PMC6018984.

This qualitative study conducted in a Peri-Urban township near Cape Town, South Africa aimed to identify and gain in-depth understanding of contextual and environmental factors pertinent to the patient that could influence T2D care and self-management. Data was collected through in-depth-interviews with healthcare workers and focus group discussions (FGDs) with patients. A new patient-led definition of diabetes in this context was elucidated. Patients defined T2D as a physically and emotionally dangerous disease influenced by socio-cultural factors, including the food and socio-cultural environment, and significance placed on physical, social, and emotional effects of T2D diagnosis. Using a patient-centred definition of T2D was shown to be key to enhancing T2D self-management. The study concluded that innovative health marketing and promotion strategies that leverage on personally rewarding benefits of physical activity and healthy diet such as anti-ageing, brain boosting, and energy boosting, which are commonly harnessed by the food, tobacco and beauty industry, should be considered in T2D self-management.

Study 2-Published- Masupe T, De Man J, Onagbiye S, Puoane T, Delobelle P. Prevalence of disease complications and risk factor monitoring amongst diabetes and hypertension patients attending chronic disease management programmes in a South African Township. Afr J Prim Health Care Fam Med. 2021 Sep 8;13(1): e1-e7. doi: 10.4102/phcfm. v13i1.2997. PMID: 34636603; PMCID: PMC8517752.

This study assessed risk factor monitoring, prevalence, and determinants of diabetes related complications among T2D and HTN patients attending two CDMPs or “clubs in a peri-urban township. The patients are expected to practice self-management of their diseases with the support of the clubs. Data was collected using a cross-sectional survey combined with a ten-year retrospective medical records analysis of adult T2D/HTN patients attending two CDMPs, using a structured survey questionnaire and an audit tool. There were 379 patients in the survey, 372(97.9%) with HTN and 159(41.9%) with T2D and HTN. 361 medical records were reviewed. Blood pressure (87.7%) and weight (86.6%) were the most frequently monitored risk factors, while foot care (0-3.9%) and eye screening (0-1.1%) were least monitored. Nearly 22% of patients reported one complication, while 9.2% reported ≥ 3 complications. Medically recorded complications ranged from 11.1% (1 complication) to 4.2% with ≥ 3 complications. The commonest self-reported and medically recorded complications were eye problems (33%) and peripheral neuropathy (16.4%), respectively. Complication occurrence was positively associated with age and female gender and negatively associated with perceived illness control. T2D/HTN patients experienced T2D related complications and inadequate risk factor monitoring despite attending CDMPs. Strengthened risk factor monitoring and increased self-management support is recommended for these patients to reduce complication occurrence.

Study 3- Tiny Masupe, Sunday Onagbiye, Thandi Puoane, Absetz Pilvikki, Helle Mølsted Alvesson & Peter Delobelle (2022) Diabetes self-management: a qualitative study on challenges and solutions from the perspective of South African patients and health care providers, Global Health Action, 15:1, 2090098, DOI: 10.1080/16549716.2022.2090098 To link to this article: <https://doi.org/10.1080/16549716.2022.2090098>

This was a qualitative study that aimed to unravel experiences, identify barriers to self-management, and solicit solutions for enhancing self-management from patients with T2D/HTN and their healthcare providers. Data was collected through in-depth interviews (IDIs) with healthcare workers and focus group discussions (FGDs) with patients in two healthcare facilities in Khayelitsha. The study identified challenges experienced by patients across the three self-management tasks of behavioural and medical management, role management and emotional management. The main challenges described by participants included poor patient self-regulation leading to non-adherence to lifestyle behaviours; sub-optimal patient-provider and patient-family partnerships; and post-diagnosis emotional grief-reaction. Perceived barriers to self-management included stigma, socio-economic and cultural factors, provider-patient communication gaps, disconnect between facility-based services and patients’ lived experiences and inadequate community care services.

Patients in this study suggested empowering community-based solutions to strengthen disease self-management. Solutions included dedicated multi-disciplinary T2D services, dedicated T2D counselling services; strengthened family support including patient buddies; patient-led community projects, and

advocacy. Providers suggested contextualised communication using audio-visual technologies and provider consultations tailored to individual patient needs. We recommend dedicated multi-disciplinary chronic disease healthcare teams that provide chronic disease counselling services with programmes that feature patient-driven projects and advocacy, all based in the community.

The 3-3-3-Self-management care package

Based on the findings from the three studies that make up this thesis, a simple 3 by 3 by 3 self-management care package is recommended towards enhancing self-management of chronic diseases among T2D/HTN patients in the two Peri-Urban Townships where this study was done. The package ensures a set structure for patients to follow at facility and community level and with guidance and drive from the policymakers. The package consists of three layers: (1) the environment in which self-management occurs (facility, community, policy). (2) the constituents of the package (medical education and governance); and (3) the people or actors (facility-based healthcare providers, community-based healthcare providers and peer supporters)

Conclusions

The current status quo needs to be challenged when it comes to strategies used for promoting self-management of T2D and HTN. This need has been documented in this study using findings from in-depth exploration of factors influencing health seeking behaviours such as the uptake of physical activity, healthy diet and general knowledge about T2D. Diabetes was shown to carry a different meaning for the patient compared to the healthcare professionals, and that meaning places significance on the physical, social and psychological changes that result from the diagnosis. Patient literature on T2D should incorporate this patient definition of T2D. self-management of the disease is also interpreted from a social ontological perspective that healthcare workers often pay little attention to. Harnessing the important rewards-based benefits of physical activity and healthy diet that include defying age, brain boosting, energizing and detoxification should be given due consideration as part of health promotion activities for T2D patients. Public health professionals need to consider use of so-called “stealth interventions” to promote physical activity and healthy eating among T2D patients. Stealth interventions are those interventions aimed at increasing physical activity and healthy eating in a way that patients do not feel it is hard work. An example would be using drama to promote healthy eating or dancing to locally produced music as way to increase physical activity. Further implementation science-driven research is recommended to evaluate some of the innovative patient-centred interventions suggested in this study. This will be in keeping with advances in disease prevention and management suggested in the WHO Report on Innovative Care for Chronic Conditions. Patients experienced multiple complications from T2D/HTN despite attending the CDMPs, which provide services aimed at early detection and prevention of complications through risk factor monitoring. Important determinants of complications included age and sex as well as the modifiable risk factors of education, disease knowledge and perceived disease control. self-management was found to be complex in real life with patients experiencing several challenges and barriers to self-management. On a positive note, solutions for optimizing self-management and therefore disease control were elicited from patients and healthcare workers. They expressed a need for empowering community-based rather than facility-based solutions to strengthen patient self-management behaviour, supported by advocacy strategies for patients’ empowerment. The self-

management and Reciprocal learning for Type 2 Diabetes (SMART2D) self-management framework was found to be an ideal framework to guide development of a contextualised simple self-management care package for T2D/HTN patients attending public sector primary healthcare services in this township. A three-layered self-management care package to enhance disease self-management was designed and is recommended to policy-makers for consideration.



I declare that *Early detection, prevention and Self-Management of Type 2 diabetes mellitus and hypertension in an urban township in the Western Cape...* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete references.

Full name...Tiny Masupe..... Date.21 March 2023.....

Signed..... 

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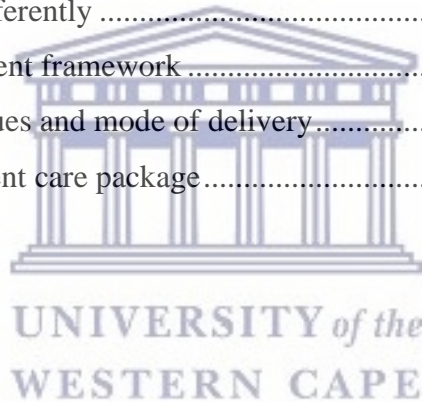
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Chapter 1: Introduction

1.1 Background

Chronic non-communicable diseases (NCDs) are diseases characterized by a long duration, slow progression, non-curability, and non-transmissibility. The increasing burden of NCDs worldwide has been a recurring theme in the last decade (1) and presents a major barrier to the achievement of the Sustainable Development Goals (SDGs), and SDG3.4 in particular (2,3) especially in Sub-Saharan Africa (SSA) which is one of the most affected regions (4). While the pattern of NCDs in developed countries continues to affect mainly the older age groups, the situation in SSA is further complicated by the “colliding epidemics of NCDs and Infectious Chronic Diseases” (5), particularly with the advent of the HIV/AIDS epidemic. The significant contribution of NCDs to mortality and morbidity globally has been recognized in the SDGs. The SDG3.4 is a measurable target which aims to reduce premature mortality from NCDs and mental health by 33% by year 2030 primarily through use of effective disease prevention and health promotion measures (6). NCDs also contribute a significant proportion towards disability adjusted life years (7) and early mortality (8). The most prevalent NCDs are those affecting the cardiovascular system, metabolic system, and mental health. Diabetes and cardiovascular diseases, including hypertension (HTN), stroke, and myocardial infarction are among the four major types of NCDs (6). A high prevalence of type 2 diabetes (T2D) has been reported in SSA (9).

As a middle income country South Africa has also been significantly affected by rising levels of T2D with an estimated prevalence of 12.8% among adults in 2020 (10). The prevalence is higher in specific populations, for example 13.1% among urban dwelling black South Africans (11) and 26.3% among the coloured population (12). While there are comprehensive services for T2D care and management in South Africa (13), the coverage is not universal and is of varying quality (14). Services are generally perceived to be poor (15), especially in the public healthcare system (16). Previous studies in the township where two out of three studies in this body of work were conducted have revealed a high prevalence of HTN (88.6%) and self-reported T2D (12.5%) (11,17). One of the key strategies for managing T2D and HTN is education and self-management (18), which is considered to be sub-optimal in South Africa. Education and self-management can be provided by community health workers (CHWs) in Townships such as these. CHWs are healthcare workers who operate in the space where patients live their lives and have the opportunity to intervene through effective community based self-management support. They have however been found lacking in knowledge, attitudes and beliefs to optimally manage T2D (19), which could have a negative impact on patient self-management given that it is the healthcare workers who teach patients self-management. They are however considered to play an important role in supporting patient adherence and linkage to care.

T2D and HTN are among the nine voluntary targets in the 2013-2020 global NCD action plan for reducing morbidity and mortality from NCDs by 2025 according to the WHO Global Status Report on NCDs (2020) (20). The report identifies paucity of research on effective context specific interventions for Low- and Middle-Income Countries (LMICs) and suggests strategies to tackle these NCDs globally. Historically,

following a diagnosis of T2D or HTN, patients are taught how to self-manage their condition and advised about the lifestyle changes required to prevent future complications (21). The mainstay of T2D drug treatment is long term oral hypoglycaemic drugs and/or insulin at a later stage, while for HTN oral drugs are generally prescribed in South Africa (22). Drug treatment is usually combined with recommendations for lifestyle management, including diet and physical activity. Self-management tends to focus on medication adherence and risk factor management through lifestyle changes such as improved diet, smoking cessation, reduction of alcohol consumption and physical inactivity and maintaining good mental health. These require a significant degree of patients' understanding, engagement with the process and psychosocial support, including CHW support, peer support in the community, or family support, which are however not always available (23).

The concept of self-management as applied to NCDs is defined as “learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of chronic conditions” (24). Lorig and Holman (25) further developed this definition borrowing from work done by Strauss and Corbin (26), who identified the three types of work facing a patient diagnosed with chronic illness, which are self-care for disease management, maintaining normality amidst chronic illness, and the emotional work that is needed to deal with chronic illness and its consequences. Lorig and Holman (25) further delineated three self-management roles required of patients, which consist of three tasks: medical or behavioural management, role management and emotional management (25).

1.2 Problem statement and justification

The rising burden of disease due to T2D and HTN worldwide requires innovative approaches to disease prevention and management. The 2014 WHO Global Status Report on NCDs provides a general set of recommended interventions to address NCDs that are, however, not country and context specific (18). Contextualized interventions are needed, especially since the impact of the NCDs epidemic is set to hit low resourced settings hardest in the next decade according to the above-mentioned report. T2D and HTN are NCDs that are preventable through early detection of risk factors and their management, as well as disease monitoring for prevention of complications, which encompasses principles of self-management.

Despite the fact that T2D and HTN are amenable to early detection and hence prevention of complications, late diagnosis remains problematic, burdening already stretched health systems in LMICs. This calls for the restructuring of health systems from a focus on management of acute presentations and treatment of complications of T2D and HTN to effective early detection and prevention of complications through strengthened patient self-management support strategies.

The burden of disease due to T2D and HTN in South Africa remains significant. NCDs have been shown to increase the demand on health systems in countries where they are prevalent (27) and this is also likely to be the case in South Africa. In recognition of this, the South African government has put measures in place to address the scourge of NCDs, including through the establishment of chronic disease clubs at primary care level. These clubs encourage self-management of NCDs, including T2D and HTN. Self-management requires a change in mindset of both patients and their healthcare providers in recognition of the long-term relationship that NCDs require between both parties.

Hence there is a need to gain more understanding of healthcare provider and patient experiences, and of the challenges they face in applying self-management principles. The self-management principles are operationalized at primary care level through chronic disease clubs, but there is paucity of information on how patients experience self-management while receiving health care in these clubs, and on whether attending the chronic disease management clubs helps patients to ward off complications due to T2D and HTN. Few studies have deliberately aimed to seek input from patients and their care providers to inform innovative solutions that can lead to enhanced self-management. This body of work investigates the social and environmental context in which self-management takes place and deliberately seeks ideas from patients and providers on how to improve their self-management.

The aim is to formulate recommendations for evidence based, context specific, and culture sensitive interventions and guidelines, and contribute new knowledge towards enhancing self-management support. Given that chronic conditions share similar characteristics, solutions found for T2D and HTN could be adapted and applied to other NCDs in settings which are similar to the townships where the data for this body of work was collected from. The COVID-19 pandemic has added another impetus for strengthening self-management. With most health systems struggling under the effects of COVID-19, patients are increasingly asked to self-isolate and self-manage their disease at home. Similar principles applied to self-management of NCDs therefore also apply to infectious diseases, including the long-Covid syndrome.

1.3 Rationale and motivation for the study

Critical to this study is the fact that self-management being the cornerstone of chronic disease management, is implemented poorly in SSA. The question then is what is being done wrong? Is it the patient or their healthcare providers? Is it the environment or other social aspects such as culture and socio-economic determinants or is it a combination of all these factors? If it is a combination of all these factors how do the factors interact to produce poor self-management in our study setting?

To help unpack these issues, a framework for self-management was used based on the SMART2D project (28). SMART2D was a multi-site adaptive implementation trial focusing on T2D whose overall aim was to formulate and implement a contextually appropriate T2D self-management approach using facility and community strategies in three settings: a rural area in a low-income country (Uganda), an urban township in a middle-income country (South Africa), and vulnerable immigrant populations in a high-income country (Sweden). The study objectives were to evaluate the outcome of the self-management approach and the added benefit of the community component compared to the facility component and to translate the findings in dialogue with stakeholders into relevant guidelines for policymaking, using reciprocal knowledge transfer across the different sites (29). The SMART2D framework depicted below, describes the different systems (health system, socio-cultural environment, physical environment), actors (patient, family, friends, community, healthcare providers), mediating factors (learning strategies, perceived relatedness, perceived autonomy, self-efficacy, supportive illness presentation); self-management skills (resource utilization, decision-making, taking action, forming partnerships, problem solving) and self-management tasks (medical management, emotional management, lifestyle management, role management) that influence self-management (28).

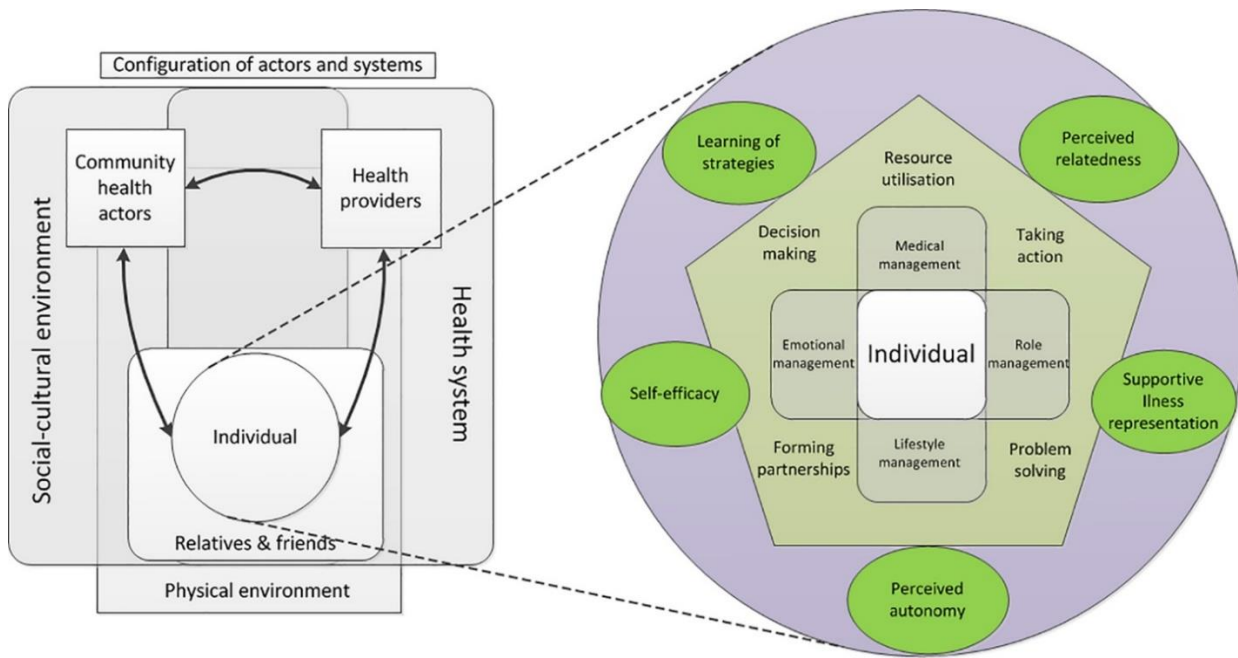


Figure 1: SMART2D Self-Management Framework (De Man et al, 2019)

1.4 Aim and Objectives

1.4.1 Aim

The aim of this body of work is to design and recommend a model of self-management support in Peri-Urban Townships in the Western Cape, South Africa, which is tailored to the local context, and that promotes optimal self-management of T2D and HTN.

1.4.2 Study objectives

1. To identify and gain in-depth understanding of contextual and environmental issues pertinent to the patient that could influence T2D and HTN care and self-management.
2. To explore the experiences of applying the concept of self-management of T2D and HTN from a patient and healthcare provider perspective.
3. To identify the barriers towards optimal self-management of T2D and HTN from a patient and provider perspective.
4. To evaluate health service provision within chronic disease clubs using annual risk factor monitoring of T2D and HTN patients.
5. To recommend a simple care package for optimal self-management of T2D and HTN in this setting.

1.5 Overview of identified research themes

- Environmental and contextual factors influence T2D/HTN self-management among patients diagnosed with these conditions.
- Patients' experience and their interpretation of the meaning of a diagnosis of T2D is complex and not always congruent with that of healthcare providers.

- Self-management presents challenges for both patients and their healthcare providers.
- Despite self-management support from the chronic disease clubs, patients experience disease complications and risk factor monitoring is inadequate.
- Practical solutions suggested by the patients and healthcare providers to enhance T2D/HTN self-management are available and reasonable.
- There is a need for innovative care processes that enhance self-management at community level.

1.6 Importance of the studies undertaken

The studies mapped out the key contextual and environmental factors to undertake optimal self-management and identified challenges and barriers towards optimal self-management among patients diagnosed with T2D and HTN. Through soliciting solutions from patients and providers, a simple model of care to enhance self-management of T2D/HTN in the study population is provided.

1.7 Outline of the study

This body of work is structured as follows: Chapter 1 briefly introduces the body of work by providing a summary of the whole study, rationale, purpose, theoretical framework, and objectives. Chapter 2 describes the literature that informed the study processes and findings. Chapter 3 focuses on the methodological considerations used in the study to address the study objectives. Chapters 4-6 provide the individual studies published from this research. The first paper in Chapter 4 presents the qualitative study that aimed to identify and gain in-depth understanding of contextual and environmental issues pertinent to the patient that influence T2D care and self-management. The second paper in Chapter 5 was a qualitative study that aimed to unravel experiences of self-management identify barriers to self-management and solicit solutions for enhancing self-management from patients and their care providers. Chapter 6 was a quantitative cross-sectional survey combined with a ten-year retrospective medical records analysis of adult T2D/HTN patients attending two Chronic Disease Management Programmes (CDMPs) that aimed to assess risk factor monitoring, prevalence, and determinants of T2D/HTN related complications among patients attending two CDMPs in this setting. Chapter 7 provides a narrative on designing the self-management care package while chapter 8 concludes the findings from the whole study and their implications for policy and practice as well as recommendations for future research.

1.8 Chapter summary

In this chapter, the reader was introduced to the study context and setting. Additionally, the purpose, justification, theoretical framework, and study objectives were described. The chapter also provided an overview of identified research themes arising from this work.

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Chapter 2: Literature Review

2.1 Chapter outline

The aim of this literature review is to provide an overview of the body of knowledge on current trends and disease burden due to NCDs, especially T2D and HTN; a brief summary of the epidemiology of T2D and HTN and their complications, and an overview of NCDs self-management principles and frameworks. The theoretical frameworks underpinning this study and informing the suggested care package will also be discussed.

2.2 Burden of disease due to NCDs

Chronic non-communicable diseases (NCDs) are diseases characterised by a long duration, slow progression, non-curability, and non-transmissibility and multifactorial genetics, physiology, environmental and behavioural factors implicated in their aetiology (1). The increasing burden of NCDs worldwide has been a recurring theme in the last couple of decades (2). There has also been emerging evidence that NCDs are not only on the rise but have contributed to an estimated 50% of morbidity in LMICs in the last decade alone (3). While the pattern of NCDs in developed countries continues to affect mainly the older age groups, the situation in developing countries is further complicated by the co-existence of NCDs and Infectious Chronic Disease epidemics in SSA (4). The relentless rise in the burden of NCDs has continued and current estimates show that NCDs significantly contribute to morbidity and mortality, with 71% of deaths globally and 47% premature deaths in LMICs attributed to NCDs in 2019 according to data from the WHO Global Observatory (5). Of major concern is the observed prevalence of behavioural risk factors among young people aged 10-24 in Sub-Saharan Africa, which predisposes them to developing NCDs in the near future. According to a policy brief based on data from WHO entitled *Noncommunicable Diseases in Africa: Youth Are Key To Curbing The Epidemic And Achieving Sustainable Development*, nearly a quarter of youth in Zambia and South Africa use tobacco products. The brief also notes that 70% of premature deaths in adulthood are as a result of behaviours picked up during adolescents' stage [(6)]. The IDF has noted an increase in type 2 diabetes in children and adolescents (7). A recent study done to investigate prevalence of NCDs among youth and adolescents living with HIV in South Africa also identified multimorbidity and prevalent risk factors for NCDs. In the study done in Cape Town, hypertension and obesity were reported in 5% and 37% respectively. Additionally, the prevalence of behavioural risk factors for NCDs was high. Binge drinking was reported at 24%, smoking 30%, vegetable diet 31% and physical inactivity at 31%.(8)

2.3 Burden of disease due to T2D and HTN

2.3.1 Burden of disease due to T2D

According to the International Diabetes Federation (IDF) Atlas of 2021, T2D poses a serious global health challenge as evidenced by the rise in number of people aged 20-79 diagnosed with T2D, from 151 million in 2000 to 537 million in 2021 and projected to increase to 783 million by 2045 if impactful action is not

taken (7). The increase in prevalence can be partially explained by the lack of cure for diabetes and ageing population, but it is also fuelled by the high annual incidence rates of diabetes globally, which are estimated to have increased by 102.9% from 234 to 285 persons per 100,000 between 1990 and 2017 (9). In addition, there is a differential increase in diabetes incidence, whereby SSA seems to be hardest hit and will likely continue to experience high incidence rates in the future. The IDF estimates that in Africa the prevalence of diabetes is likely to increase by nearly half (48%) by the year 2030 and 145% by the year 2045, topping all other IDF regions. In Africa, 75% of deaths due to diabetes occur amongst those under 60 years of age and nearly 60% occur in middle-income countries (MICs) such as South Africa, which had the highest prevalence at 1.8 million people in 2019 (10). This is underscored by findings of the NCD Risk Factor Collaboration – Africa Working Group study done in 200 territories including 53 countries in the African region. The collaboration identifies overweight/obesity as the main driver of the diabetes pandemic in Africa (11). The high burden is due to T2D more than Type 1 Diabetes (T1D). A high prevalence of T2D has been reported in several African countries (12), including South Africa. This is in line with the findings from a systematic review and meta-analysis of pooled data from 11 studies, which estimated a T2D prevalence rate of 15.25% among South Africans aged 25 years and above (13). The prevalence of T2D also differs in population subgroups, varying from 13.1% among urban dwelling black South Africans (14) to 26.3% in the coloured population (15). There has been a noticeable trend in South Africa on the growing prevalence of T2D in rural areas, contrary to previous trends where the prevalence was found to be higher in urban areas. The OR Tambo district in Eastern Cape Province was recently found to have the highest average proportion of new patients diagnosed with diabetes in 2018 (16).

According to the IDF atlas of 2021, more than half (54%) of people living with diabetes in Africa in 2021 did not know their diagnosis (7). [IDF] Although there is plenty of information on diabetes through several platforms including social media and, websites such as IDF, WDF, and world health organization, there is evidence that newly diagnosed patients with diabetes still present with disease complications (17), suggesting that awareness levels for common presentations of diabetes are still inadequate. Similar findings on lack of knowledge and awareness of diabetes complications have been reported in LMIC such as the Gambia (19). Another study in South Africa which used South African Demographic Health survey data of 2016 to estimate the prevalence of diabetes and prediabetes reported similar findings. In this study, 10% females and 6% males who had never tested for diabetes were found to have diabetes while 67% had pre-diabetes (20). Another study that evaluated the health system response to patients with diabetes using data from the SANHANES recorded a diabetes prevalence of 10%. Among those with diabetes, 45% of whom had never been screened while amongst those who were diagnosed, only 2% were on diabetes treatment and of those on treatment, 18% were not controlled (21)

Chronic ill health as posed by T2D has been shown to cause an economic burden for patients in LMICs (22). In the South African public health sector, the costs of T2D management were estimated at 21.8 billion (ZAR) in 2018 and projected to increase to 35.1 billion (ZAR) by 2030, with 49% due to treating complications (23). Diabetes has similarly been linked to high levels of “catastrophic out-of-pocket” spending and increased poverty levels, according to a study done in Tshwane (24). While there are comprehensive diabetes services in South Africa (25), coverage is not universal and services are of varying quality (26) and generally perceived to be poor (27), especially in the public healthcare system (28).

2.3.2 *Burden of disease due to hypertension*

Cardiovascular diseases, including HTN, stroke, and myocardial infarction, are identified as one of the four major types of NCDs (1). HTN is also a major cause of morbidity and mortality globally, estimated to affect nearly 1.3 billion adults aged 30-79 years in 2021 predominantly among those living in LMICs (29). Uncontrolled HTN is associated with increased risk of cardiovascular mortality (30) and therefore a cause for concern. HTN is common in most settings, however there is consistent evidence from the May Measure Month studies conducted by the International Society of HTN since 2019 across more than 100 countries, that significant proportions of populations across different income settings do not know that they have HTN (31–33).

South Africa has also been affected by the scourge of HTN across localities, including the Western Cape where this study was done. Previous studies in the township where the study was conducted have revealed a high prevalence of HTN (88.6%) and self-reported T2D (12.5%) (14,34). Other parts of South Africa are also affected by a high prevalence of HTN, including the rural Eastern Cape, with an estimated undiagnosed HTN prevalence of nearly 40% and a confirmed prevalence of diabetes of 5% (35). Similar findings were reported in KwaZulu-Natal, with 33% HTN and 4% hyperglycaemia among an HIV-infected population that was also overweight and/or obese (71%) (36). Findings of high prevalence of HTN (27.5%) and overweight/obesity (33.5) were also found among adults attending HIV testing centres in Soweto in 2019, with women disproportionately affected (37).

2.3.3 *Risk factors for diabetes and hypertension*

Both modifiable and non-modifiable risk factors for T2D/HTN have been identified in the literature. Non-modifiable risk factors include age, gender, genetics, race, and ethnicity while modifiable risk factors include unhealthy diet, physical inactivity, tobacco use, alcohol consumption, stress, and socio-economic, socio-cultural, and environmental factors. Self-management focuses on managing the disease and its modifiable risk factors and constitutes the subject of this body of work.

In the PURE study (32) which followed a cohort of participants without cardiovascular disease between 2004 and 2014, 70% mortality was attributed to modifiable risk factors, especially metabolic risk factors (42%), with HTN the leading cause of mortality among metabolic risk factors (22%). The findings from PURE study also indicated that risk factors depend on the context, with LMICs having the highest mortality due to low education, poor diet, and air pollution (38). Modifiable risk factors are important to identify because they are amenable to intervention through self-management support. In another large study combining a pooled analysis from four large prospective cohort studies consisting of 133,118 participants, another important modifiable risk factor, sodium intake, was investigated. Increased sodium intake was associated with increase in systolic blood pressure and cardiovascular events and death among those with HTN compared to non-hypertensive participants, leading authors to recommend lowering of sodium consumption in those with HTN (39). Similar findings were reported in 2018 in the PURE study where increased sodium intake in China was associated with major cardiovascular outcomes, especially stroke, but decreased cardiovascular disease outcomes with increased potassium intake (40). This results in the need for self-management principles on diet, focusing on lowering salt intake and eating food higher in potassium across these countries.

A substantial body of evidence indicates the importance of addressing modifiable risk factors of NCDs in self-management interventions. Commonly identified risk factors include unhealthy diet, physical inactivity, tobacco and alcohol use, and more recently stress and work-related factors (41) have become prominent. In this body of work we will argue for innovation when it comes to addressing these risk factors where we will argue that one-size-fits-all no longer works, business as usual no longer works and as much as we have leveraged on successes of HIV management, we also need to leverage on successes of other industries in terms of how they market their commodities in the way we market our health as a commodity (42), especially pertaining to risk factors for NCDs.

Since its inception the term risk factor has come under scrutiny (43) because of the perception that it was framed using biomedical models and lifestyle frameworks which seem to compartmentalize the whole and bring in issues of individual blame without looking at the bigger health system, and environmental challenges that individuals live in without any choice (44). In the era of co-existing epidemics, a focus on the socio-economic and cultural environment is needed to discuss risk factors for NCDs. This study not only looks at risk factors from an individual perspective, but also interrogates the environment in which these diseases take place and in which self-management occurs. One key strategy of managing T2D and HTN risk factors is education and self-management (45), which is considered to be lacking in South Africa.

2.4 Complications of diabetes and hypertension

The prevalence of diabetes and HTN related complications has been established over several years. In South Africa, patients attending public sector health facilities were found to have high levels of complications, including diabetes retinopathy, peripheral neuropathy, absent foot pulses, persistent proteinuria and foot amputations during an audit of primary diabetes care in the late 1990s (46). Similar findings were documented in KwaZulu-Natal where among patients with T2D, the prevalence of HTN was estimated at 65% and only 14% of those on prescribed medication were normotensive (47). In both studies, diabetes retinopathy was the most prevalent complication at 55% and 40%, respectively.

Co-morbidity of T2D and HTN has also been found to increase the risk of other complications such as diabetes nephropathy in a systematic review and meta-analysis of studies done in SSA (OR 1.67; CI 1.31-2.14) (48), again underscoring the negative interaction between diabetes and HTN in terms of complication occurrence. The meta-analysis included studies which recorded proteinuria or microalbuminuria in addition to those specifying nephropathy. Other factors such as obesity have also been linked to diabetes nephropathy among African patients in a study done in Nigeria (49). Although this was a small study, it adds to the body of knowledge regarding risk factors for complications in diabetes patients and underscores the model proposed by Petrie et al, 2018 (50) depicting the mechanism of action for the development of complications.

Although complications from T2D have been studied over the years, there is no evidence that their prevalence has decreased. Among patients attending public health clinics in Tshwane in 2015 the prevalence of complications was estimated as follows: retinopathy 29%, maculopathy 22%, neuropathy 5%, nephropathy 7%, possible infarction 17% and a very high severe erectile dysfunction at 36%. Among these patients, screening for complications was considered sub-optimal, and more than 60% of those with

HTN were not well controlled (51). The cost implications for poorly resourced health systems in LMICs are evident. A cost of illness study done in South Africa in 2018 estimated that treatment and management of T2D alone costs 2.7 billion ZAR and 21.8 billion per annum if undiagnosed patients were considered. Additionally, nearly half (49%) of those costs were attributable to diabetes complications, which are predicted to increase significantly by 2030 (23). One of the key measures to reduce complications from T2D and HTN is through health education and strong self-management support, as described in the next section.

2.5 Self-management principles

2.5.2 Definition

Self-management as a concept is complicated as illustrated by the large number of studies on the subject. Its meaning and operationalization remain elusive according to Vande Belt et al. (52) who argue that despite its consistent use in healthcare, self-management remains complex and misunderstood. Hence they define their understanding of self-management according to three major attributes, which consist of patient-oriented attributes; person-environment attributes; and medical and emotional attributes. This is similar to what was described by Lorig and Holman (53) as well as Corbin and Strauss (54). The complexity of self-management is evident, with some studies trying to further unpack the various aspects of self-management to include goal setting and action planning (55).

Lorig and Holman define self-management as an activity that has three tasks and five core skills, and more importantly requires that the person with the disease has to engage with the day-day management of the disease. They also provide USA based evidence which shows that if implemented according to this definition, self-management can improve patient-related outcomes (53). The model by Lorig and Holman is depicted in Table 1 below as described by the authors but interpreted by the study researcher.

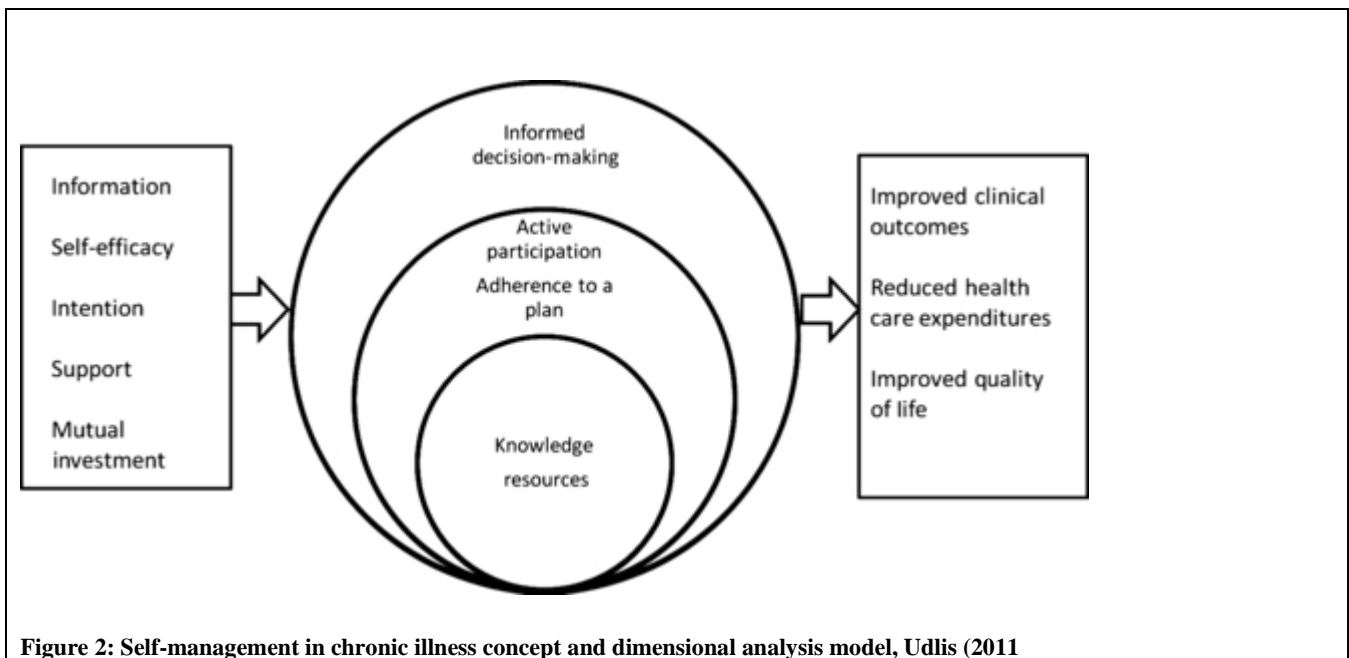
Table 1: Interpreted model of self-management

SELF-MANAGEMENT						
Self-management tasks						
MEDICAL/ BEHAVIOURAL MANAGEMENT				ROLE MANAGEMENT	EMOTIONAL MANAGEMENT	
Practical examples						
Taking medication	Adhering to diet	Adopting new	Maintaining good	Adopting new role of disease manager	Managing emotions	Fear anger frustration
5 Self –management skills						
Problem solving		Decision-making		Managing resources	Forming partnerships	Taking action
IMPROVED PATIENT OUTCOMES						

The concept of self-management has undergone further analysis to make its understanding and application uniform. Udlis 2011, (56) unpacks self-management of chronic illness and provides a framework which consists of three legs (Figure 3) (56). The first leg consists of information, self-efficacy, intention, support,

and mutual investment, with information at the top, followed by self-efficacy before intention and support and ultimately mutual investment. The emphasis on information and the correct information format is important. Only when patients have access to such information can the next ingredient, self-efficacy, be considered. Self-efficacy is defined by Bandura (57) as the ability to confidently feel that one has the capacity and satisfactory degree of control to engage in healthy behaviours regardless of the environment or circumstances. This means that the patient is truly grounded in the knowledge and understanding of the importance of self-management as the lock that is unlocked through self-efficacy. It is therefore important to understand this concept if we are to talk about optimal self-management of chronic disease and to ensure that those expected to practice self-efficacy understand the concept. The next ingredient in this model is intention, which is required for self-management to occur. The authors acknowledge that good intention without support structures, including goals and plans, will not bear fruits, and hence support is the next ingredient of self-management. Mutual investment is another interesting raw ingredient of this chronic disease self-management model, questioning who the investors are and what they are investing in. The investment currency here would be self-management while the investors would be both patient and healthcare provider, If one or both investors are weak, then the investment suffers.

The second leg of the model consists of three action items that must result from the raw ingredients discussed above and one anchor that allows for the action items to unfold. The action items include active participation, adherence to a plan and informed decision-making. The anchor is formed by the knowledge resources. This leg links with the first leg as it starts to look at what needs to be in place to ensure that the investment does not fail, that there is information, self-efficacy, intention, and mutual investment. Knowledge resources are needed to ensure that the investors both have access to information that will enhance their self-efficacy and therefore encourage intention through informed decision-making. It also speaks to how intention can be operationalized, which is through having a plan and adhering to it through active participation. The support aspect of leg one does not seem to come through strongly in leg two, however. Where is the support coming from, what are the resources needed for this support to take place and who are the investors when it comes to this support? Despite this weakness in the second leg, the third leg completes the picture by focusing on the so what. If the two legs work very well, then the investment is assumed to result in dividends. These dividends include improved clinical outcomes, reduced healthcare expenditures, and improved quality of life.



The literature however indicates that self-management continues to present a challenge in its operationalization and its aim to achieve envisaged clinical outcomes. A scoping review of diabetes self-management education which included 19 studies in Africa showed mixed effects (54). The review showed that self-management education programmes were successful in managing blood pressure, blood sugar, diabetes knowledge, foot-care and Haemoglobin-A1c (HbA1c), but did not show improvement of lifestyle factors of weight management (Body Mass Index (BMI)), alcohol use, physical activity, smoking, blood glucose monitoring and self-efficacy (58). This is of concern, given that these are not only risk factors for disease complications, but also risk factors for other NCDs. A systematic review of self-management programmes in the Middle East, however, showed significantly improved patient outcomes when comparing patients attending self-management interventions with those who did not receive any. Improvements were related to BMI, glucose, diabetes knowledge, self-efficacy, HbA1c, cholesterol, health belief and quality of life (59). The differences noted could be due to the level of development and access to health services in the Middle East compared to Africa and the differences in types of care models used in these two regions.

Self-management is central to the successful management of other diseases and not only chronic NCDs, including communicable diseases. The need for self-management has been re-emphasized during the COVID-19 pandemic when patients had to self-isolate at home and in the community and manage their COVID-19 symptoms in addition to chronic disease, as observed in a study in India among patients with T2D (60). A Zimbabwean study which also assessed self-care of diabetes during COVID-19 recommended strengthening the usual aspects of self-management, such as managing the risk factors of physical activity, diet, smoking as well as disease monitoring, but added the psychological component of stress management (61), again underscoring the importance of self-management. There is evidence from the literature that self-management programmes can make a positive impact on the quality of life of T2D

patients. Such programmes include community-based self-management programmes for the elderly with additional co-morbidities (62) and web-based programmes aimed at T2D patients in the UK (63).

Several studies have been done around self-management behaviour in SSA, but a recent systematic review of self-management studies shows that self-management remains poor and is even considered to pose a threat to already burdened healthcare systems in SSA (64). These findings are similar to those described by Dube et al. 2015 (65) based on a mixed methods audit of self-management education programmes in South Africa in 2015, which identified several shortcomings including lack of structured diabetes self-management education programmes, unavailability of opportunities for continuous professional development of diabetes practitioners, lack of cultural sensitivity of available diabetes self-management education programmes and absence of monitoring and evaluation of these programmes (65). This could further explain the continued pursuit of self-management of chronic diseases in the region.

Studies have also tried to measure self-management and the effect it has on health outcomes such as diabetes complications, quality of life and understanding of the concept. The American Diabetes Association for example, identifies factors or indicators to be measured when assessing self-management care or behaviours. These include healthy eating, living an active life, taking medication, disease self-monitoring, reducing risk, and psychosocial aspects (66), with the support element added to emphasize the importance of ongoing patient support during self-management.

2.6 Theoretical frameworks for self-management

2.7.1 Care models for chronic diseases

Several chronic disease care models have been described in the literature, including the Chronic Care Model, Stanford Care model, Innovative Care for Chronic Disease model (ICCC) and transitional care model. These models include two common elements, viz. healthcare delivery and self-management support (67).

2.7.2 Wagner's chronic care model

One of the key approaches to managing T2D is by patient education and self-management, as described in Wagner's chronic care model (68). This commonly researched model consists of six elements, including health system or healthcare organization, clinical information system, decision support, delivery system design, self-management support, and community-based needs and resources (67) These elements need to be applied optimally and consistently for the model to result in good patient outcomes. The model has been supported and adopted by the World Health Organization (WHO) in the WHO Innovative Care for Chronic Conditions (ICCC) framework and applied to other chronic diseases, including HTN (WHO, 2002) and outlines how to benefit and improve the quality of care of patients living with chronic disease. The effectiveness of applying the ICCC framework to chronic diseases remains uncertain in resource limited settings, however, which is partly due to the complex nature of chronic diseases and to how the patient makes sense of their condition and the co-existence of other co-morbid chronic infectious diseases, such as HIV. Some authors have suggested a modified conceptual framework of chronic disease management for populations experiencing the epidemiological transition (69), whilst others have compared the chronic nature of both HIV and diabetes and suggested leveraging on their respective models of care to enhance the quality of chronic disease care in SSA (70).

2.7.3 Chronic Care models for T2D/HTN in South Africa

The calls for leveraging on lessons learnt from providing care to a large population of patients with HIV who are now living longer were heeded and captured in the integrated chronic disease management (ICDM) model in South Africa. This model was developed taking into consideration other chronic disease management frameworks such as the WHO ICCC, and Medical Research Council (MRC). The IDCM model adopts a primary care-based approach using the core elements of the health system building blocks, including human resources, health information, pharmaceutical supply and management, governance (stewardship and ownership) and healthcare delivery activities (Figure 4).

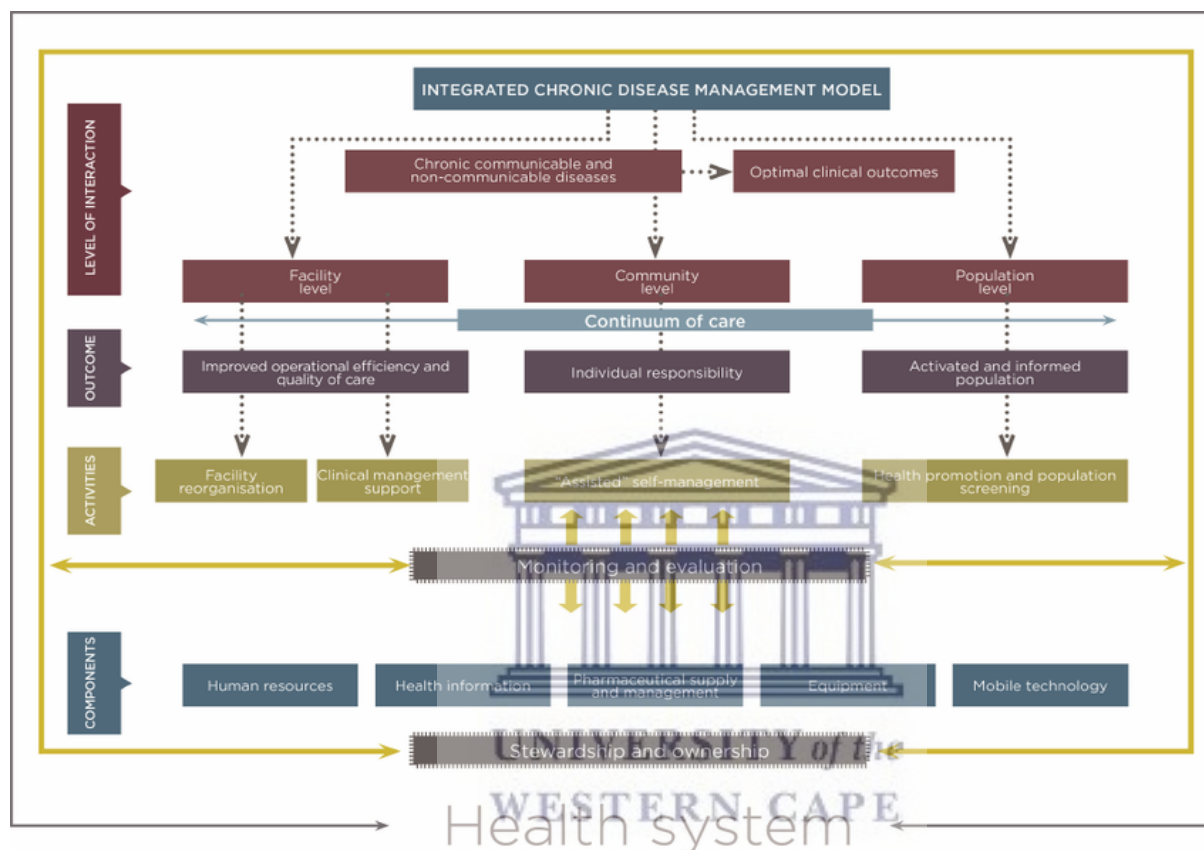


Figure 3: Integrated Chronic Disease Management model (ICDM) by Mahomed et al (2015)

This model was evaluated by Mahomed et al. 2015 (71) and found to have several strengths but also important challenges, including changing the status quo. Moving from a focus on curative treatment to chronic disease management is not easy. The mindsets, political will, and health system infrastructure proved to be challenging to allow smooth implementation of this model (72), and it was deemed suitable for refinement and further evaluation. The ICDM model follows other initiatives to improve chronic disease care in South Africa, including re-engineering primary care model.

2.7.4 The Community Oriented Primary Care model in South Africa

In 2013, the National Department of Health embarked on a primary healthcare re-engineering process which aimed, among others, to strengthen the management and control of chronic diseases at primary healthcare level. The Western Cape government set up a task force to review the primary health care (PHC) provision in South Africa focusing on the implementation of the recently adopted community

oriented primary care model (COPC). The task force came up with a framework for implementation of (PHC) in line with the COPC principles described by Mash et al 2020 (73). The framework consists of 10 building blocks or elements. Although all the 10 elements are important for chronic disease self-management, two key elements deserve a mention. These are the clear description of the composition of the primary care team and the importance of integrated collaboration between facility based and community-based primary care teams. The COPC implementation framework describes an ideal composition of the PHC team consisting of community health workers, a team leader from among the community health workers, a professional nurse, a clinical nurse practitioner, and a medical officer, with the latter two employed directly by health facilities. The PHC team could also include other healthcare professionals such as physiotherapists, dieticians, and social workers. The team is considered suitable to provide effective care for all patients including those with T2D and hypertension in South Africa.

Efforts at improving patient self-management for chronic diseases have been on-going for several years in South Africa. The first chronic disease club established in Khayelitsha where this study was done, was for patients with hypertension in 2002.(74). The health club was run by CHW who had received appropriate training. The focus was on reducing modifiable risk factors for NCDs such as weight and physical inactivity while also monitoring blood pressure and BMI. The club attendance was however hindered by environmental factors including migration. Other patient needs for improving self-management were also becoming evident over the years, such as the importance of biopsychosocial factors including culture, doctor-patient fit, illness behaviour and health locus of control(75) . There was also the “take five school” programme which aimed to educate patients with diabetes on self-care and introduce a peer-to-peer support. The programme was able to positively improve adherence to diet, physical activity and foot care but had no impact on tobacco use and medication adherence(75). The effect of health education was also not immediately noticed. Other additions towards improving self-management for chronic diseases in South Africa include brief behaviour change counselling and motivational interviewing(76) with varying successes. Challenges to effective self-management have continued to plague the concept and in South Africa some of these challenges include health system and care delivery issues, healthcare worker attitudes, patients’ personal and clinic experiences(77). Other challenges include individual and behavioural factors, social determinants, cultural practices, and socio-environmental factors (78). Technology uptake and its use to enhance self-management for diabetes is another recent addition to the many challenges faced by the patients practicing self-management in South Africa(79). Given the on-going challenges with optimizing self-management for patients with chronic diseases in South Africa, other models have subsequently been developed and tested using lessons learnt locally. One of those models includes the SMART2D framework which also addresses chronic disease self-management with a strong focus on contextual issues often not well articulated in other models.

2.7.4 The SMART2D self-management framework

The SMART2D self-management framework captures the determinants of self-management and key interactions between the individual and their socio-cultural environment (80). The framework was developed as part of the SMART2D study, a multi-site adaptive implementation trial which aimed to formulate and implement a contextually appropriate T2D self-management approach using facility and community strategies for prevention and control of T2D in three settings: a rural area in a low-income

country (Uganda), an urban township in a middle-income country (South Africa), and vulnerable immigrant populations in a high-income country (Sweden) (81). The study evaluated the outcome of the self-management approach and the added benefit of the community component compared to the facility component with a view to translate the findings in dialogue with stakeholders into relevant guidelines for policymaking, using reciprocal knowledge transfer across the different settings (82) (Figure 5).

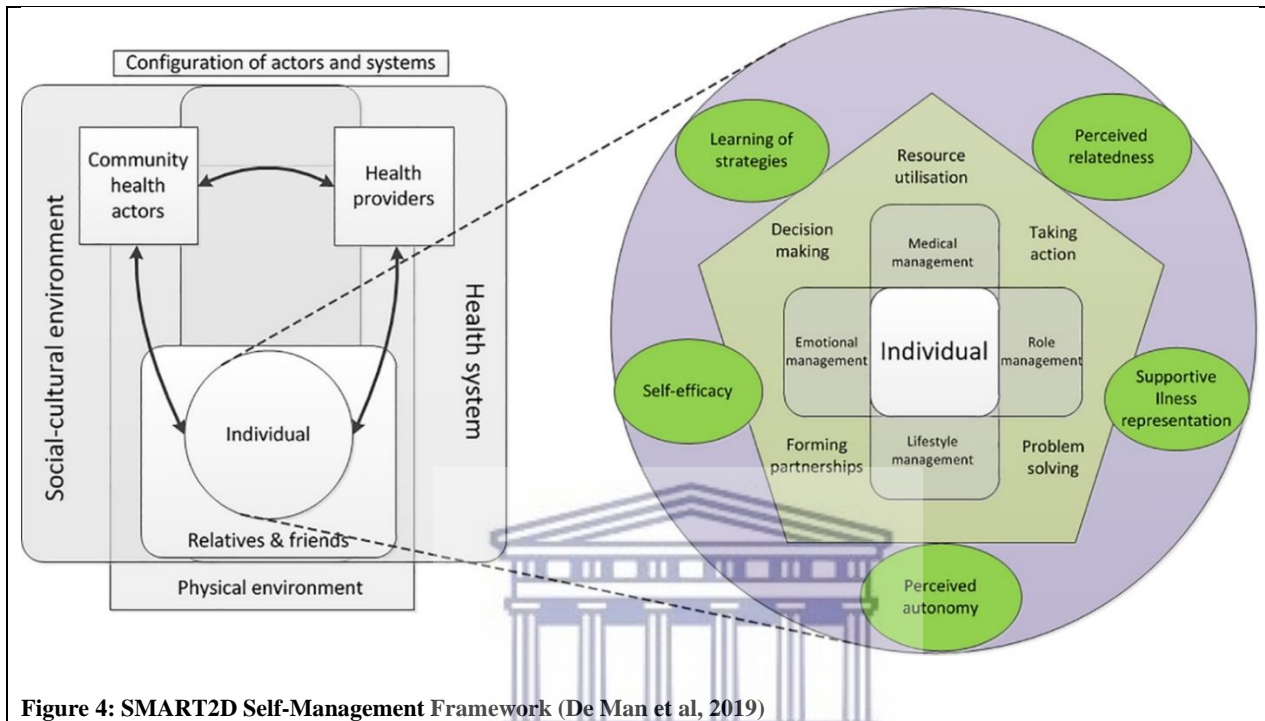


Figure 4: SMART2D Self-Management Framework (De Man et al, 2019)

The framework encapsulates the essence of other models discussed in the preceding sections and is considered an ideal multi-pronged approach to self-management. The model unpacks self-management in two settings. In the circle, self-management concepts that heavily focus on individual level factors for successful self-management are described; the four self-management principles of medical management, lifestyle management, and emotional management are first in the inner circle closest to the individual. These are then followed by individual skills required for self-management which are decision-making, resource utilisation, taking action, problem solving and forming partnerships. Additionally, the factors that promote self-management are also identified which are having a set of learning strategies, self-efficacy, perceived relatedness, perceived autonomy and supportive illness representation. Next to the circle is the square which also put the individual at the centre. The square primarily denotes environmental factors key to supporting self-management. These include health system factors, physical environment, actors and systems with the patient’s socio-cultural environment and health system. The model demonstrates the complexity of self-management practice for the patient and the importance of balancing all these factors.

Based on the above, self-management as a concept clearly requires further refinement in terms of operationalization. A lot has been written about self-management but realizing the clinical benefits and

dividends continues to be challenging. This literature review has identified some of the challenges with implementation of self-management models, especially in resource limited settings. This study suggests a simple self-management care package that will further contribute to new ways of making self-management operational and hence beneficial to patients and their families. To develop this care package, the theoretical domains framework (TDF) for developing and implementing interventions will be used (83).

2.7.5 The Theoretical Domains Framework for intervention development

The TDF provides a stepwise approach to developing interventions that are contextually relevant and appropriate, consisting of a four-step approach to developing a theory informed intervention (83). While it is designed for complex interventions, in this body of work it is used for the development of a simple self-management care package, based on the assumption that the complexity of an intervention becomes more apparent during the intervention phase and that it is important to avoid missing important aspects of the intervention. The framework (Figure 6) is used in combination with the Lorig and Holman self-management and SMART2D self-management frameworks used in this study to develop the care simple 3-3-3 care package for patients in this study and is described in detail in chapter 7.

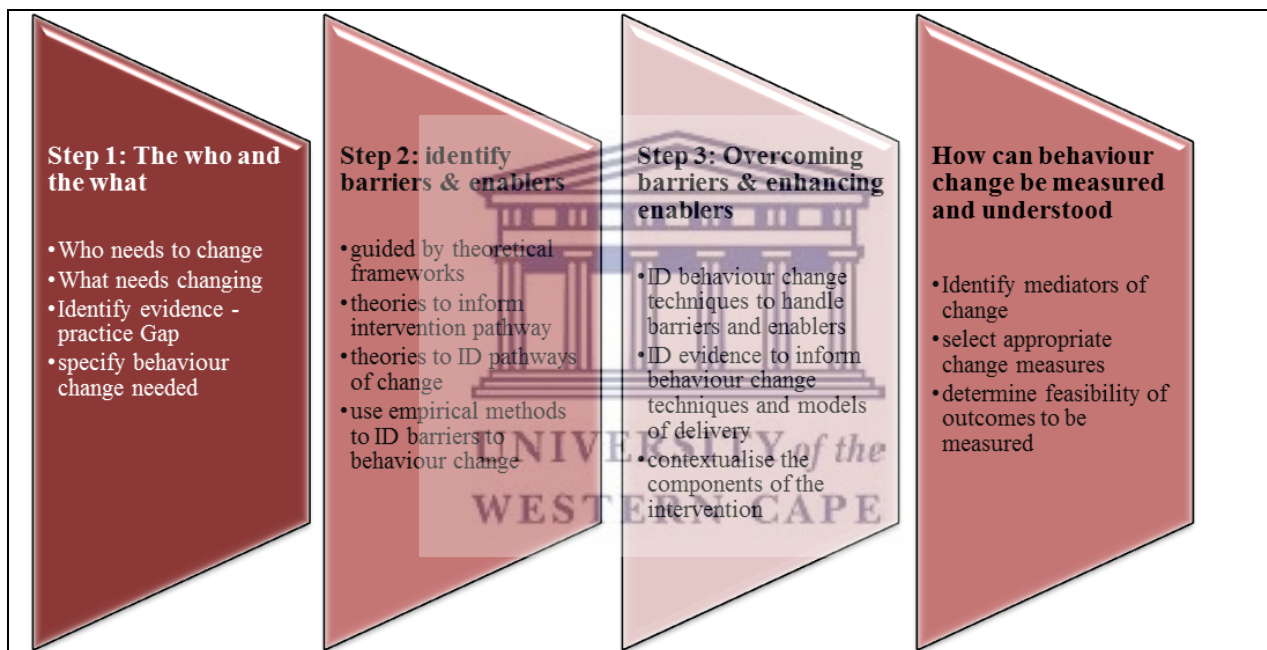


Figure 5: The Theoretical Domains Framework (French et al. Implementation Science 2012, 7:38)

Step 1- Who needs to do what differently (the who and the what)

It is important that things are not changed for the sake of change or for the sake of what is fashionable. Health system improvements often involve coordination between various partners such as governments, private entities, and development partners. There is experiential evidence that health system interventions are sometimes based on the agenda of developmental partners, especially in the realm of global health, which can lead to misalignment between country and partner priorities (84). In other cases, individual behaviours of those who are supposed to drive important interventions at national level such as healthcare

workers may also pose challenges to implementation of health system improving interventions. This was noted with implementing the chronic disease care model posing challenges for its optimal implementation in South Africa (72). It is also important that both the evidence-practice gap and behaviour change needed to be modified through the proposed intervention are informed by real evidence which is based on robust unbiased data. This study will identify which change agents are needed for the proposed care package to work as envisaged in our setting. The SMART2D self-management framework will be key to identifying what needs to change in terms of the self-management tasks of: T2D/HTN role management, emotional management, medical management, and lifestyle management.

Step 2- Identifying barriers and enablers

This step delineates three (3) key requirements in an intervention design process. These are i) identification of theories likely to inform the intervention pathway; ii) using theories to identify pathways of change; and, iii) use of quantitative or qualitative research methods to identify barriers to behaviour change (83). This step anticipates potential implementation pathways and asks researchers to plan a route for the intervention which is of least resistance, based on evidence from theory and empirical studies. The SMART2D framework provided a holistic theory underpinning the most likely pathway that the proposed intervention would take. It identifies a main route or pathway of change for the intervention, viz. the socio-cultural environment. Destinations along this route which the intervention has to contend with are the individual (patient), people in the individual's life (relatives and friends), the physical environment, community health actors (community-based organizations) traditional healers, religious leaders, political leaders, healthcare providers, and the health system itself (poorly resourced in this case). The framework therefore situates the context in which the proposed intervention will be implemented.

The inclusion of individual, community actors, health system and physical environment paves a way for the identification of health system and individual barriers likely to affect intervention implementation. The WHO health system building blocks (85) are also implied in the framework, despite not being explicitly stated. For example, community actors such as community leadership, traditional healers, spiritual leaders form a key health system building block. Healthcare providers are the key to the human resource building blocks; and community health actors can be assumed to include political leadership and policy-makers who decide on the availability of resources.

Identification of barriers to behaviour change should also include empirical methods according to the TDF. In this study a mixed methods approach will be used to collect empirical data on several contextual issues pertaining to self-management of T2D and HTN. The study explores and identifies barriers and solutions to self-management from both healthcare providers and patients using qualitative FGDs with patients practicing self-management and IDIs with healthcare workers recommending self-management. Additionally, quantitative methods were used to audit services and risk factors monitoring for T2D and HTN patients attending CDMPs aimed at, among others, enhancing self-management. The audit was a process audit of functions of disease risk factor monitoring and a cross sectional survey of patient clinical outcomes.

Step 3: Techniques for overcoming barriers and enhancing enablers.

This step requires that evidence-based techniques which will help to overcome the barriers and enhance enablers to optimal self-management are identified and applied to the contextualized intervention. This step aims at leveraging what we know has worked and contextualizing it to meet the needs of our investors, who are the patients and their providers. Health promotion or health marketing techniques are available in the literature and have been shown to work. These include techniques used by the food, alcohol, beauty, and tobacco industry. In addition, for the intervention to work it is important to recognize the critical role played by the gratification appeals at individual level driven by the taste-olfaction system in engaging with healthy diet (86), the allure of convenience food, association of beauty and weight, connection between physical activity and pleasure and physical activity and slowing down the ageing process (42).

The FGDs and IDIs provide more information on the context in terms of how patients are handling self-management in order for strategies that work and are deemed safe to be taken into consideration. This intervention will likely include behaviour change techniques that are radical and unconventional and those that the healthcare profession has shied away from for many years. With the advent of social media, COVID-19, and climate change this perception may however have changed. In addition, the social marketing aspects of health also need to change. Finally, the intervention will not succeed without strong partnerships between patients and stakeholders, because these partnerships are required to optimally operationalize self-management. The SMARTD framework recognizes these as surrounding the individual and therefore enabling decision-making, resource provision and mobilization, problem solving and forming partnerships. In fact, forming working partnerships can be considered to capture the other aspects and can act as an umbrella term in this part of the framework.

Step 4: How can behaviour change be measured and understood

This step requires researchers to identify what is likely to be feasible, locally relevant, and acceptable, and to combine selected components into an acceptable intervention that can be piloted by policy-makers. This information will be based on the findings from the three studies in this body of work as well as the literature. Here, the three steps above are combined to design a simple self-management care package for T2D/HTN patients in the Peri-Urban Townships. This package is expected to result in the strengthening of self-management using different, innovative, and achievable solutions as suggested by patients and their healthcare providers operating within this context. It will also ensure that indicators measured are relevant, feasible and contextualised in contrast to measures that are adopted from other settings.

Limitations of the TDF include time and resource constraints. While it has not been specifically applied to test interventions in our setting, we believe that it is most suited to inform our proposed package of care given its requirement for the contextualization of any envisaged interventions. Additionally, the use of this framework is triangulated with a robust theoretical framework, (SMART2D) which was developed in the context in which the research is taking place. This strengthens the choice of this framework.

2.8 Chapter summary

This chapter presented the current body of knowledge on chronic disease management, starting with the burden of disease due to NCDs, and specifically T2D and HTN, as well as the epidemiology of the two

conditions, including their risk factors. Recognizing the impact of these conditions on morbidity and mortality globally and locally, models of care currently available to manage these conditions were identified and interrogated. The review then focused on the concept of self-management and its definition, highlighting its complexity and the large volume of studies on this topic. The review identified the SMART2D self-management framework as the anchor of the study, supplemented by the TDF framework for development of a simple intervention in the form of a care package designed for the setting in which the study took place.

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Chapter 3: Study Methodology

3.1 Study setting

This study took place in two Peri-Urban Townships in Cape Town, Langa and Khayelitsha.

3.1.1 *Setting 1: Langa Township*

The first study was a qualitative study done as part of the formative phase of the SMART2D project in Langa among patients enrolled in the Prospective Urban and Rural Epidemiological (PURE) study. The PURE study tracks lifestyles, risk factors and chronic diseases among 150 000 people over a period of 15 years across 17 high to low-income countries (1,2). Langa is a township located about 11km Southeast of Cape Town and was established in 1927 (3). The predominantly black township has an estimated population of 52 000 (17 402 households), with 60% living in formal dwellings owned or rented by 28%, 22% having no income and only 7% having completed higher education (4). The township is underdeveloped, lacks infrastructure and civil services and had an estimated unemployment rate of 40% according to census data of 2011 (5). The population is served by two health facilities of which only one offers chronic care services.

3.1.2 *Setting 2: Khayelitsha Township*

The mixed methods study was based in two health facilities, Site B and Michael Mapongwana clinics in Khayelitsha. This township was established in 1980 and is located 25km Southeast of Cape Town. It has grown to become the second largest township in South Africa, mainly due to migration from the Eastern Cape (6). This predominantly black African (99%) suburb has an estimated population of 391 749 (Statistics SA, 2012), although recent estimates are likely to be higher. The average household size is 3.3 and unemployment levels stand at 38% with the majority (70%) earning an income below R 6 400 per month and 18% having no income at all (5). The suburb has seven government-run public healthcare facilities of which three are run by the Province and four by the City of Cape Town. The healthcare system is typically low resourced and burdened with both communicable and NCD care demand.

3.1.3 *Healthcare provision in both study settings.*

A key component of the COPC framework is the composition of the primary care team. The COPC implementation framework describes PHC team consisting of community health workers, a team leader from the community health workers, a professional nurse, a clinical nurse practitioner, and a medical officer, with the latter two employed directly by the health facility. The PHC team could also include other healthcare professionals such as physiotherapists, dieticians, and social workers. Healthcare delivery therefore takes place at both facility and community settings. From observation during data collection at the two health facilities in this study, the chronic disease clubs were located within the health facilities under study run as outpatient service by mainly by clinical nurse practitioners. The staff composed of a medical officer, clinical nurse practitioners, dietician, health promoter and on occasions, a social worker. In one of the facilities, the clinical nurse practitioner also held the role of a facility manager. The staffing complement in these facilities was similar to that described in another study done in the Western Cape by Delobelle et al (8) in 2020 which rapidly appraised care provision and the management of NCDs in the

Western Cape during COVID-19. Consultations were done by the clinical nurse practitioners who were also able to prescribe medication for the patients. The clinical nurse practitioners also carried out screening for disease complications. The nurse practitioners would then refer patients for further consultation with a doctor if their medical condition was not well controlled or they developed disease complications. The doctors would refer patients for further specialist care such as the retinal screening programme. The nurse practitioners also referred patients to dietician, health promoter or social worker depending on the patient's need. Patient education sessions were predominantly provided by the nurse practitioners but also by the dietician and health promoter. Clubs for diabetes and hypertension ran on a weekly basis while each individual patient attended on a monthly basis if they were stable.

3.2 Study design

This body of work used a mixed methods design to address the different research objectives. Mixed methods study designs have gained prominence in recent years due to their perceived advantage of combining strengths of both qualitative (deeper understanding of the problem) and quantitative methods (magnitude of the problems) (9). The concept of mixing different methods through triangulation is considered to have been first described by Jick (1979) who studied the effectiveness of leadership both through observation and a review of organizational records, with the view that when both methods were triangulated and congruent, they would provide a better validation of leadership effectiveness compared to the separate use of these methods.(10) Creswell defines mixed methods as those approaches that use qualitative and quantitative methods which are distinct and may use different theoretical approaches, collect different types of data and then integrate the two types of data to provide richer information on the subject of study (11). Different types of mixed methods study designs are described in the literature with convergent designs, sequential explanatory designs and sequential exploratory designs being the most frequently used designs (9,12).

For this study, we explored participants views using a qualitative approach, analysed the findings, and used those findings to inform the next phase which is usually a quantitative study (12). The first phase of this study was a qualitative study in Langa followed by a quantitative and qualitative study in Khayelitsha. Mixed methods studies involve distinct approaches, which can differ depending on the aim. One of the approaches, suggested by Fretters and Freshwater (2015), is the narrative approach for reporting findings, whereby qualitative findings are reported first, followed by quantitative findings and then an integration of both to tie the findings together in the mixed methods findings section (13). In this body of work, the findings are reported following this narrative form, and then the mixed methods findings are synthesized and used to develop a simple 3-3-3 self-management care package for the settings where this body of work took place.

3.3 Data collection

Methods used to collect data that informed this body of work are described in this chapter.

3.3.1 Qualitative methods

3.3.1.1 Contextual factors influencing T2D care and self-management (Objective 1)

This aspect of the study addressed Objective 1: To identify and gain in-depth understanding of contextual and environmental issues pertinent to the patient that could influence T2D and HTN care and self-management.

Contextual factors influencing T2D care and self-management were explored through a qualitative study conducted in Langa. Participants included 56 purposively sampled diabetes and or pre-diabetes patients from the community, PURE study database, facility health club and healthcare providers. Data collection employed two (2) semi-structured interviews and seven (7) FGDs using interview guide and a FGD topic guides.

3.3.1.2 Healthcare worker understanding and experiences of self-management

This aspect of the study addressed Objective 2: To explore the experiences of applying the concept of self-management of T2D and HTN from a patient and healthcare provider perspective.

Knowledge, beliefs, and perceptions of healthcare workers (HCWs) of the concept of self-management were investigated through face-to-face, two semi-structured interviews using an interview guide, with healthcare providers working with T2D and HTN patients attending chronic disease clubs at the selected facilities in Khayelitsha. Purposive snowballing sampling was done to include all HCWs caring for T2D and HTN patients at each study facility. IDIs were conducted by trained field workers in the local language (Isi-Xhosa) and English. Interviews were tape-recorded and augmented by field notes.

3.3.1.3 Unravelling patient's experiences and barriers to self-management

This study addressed objective 3 which was to identify the barriers towards optimal self-management of T2D and HTN from a patient and provider perspective. Experiences and barriers to self-management from a patient perspective were explored using a phenomenological study design, based on tape recordings of four FGDs with patients attending chronic clubs for T2D and HTN at the two study facilities in Khayelitsha. The phenomenological design was chosen because the research question aimed to understand lived experiences of patients experiencing the phenomenon of self-management. A FGD topic guide was used.

3.3.1.4 Sampling procedures

Sampling was purposive in the qualitative phase. According to Marshall (1996), purposive sampling or 'judgment sampling' involves a process whereby the researcher actively selects participants based on their ability to provide the most useful information to answer the research question. A range of different methods to purposive sampling is described by Ritchie & Lewis (2003), including homogeneous, heterogeneous, case deviant, case intensity, snowballing etc. Some of these approaches were to assist the researcher to select members of the healthcare workers and the different patient focus groups. The specific sampling procedures are detailed under each study.

3.3.2 Quantitative methods

The quantitative phase of this mixed methods study addressed objective 4: ‘To evaluate health service provision within chronic disease clubs using annual risk factor monitoring of T2D and HTN patients as the index measure.

Assessment of health service provision of risk factor monitoring and prevention of disease complications in the facilities in Khayelitsha providing chronic care and self-management of T2D and HTN was done through a standards-based outcome audit using standards derived from the Practical Approach to Care Kit (PACK) which incorporates the South African PC101 guidelines (14) and the guidelines developed by the Society of Endocrinology, Metabolism and Diabetes of South Africa (15).

3.3.2.1 Outcomes audit

This audit was a facility based descriptive cross-sectional survey of 372 patients with Type 2-diabetes mellitus (T2DM) and / or HTN receiving care at the two facilities described above. This design was chosen because of its usefulness in assessing the prevalence of complications of T2D and HTN in this population undergoing self-management care for a chronic disease. A survey questionnaire was used for data collection. Trained research assistants and CHWs conducted the field work. A summary of patient’s variables collected is shown in table 2 below.

Table 2: Patient Variables collected

Dependent Variables	Independent Variables
Self-efficacy, self-management	Age
Lifestyle behaviour (exercise, diet, smoking, alcohol)	Gender
Self-reported T2D complications	Occupation and income
Clinically confirmed (medical records or measured) diabetes complications (retinopathy, peripheral vascular disease (amputations), foot care)	Level of Education
Blood pressure measurement, BMI, waist circumference	

Inclusion criteria were patients aged 18-74 years old; having had T2D/ HTN for at least 6 months; living and using healthcare services in the selected facility for at least 6 months prior to enrolment in the study; no acute illnesses; able to undergo anthropometric evaluation; and able to give informed consent. Exclusion criteria included co-morbid conditions that could affect occurrence of disease complications and conditions that could affect patients’ ability to provide full informed consent.

3.3.2.2 Sample size estimation

In a study in three community health centres in Cape Town, diabetes retinopathy was estimated to have a prevalence of 55.4% (CI 48.90-62.9); peripheral neuropathy was 27.6% (CI 15.2-39.4); amputations 1.4%; persistent proteinuria 5.3% (CI 2.5-8.1) and elevated albumin creatinine 36.7% (CI 29.0-44) (16). The

prevalence of diabetes retinopathy was highest and was hence used for sample size calculation in this study.

The following formula for sample size calculation for cross sectional studies, was used (17): $n = \{Z_{1-\alpha/2}^2 p(1-p)\} / d^2$ whereby n =sample size, $Z_{1-\alpha/2}^2$ =statistics level of confidence=1.96, d =precision level =0.05 (5%), p =expected proportion of T2D retinopathy based on the above study $p=55.4\%$ (0.55). A sample size = $\{1.96^2 \times 0.55(1-0.55)\} / 0.05^2 = 380$ was calculated, with each clinic providing half of the required minimum sample.

3.3.2.3 Sampling method

Systematic random sampling was used as most practical for this setting. A clinic attendance register for each day was used as the sampling frame. Oral communications with staff at both clinics estimated that at least 30 patients are seen daily for T2D or HTN. Each day during data collection, every second patient was sampled for enrolment. This process was repeated until the sample size was reached. Patients whose names had been selected from the register were approached after they received medical attention. They were given information about the study and asked for permission to participate. Following that, they were taken through the informed consent process and enrolled in the survey. Patient outcomes were estimated as prevalence (%) of different diabetes and or hypertension related complications.

3.3.2.4 Process audit

The process audit was done at the same facilities in Khayelitsha that were selected for the SMART2D project as the two largest clinics providing public health services to the community. The process audited was that of risk factor monitoring on patients attending the chronic disease clubs to assess how well the risk factors were assessed, documented and monitored during consultations with patients. This audit consisted of retrospective records review of the patients enrolled in the survey above, for a 10-year period from 2009-2018. The period was selected because the Western Cape government introduced an annual integrated chronic disease audit in 2009 (18). Within each facility, medical records of patients attending chronic disease clubs for T2D and HTN to be audited were selected to match the patients enrolled in the cross-sectional survey. These records therefore belonged to the same patients included in the survey described above. The sample size for this population was estimated as follows: $n = \frac{Z^2 P(1-P)}{d^2} = \frac{1.96^2 \times 0.131(1-0.131)}{0.05^2} = 174$ where n =sample size, Z =statistic level of confidence=1.96, d =precision level =0.05 (5%), P = T2DM prevalence in Khayelitsha ($P=13\%$; 0.131) in 2012 (19). A minimum sample of 174 medical records was audited from each facility. A newly designed audit tool was piloted and used for the audit (Annex 4). Key variables assessing diabetes control and risk factor management to be audited included: screening / diagnosis (SD), care delivery (CD1), education–observation (ED), psychological care (PSM), lifestyle management (LSM), glucose control levels (GCL), clinical monitoring (MO), self-monitoring (SM), glucose control – tablets (GCT), glucose control – insulin (GIN), blood pressure control (BP), cardiovascular risk protection (CV), eye screening (ES), kidney damage (KD), foot care (FT) and nerve damage (ND). These variables were adapted from the IDF minimal care package and PC101 guidelines for the management of T2D and HTN. Socio-demographic and biomedical characteristics of participants in the process audit and the number of times the standard for each topic was met are reported,

resulting in an overall assessment of risk factor monitoring and management for patients with T2D and HTN in these facilities.

3.4 Self-management Care Package Development

This aspect of the work addresses objective 5: ‘To recommend a simple care package for optimal self-management of chronic diseases in Khayelitsha using T2D and HTN as examples. Diabetes self-management is considered critical for patient care to prevent complications and to cope with the required lifestyle and behaviour changes (20). Diabetes self-management education was however found to be poorly addressed in the South African policy guidelines in an audit of T2D self-management programs (21), which highlights the need to recommend a contextualised self-management care package for enhancing self-management of T2D and HTN in this setting. Addressing HTN self-management is equally important given the shared risk factor profile for CVD as explained in the pathophysiology section in the literature review.

3.4.1 Theoretical framework for the self-management care package development

Two frameworks were used during development of the proposed self-care package. The SMART2D Self-Management framework situated the study in identifying the factors that influence self-management experiences of both patients and healthcare providers and was also used to inform recommendations. The adapted TDF (22) was used to develop the self-management care package because of its utility in developing and implementing health interventions.

3.4.2 Chapter interconnectedness- overarching theme

Given that the aim of this study is to design a simple self-management care package tailored to the local context, that enhances self-management of T2D and HTN, objectives 1-4 provided key background information on the context under which the suggested intervention in objective 5 will operate. Because health related interventions are usually implemented by healthcare workers, this required assessing their understanding and experiences of self-management in order for gaps to be identified and addressed during the intervention development (objective 2). Patients will be the consumers of this self-management care package. We therefore need to understand their experiences when practicing self-management, as well as the potential factors that are barriers to self-management (objective 3), which may prevent uptake of the intervention before the intervention is designed and recommended. This enhances the acceptability and increases likely success of the care package. Objective 4 provided pertinent programme information on gaps in risk factor monitoring for early detection and prevention of disease complications among the patients attending CDMPs where self-management support takes place. The information on gaps identified in the chronic disease clubs process and outcomes audit was further used to inform the intervention being proposed in the form of a simple self-management care package. Objective 5 was achieved by providing the suggested self-management care package informed by the TDF combined with the SMART2D self-management framework.

3.5 Data management and analysis

This section describes the summary of data management and analysis methods for the whole study. The details of the specific analyses are described in the individual published papers in Chapter 4-6

3.5.1 Qualitative data management and analysis

Recordings of IDIs with healthcare workers and FGDs with patients were transcribed verbatim and translated into English. Thematic analysis was undertaken to derive emergent themes using ATLAS.ti version 7.5.1.5 software. Validity and trustworthiness were ensured by triangulation using different coders; researcher bracketing during data collection; use of bilingual field workers trained in T2D, and researchers trained in qualitative data analysis; use of a transcriber who was not part of the data collection team and monitoring and reviews by academic supervisors.

3.5.2 Quantitative data management and analysis

Data was taken from the completed audit tools and survey questionnaires and entered into Redcap, cleaned and transferred to an Excel spreadsheet. After further cleaning of the data, analysis was undertaken using SPSS statistical software version 22 and logistic regression analysis done using R-Software. The primary analysis for clinical audits was done at the end of the follow up period and included all patients with complete data tools and follow up. Descriptive statistics using measures of central tendency and dispersion were calculated using bi- and multivariate analysis. For the cross-sectional survey, the proportion of patients with specific complications were calculated to estimate the prevalence of each of these complications. Determinants of complications among the patients were analysed through a 3-step multivariable regression analysis model.

3.5.3 Maintaining Rigour in the study

3.5.3.1 Validity and reliability of quantitative data collection

Two types of validity threats were identified for this study, including internal and external validity (11). Potential threats to internal validity included participant selection and instrumentation. Participant selection was addressed through systematic random sampling. Validity of the audit tool was established by piloting the tool among a similar population, the results of which were excluded from the audit findings. While the survey questionnaire had been derived from a composite of questions based on previously validated instruments, it was further validated through pilot testing in a similar population. Threats to external validity could arise from statistical conclusions by making inferences and generalizations to populations which are different from the population from which the sample was drawn. In this study, statistical inferences are only generalizable to the Khayelitsha patients with T2D and HTN. Threats to construct validity arise when there is ambiguity in defining concepts being studied (23). This was minimized through a clear definition of key concepts around self-management based on the literature.

Reliability was assured through literature review, clear study eligibility criteria, randomised sampling, identification of potential confounders, and use of regression models to account for confounding. The researcher practiced academic honesty in reporting and dissemination of results. Additionally, there was on-going monitoring and reviews by academic supervisors.

3.5.3.2 Validity and reliability of qualitative data collection

For qualitative data, validity and trustworthiness were ensured through triangulation by using different data collection methods (HCW in-depth interviews, patient FGDs); researcher bracketing during data collection, use of two coders, data analysis both by the researcher and supervisors; and by monitoring and reviews of academic supervisors.

3.5.3.3 Ethical considerations

Ethics clearance was received from the University of The Western Cape biomedical ethics review board REC NUMBER -130416-050 and the Western Cape government granted access to the study sites through the respective facility managers (permit WC_2017RP50_730).

3.5.3.4 Chapter 3 summary

This chapter provided the overall methodological considerations that were followed during the conduct of this study including both the qualitative and quantitative phases of the study. The chapter concluded with data management and ethical considerations. The next three chapters describe the individual published studies for this thesis in detail.

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Chapter 4: Study 1: Redefining Diabetes and the Concept of Self-Management from a Patient's Perspective: Implications for Disease Risk Factor Management

Masupe TK, Ndayi K, Tsolekile L, Delobelle P, Puoane T. Redefining diabetes and the concept of self-management from a patient's perspective: implications for disease risk factor management. *Health Educ Res.* 2018 Feb 1;33(1):40-54. doi: 10.1093/her/cyx077. PMID: 29315392; PMCID: PMC6018984.

4.1 Introduction to the chapter

This paper addressed objective 1 which aimed to identify and gain in-depth understanding of contextual and environmental issues pertinent to the patient that could influence T2DM care and self-management. At the time of writing this paper, the acronym T2DM representing type-2-diabetes mellitus, was in use and the paper was published with the acronym. In subsequent publications the acronym T2D is used.

4.1.1 Role of the candidate

Across the three publications, the role of the candidate was study conceptualization, proposal writing and development, lead data collection processes, lead data management and analysis, lead manuscript conceptualization, writing, finalization, submission, and responses to reviewer comments.

4.1.2 Role of co-authors

Different co-authors participated at different levels of the thesis and manuscript writing process. They added comments, provided guidance, literature sources, support with response to reviewer comments, and approved manuscript submissions on request of the candidate.

4.2 Abstract

The colliding epidemics of non-communicable diseases including diabetes with chronic infectious diseases in Sub-Saharan Africa (SSA) requires contextualized innovative disease management strategies. This qualitative study conducted in a Peri-Urban township near Cape Town, South Africa aimed to identify and gain in-depth understanding of contextual and environmental issues pertinent to the patient that could influence Type 2-diabetes mellitus (T2DM) care and self-management. Participants included purposively sampled patients living with diabetes or diagnosed with pre-diabetes from the community, PURE study database, facility health club and healthcare providers. Data collection employed IDIs and FGDs using structured interviews and FGD topic guides. Thematic data analysis was done to identify recurrent themes. Themes identified: knowledge and awareness about T2DM; health-seeking behaviour; weight perceptions; healthy lifestyles; self-management; health education needs and healthcare provider experiences. Patients defined T2DM as a physically and emotionally dangerous disease caused by socio-cultural factors, influenced by the sufferers' food and socio-cultural environment with significance placed on physical, social and emotional effects of T2DM diagnosis. Patient-centred definition of T2DM is key to enhancing T2DM self-management. Patients suggested that personally rewarding benefits of physical activity and healthy diet such as anti-ageing, brain boosting, energy boosting which are commonly harnessed by food, tobacco and beauty industry should be considered in T2DM self-management strategies.

4.3 Introduction

Chronic non-communicable diseases (NCDs) have been rising over the years, with 68% of global mortality attributed to NCDs in 2012 and estimated to cost seven trillion US\$ cumulative economic losses in low- and middle-income countries between (LMICs) 2011 and 2025 if no concrete action is taken to combat the epidemic (1). The highest burden is estimated to be in developing countries (2). Cardiovascular diseases and metabolic conditions account for the highest prevalence (1). In South Africa, a high prevalence of Type 2-diabetes mellitus (T2DM) has been reported across the population, estimated at 8.3% among people aged 20–79 years in 2013 (3) and even higher at 13.1% among urban dwelling black South Africans (4) and at 26.3% in the coloured population (5). The prevalence of T2D and hypertension in the setting of this study, a Peri-Urban predominantly black township in Cape Town is likely to be high. Given the emerging pandemic of NCDs, new innovative approaches to disease prevention and management are critical.

Historically, diabetes has been defined in terms of abnormal glucose metabolism detected by various biochemical tests (6) or, in the case of T2DM, due to abnormal exocrine pancreatic function (7). T2DM in the patient education literature is also defined in terms of abnormal tests of glucose metabolism (8,9). The research question for this study relates to what diabetes really means to the lay person and the patient from a phenomenological and social ontological perspective. Based on our findings, we will define diabetes from a patient's perspective and argue that lack of this appreciation from a healthcare professionals' perspective significantly hampers diabetes control and patient self-management. We also argue that the concept of self-management is more complex than discussed in the literature and does not take into account the understanding and interpretation of the concept, by the very patient for whom it is designed.

The concept of self-management in its ideal form should be patient-centred, encompassing the different facets of patient context, multi-disciplinary healthcare teams and a responsive healthcare system (10). Chronic disease self-management programmes (CDSMP) have been in existence for many years and focus on behaviour change for the major risk factors (physical activity, smoking cessation, alcohol consumption and diet) as well as patient self-efficacy for specific disease management. Guidance on T2DM management in South Africa has been provided by the Society for Endocrine Metabolism and Diabetes of South Africa (SEMDSA), it includes a focus on self-management (7). According to SEMDSA, self-management is centred on patient education, which should include training on basic diabetes knowledge; glucose self-monitoring; recognition and management of both chronic and acute diabetes complications; risk factor modification behaviours such as smoking cessation, physical activity, diet and alcohol minimization and coping mechanisms such as psychosocial support. As in many other settings in the region, however, comprehensive patient education and assurance of patient adherence remains impossible to achieve (11,12).

The literature suggests that patients enrolled in CDSMPs have better health outcome measures compared to those receiving the usual standard of care for T2DM (13) and other chronic diseases (14,15). Studies describing these programmes, however, tend to be randomized controlled trials with a short follow-up period of 6–12 months. Evidence from a systematic review of interventions tailored for self-management

by Radhakrishnan (16) also casts doubt on the true effectiveness of these interventions when reviewed holistically taking into consideration all other resources required to provide such care and suggests that these interventions may not be superior to standard of care interventions. These findings are also supported by others (17).

The current study is nested within the SMART2D project. SMART2D is a multi-site study on T2DM of which the overall objective is to formulate and implement a contextually appropriate T2DM self-management approach through facility and community components for prevention and control of T2DM in three settings: a rural area in a low-income country (Uganda), an urban township in a middle-income country (South Africa) and vulnerable immigrant populations in a high-income country (Sweden). The study aims to evaluate the outcomes of the self-management approach and added benefit of the community component compared to the facility component only; and to translate the findings in dialogue with stakeholders into relevant input for national guidelines and policies, using reciprocal knowledge transfer across the different sites.

4.4 Methods

4.4.1 Type of study and setting

The study was undertaken in Langa township, a mainly Xhosa speaking part of Cape Town, South Africa. The study site was selected because of complementarity with another study conducted in this area, the Prospective Urban and Rural Epidemiological (PURE) study, which tracks lifestyles, risk factors and chronic diseases among 150 000 people over a period of 15 years across 17 high to low-income countries (18). The township was established prior to the apartheid era for black Africans and in 2011 had a population of around 52 000, of whom nearly half was younger than 25 years old and six in ten did not complete secondary education (19). The settlement is underdeveloped, lacks infrastructure and civil services, and the population is served by two health facilities of which only one offers chronic care services including T2DM care and management. Factors associated with rising levels of NCDs in this population have been described by Puoane and Tsolekile (20), and one such major contributor was socio-cultural factors driving health behaviours in the townships. For example, eating lean meat was considered ‘stingy’ and preference is given to eating fried foods such as fried chicken skins which are tasty and affordable. Walking as part of physical activity on the other hand was associated with chores that people who have now moved from rural to urban areas do not want to be associated with anymore. These include walking to fetch water, gather firewood and tend animals. When it comes to diet, food is considered as part of showing love, acceptance and humanity and for those living in the townships, eating food items such as meat daily is considered a sign of higher social status (21).

4.4.2 Study design

This was a qualitative study with a phenomenological design using IDIs and FGDs. The study design was chosen because the main objective was to gain a deeper understanding of what diabetes means to patients living with it and their experiences of engaging in self-management of T2DM.

4.4.3 Study population

The study sample was selected from the population of adult patients having lived with diagnosis of T2DM and receiving services for their T2DM in the selected facilities in Langa Township. A purposive sampling approach was used to include only patients who can provide information that will lead to a deeper understanding of living with T2DM. Participants for this study were sampled from the PURE database and by referral from health facility staff and included males and females aged 35–72 years old; having been diagnosed with T2DM or known to be at risk of T2DM and selected from the health club attached to the facility or from their community. In addition, healthcare workers involved in the care and management of T2DM patients were purposively selected, including physicians, nurses and community health workers (CHWs) in charge of the health clubs. Healthcare workers eligible for the study were those actively caring for patients diagnosed with T2DM in Langa Township.

4.4.4 Data collection

Data were collected using IDIs and FGDs. There were seven FGDs with eight participants per group conducted with men and women. In addition, two IDIs were conducted with healthcare workers. Data were collected using a semi-structured interview guide, that was translated in the local language (isiXhosa) and preliminary analysis conducted to refine these instruments, while further FGDs and IDIs were organized until saturation was achieved.

Written consent was sought from all study participants and permission to use a recording device obtained. Interviews and FGDs were conducted in isiXhosa lasting between 45 and 90 minutes and all recordings were transcribed verbatim. These interviews were done by research assistants trained in conducting qualitative interviews including FGDs and IDIs. The research assistants were supervised by researchers in the study who are trained in qualitative research methods. All data collectors were bilingual and fluent in both English and isiXhosa, live in the area and understand the culture and norms. The study area is mainly inhabited by Xhosa South Africans.

Data were analysed using thematic analysis with codes to identify recurrent themes, by systematically searching transcripts in line with a set of predefined themes. This approach, known as the framework approach (22) was found to be suitable for analysis of qualitative data in multi-disciplinary health research (23). Continued data analysis was used alongside data collection to allow further refinement of research questions and avenues of enquiry to be developed. Reliability of study findings was assessed using consistency checks, by comparing the findings with results from prior/co-existing research, using within-project triangulation, feedback from research participants and feedback from end-users of the study findings (stakeholder checks) (24).

4.5 Results

4.5.1 Participant demographics

Seven FGDs were conducted with individuals diagnosed with T2DM. Out of these, five FGDs were conducted with participants enrolled in the PURE study (Groups 1, 3, 4, 6 and 7). Two FGDs were

conducted with female PURE participants known to be at risk of T2DM, selected according to their body mass index (BMI), age and the presence of HTN. FGD participants were between 30 and 70 years old.

PURE is a global study which seeks to identify the population level factors that drive the development of known risk factors for chronic NCDs, so that their distribution in the entire population can be shifted favourably by appropriate societal interventions (primordial prevention) (18). It includes participants from 23 countries at different levels of development, including South Africa which is a middle-income country with two study sites managed by the North-West University and University of the Western Cape. The current study was conducted in Langa, the University of the Western Cape study site, where 2058 people were recruited for study participation in 2009–2010.

Group 1: Composed of PURE participants who were all male aged between 45 and 72 years.

Group 2: an all-male group aged between 43 and 69 years. (Non-PURE) two men were also known to be hypertensive in this group.

Group 3: mixed male and female group aged 49– 66 all had HTN (PURE).

Group 4: all male group aged 35–58 diabetes (PURE).

Group 5 all women aged 32–65, all had HTN while two had diabetes (Non-PURE).

Group 6 all women aged 36–60 and diagnosed with diabetes (PURE).

Group 7 All women aged 40–68 all had diabetes (PURE).

Initial codes for the FGDs were developed by the study team from the SMART2D topic guide. Two coders were assigned to analyse the transcripts. One coder used a manual approach while the second coder used Atlas.ti software version 7.5.0, 1993–2016. Codes identified from meaning units in the texts of the transcripts were grouped into sub-categories and categories. Relationships between different categories were explored in more detail and re-analysed, leading to the emergence of several themes in accordance with the framework of the topic guide, which are summarized in Table 3.

Table 3: Themes, categories and subcategories of the thematic analysis (25)

Themes	Categories	Sub-categories	Quotation
Factors influencing Health seeking behaviour	<ul style="list-style-type: none"> Nature of and available health services Specific triggers to health seeking behaviour 	Distance from people Symptoms of disease present Symptoms perceived as serious	<ul style="list-style-type: none"> What makes people lazy to take their treatment is that the facilities are very far so it would be better if clinics were brought closer for us the elderly even if it here where the kids play... I was not feeling well, I was bleeding with my nose and it was discovered that it was high blood pressure.

Themes	Categories	Sub-categories	Quotation
			<ul style="list-style-type: none"> • She only started going to the hospital when she realised that she was on death bed
Beliefs about the causes of T2DM	<ul style="list-style-type: none"> • Conventional causation • Unconventional causation 	Genetics Diet Alcohol Stress Traditional beliefs Unusual eating patterns	<ul style="list-style-type: none"> • When I read to enhance my own knowledge I discovered that diabetes is caused by genes, if your grandmother had diabetes it is likely that can develop it through inheritance • I was going to say, it has something to do with food. You see McDonalds and restaurants; those are dangerous foods • Sometimes in males it is caused by alcohol • You see sometimes in females it is caused by stress • There she kicked a spider, the following day when she was going to work, she felt that there was something wrong and she went to the doctor. She was then diagnosed with diabetes. • One other thing is liking cold stuff, do you understand because things from the fridge are dangerous
Awareness of T2DM and its severity	<ul style="list-style-type: none"> • High prevalence • Multi-system complications • Significant severity 	A common disease Cause of mortality Cause of morbidity Emotional complications General complications	<ul style="list-style-type: none"> • Yes, they do, I can say it is 70% of them have knowledge about diabetes • It is common in Vanguard because when I visit there I see people with loads of tablets, and I assume that they are the victims of diabetes. • Diabetes is the most dangerous one. • Because if you have a sore it ends up Some end up with their legs removed. There is someone that I know that had both of their legs removed • Something that it kills as well, it's manhood, yeah. (M: okay)Even

Themes	Categories	Sub-categories	Quotation
			<p>with women that happens, it kills her feelings towards another person,</p> <ul style="list-style-type: none"> • Mhm ... and then there is another thing that is killed by diabetes, you see, eyesight, it kills eyesight
Diabetes self-management	Health professional supported Personal choices Religious beliefs Traditional practices Mixed traditional and modern practices Lack of self-acceptance	Self-discipline Overeating Eating mixtures of food Not selective with food Traditional food controlling T2DM Spiritual intervention Mixed interventions Peer pressure Self-acceptance or denial Stigma	<ul style="list-style-type: none"> • Maybe a person eats according to her/his preferences but according to the doctor you are supposed to have a healthy diet, change your eating habits like avoiding fatty foods such as fat meat, and eat fish instead. • When you do not discipline yourself in terms of food. There are people who eat everything under the sun, you can give them a bucket full of food, they eat, and you give them fish they eat. • They said this person died because he was not taking his treatment. When they went to search his house, they found sealed packets of tablets, he never touched any tablet ever since. • We do not know for sure if it is true when they say sorghum and stout controls diabetes. • I would suggest that they should go to church, in my church some people get cured of the diseases that they were suffering from. • I would say maybe s/he takes Xhosa mixtures
Factors influencing physical activity	<ul style="list-style-type: none"> • Barriers to exercise • Meaning of exercise • Benefits of exercise 	Why people do not exercise Meaning or types of physical activity Early childhood activities	<ul style="list-style-type: none"> • Most of the time people become obese because they are lazy • I am exercising by cleaning my house, moving my beds, wardrobes and cupboards. Also I do my laundry with my hands, I band my waist when I am doing my laundry, and they do not do anything, except that jogging.

Themes	Categories	Sub-categories	Quotation
		related to exercise How people exercise	<ul style="list-style-type: none"> The reason for not engaging in physical activity is laziness, having oppressed mind and unavailability of tracksuits. If we were granted the opportunity to play sport when we were growing up in our time as black people we were never brought close to sport and then we grew up lazy we complain about muscle stiffness.
Benefits of physical activity	<ul style="list-style-type: none"> Spiritual benefits General health benefits Cardiovascular benefits Anti-ageing Energizing Brain power Happiness & strength 	<p>From the creator</p> <p>Circulation benefits</p> <p>Gets rid of unwanted toxins in the body</p> <p>Alert and energized</p> <p>Happy fit and strong</p>	<ul style="list-style-type: none"> Because that is what gives you life this is written in the book. Jesus in the first place didn't not create man to just laze around, he created man to work but people do not know this The benefits are that your health is good The other things with exercising is that it health with blood circulation helping your heart as an exercising person, you heart beats well compared to a person that sits down In addition to that when you exercise the more you sweat they more things you burn in your body, exercising burns You always energetic, you always want to work. You will never feel like sleeping all the time. your brain stays alert and diseases cannot easily attack you because your body cells are active as bhuti mentioned that body cells fights with foreign bodies Strength, fitness, happiness, [laughs] and to keep your brain alert.
Factors influencing healthy diet intake	<ul style="list-style-type: none"> knowledge describing healthy diet perceived Barriers to healthy diet 	<p>Meaning of Healthy diet</p> <p>Cooking methods</p>	<ul style="list-style-type: none"> Seafood and chicken, we eat that but you must not fry it you must boil think. Skimmed milk not full cream. Another thing is to avoid cooked meat and buy a half a sheep's head. Half a sheep's head is healthy

Themes	Categories	Sub-categories	Quotation
		<p>Meaning of Unhealthy diet</p> <p>Reasons for not eating healthy diet</p> <p>Cultural perspectives</p>	<p>because it is cooked with water, no oils added.</p> <ul style="list-style-type: none"> • The most healthy meal I know is samp and beans and samp soup and pap and African salad those are our traditional foods but not we now love the new western foods • When we talk about unhealthy foods we refer to fat cookies. I am referring to fat cookies with chips, Fried meat, fried eggs • They are passing, passing always eating take aways, and they are ever hungry, they want something quick. • You buy the stews because healthy foods are expensive • We buy what we can afford • No healthy food is really affordable for real the problem is the meat because you find that it is R500 or R800 • Healthy food does not taste nice, and it is difficult to eat healthy. It is tasteless. • Braai meat, people here are lazy to cook.
Views on weight	<ul style="list-style-type: none"> • Conventional views • Lay beliefs 	<p>Health issues</p> <p>Low energy</p> <p>Physical appearance</p> <p>Employability issues</p> <p>Some stigma</p>	<ul style="list-style-type: none"> • Obesity is not right, when you are obese that means you are suffering from a disease. • It's not okay cause you not active enough, an overweight person might take 10 min to do something whereas an average weight person it will be quicker and they will have the energy • It's also easy Getting heart disease cause your heart is floating above fats. • I do not encourage obesity, because when you are obese you will think that you are healthy and forget that

Themes	Categories	Sub-categories	Quotation
			you are at high risk of getting diseases and the diabetes that we were talking about can make you blind. You will be a laughing stock

4.5.2 Health seeking behaviour

As regards health seeking behaviour, study participants accessed care from the local clinic only and therefore were inclined towards seeking medical attention for their diabetes from conventional or modern medical practitioners. Some participants however also sought care from local herbalists while some combined both traditional and modern medicine for their T2DM. Health seeking behaviour varied depending on the perceived intensity of distress from immediately seeking assistance to delayed access of care and other forms of self-care, such as buying paracetamol and home-made remedies. People delayed seeking help for diabetes symptoms unless they perceived the disease as very serious:

“She only started going to the hospital when she realised that she was on death bed”

Health seeking behaviour was also influenced by the fear of diagnosis as well as potential treatment for the symptoms

“I didn’t feel like taking tablets, I kept saying I’m going to fetch my medication but when that day came [laughs] I never went”

The perceived skills of healthcare providers and traditional knowledge and beliefs of the patients also played a significant role in whether a patient will seek medical help for their symptoms, as shown in this quote:

“Sometimes even doctors don’t know the actual cause of a certain thing that he had not encountered before, maybe after some time it will show.” (Male, 35 years)

Meaning that those who believed that doctors may not be able to diagnose their condition would prefer to wait until such time that they believe the disease process will have reached a state where they can get a correct diagnosis.

4.5.3 Knowledge and awareness about causes and risk factors for T2DM

As regards community awareness of NCDs, HTN was most frequently reported, but T2DM was also widely acknowledged as a serious condition and perceived to be part of everyday life. Gaps in knowledge were observed with regards to NCD knowledge particularly risk factors for T2DM. Traditional beliefs and beliefs about witchcraft were found to influence knowledge of NCDs, as illustrated by the following:

“There kicked a spider, the following day when she was going to work, she felt there was something wrong and she went to (see) the doctor. She was then diagnosed with diabetes.” (Female, 49 years)

Age, family history and parental influences in terms of dietary behaviour were identified as contributing to the development of T2DM. Indigenous foods, such as samp and beans, and mealie-meal mixed with pumpkin as well as green leafy vegetables, were considered to be protective and affordable, whereas unhealthy food choices, including fast food, were believed to contribute to the development of T2DM. T2DM was described as a very dangerous disease that left the sufferer with multiple complications including leg amputation and sexual dysfunction as illustrated by the quote below:

“Something that it kills as well, it’s manhood, yeah. (M: okay) Even with women that happens, it kills her feelings towards another person” (female)

4.5.4 Perceptions on weight

Participants entertained both negative and positive views with regard to overweight, including stigma, increased health problems and effects on personal relationships, but obesity was also perceived as being a sign of happiness and wealth or having a genetic origin, as illustrated by the following:

“There are people who are obese, there are people who were born obese, and there are people who are just big. They all need to do exercise, always run so that they can be flexible and not lazy”
(Male, 35 years)

4.5.5 Healthy lifestyles

Perceived barriers to physical activity included lack of willingness and resources to exercise, and social upbringing where there was no opportunity to exercise. However, some participants contested this and blamed the lack of activity on laziness. Exercise was associated with general health benefits, such as increased capacities, brain booster, detoxification, happiness and general strength. In addition, exercise was thought to confer cardiovascular benefits and have an anti-ageing effect, as illustrated by this quote:

“When you are always sitting around you get old quickly, but if you work (out) a lot you do not”
(Male, 41 years)

Physical activity was also deemed to confer spiritual benefits as illustrated in the quote below:

“Because that is what gives you life; this is written in the book. Jesus in the first place didn’t create man to just laze around, he created man to work but people do not know that this is pleasing to the creator”

The definition of a healthy diet seemed difficult to describe succinctly, while the definition of unhealthy diets was diverse and culture dependent. Some defined unhealthy diets as eating fatty local foods such as fat cakes and chips while others defined it as a non-African or Western diet, as illustrated by the following:

“But the most healthy meal I know is samp and beans and samp soup and pap and African salad those are our traditional foods but we now love the new unhealthy western foods”

Factors perceived as influencing a healthy diet included inadequate knowledge regarding the difference between healthy and unhealthy foods, the cost of buying healthy food, cultural practices, alcohol abuse and unhealthy cooking methods. Cultural influences on addressing weight seemed difficult to change, although childhood overweight and obesity were thought to be modifiable using lifestyle changes. The taste of food was also considered an important factor in eating a healthy diet as illustrated in the quote below:

“Healthy food does not taste nice, and it is difficult to eat healthy. It is tasteless.”

4.5.6 T2DM self-management

Factors reported by participants to influence T2DM self-management included personal discipline (e.g. overeating, not being selective in food choices), traditional beliefs and religious practices, as suggested by the quote below:

“I would suggest that they go to church, in my church some people get cured of the diseases that they were suffering from.” (Female, 35 years)

Other behavioural factors that contribute to poor self-management included peer pressure, attributes of the healthcare professional, fear of diagnosis and treatment as well as convenient ignorance as shown in the quote below:

“The homemade sorghum, I drank the beer on Sunday, and Monday I was going for check-up. When they checked my blood pressure, it was fine. It was not really fine, but the beer helped me”

Information sources related to T2DM included personal experience or living with a relative with T2DM but depended on availability of information and self-assessed levels of knowledge. There was a strong demand for more information about T2DM prevention and management, such as symptom management (e.g., managing hyperglycaemia) and treatment adherence, as illustrated by the following quote:

“If you arrived in a scene where the person has already collapsed, how would you know that the person collapsed because of diabetes or because of epilepsy? Maybe if you have knowledge about diabetes, you can be able to tell if the person collapsed because of diabetes.” (Female, 49 years)

4.5.7 Health education needs

Participants reported a need for more community-based education regarding T2DM self-management and treatment, with peer group education considered a preferred method of education, as well as use of trained facilitators (e.g., retired nurses). Methods of delivery and types of information sources varied; however, ranging from media-billboards and pamphlets to text based mobile health messaging. Participants also advised to start teaching children about T2DM risk factors to have a Positive impact on their lives:

“I would like to suggest that diabetes should be incorporated in the school’s curriculum, because children learn fast as they are still young and maybe the nurses should go to school just to give children guidance about diabetes and high blood pressure; now they are focusing on HIV/AIDS and do not give much attention to diabetes – but it is a silent killer” (Female with diabetes, 45 years)

4.5.8 Provider experiences on caring for T2DM patients

Nurses in the facility reported that clients, when screened for T2DM receive health education, followed by a series of follow-up visits before referring to the facility health club when the patient is considered stable. They reported issues with tracing patients who did not attend for scheduled appointments due to lack of a tracking system and reported ignorance among patients as regards T2DM complications. They advocated for community- based support and follow-up. They, however, did not favour using CHWs as this could be perceived as breach of confidentiality and opined that training the CHWs would add more workload for them. With regards to pathways of T2DM care, patients reported dissatisfaction due to long waiting times and the waste of time spent at facility clubs. In their experience, health professionals also lacked the time to offer patients adequate support regarding their condition.

4.6 Discussion

In the current study nested within the SMART2D project, we sought to identify and understand contextual and environmental issues pertinent to the patient that could potentially influence T2DM care and self-management. Findings from our study identified a new understanding of the dialogue healthcare professionals should have with their patients regarding their health seeking behaviour, physical activity and weight management, which led us to conclude that a patient-centred definition of T2DM should be considered as a starting point for enhancing diabetes self-management. Based on these findings, we also argue that new innovative approaches are required to motivate patients to engage in meaningful, sustainable self-management for early detection, prevention and management of T2DM.

Self-management is interpreted as a self-control exercise which is heavily influenced by complex interaction between sufferers’ traditional and religious beliefs, social norms and peer pressure, and something that requires individual capability. Health seeking behaviour, self-acceptance, peer pressure and self-discipline are critical for its success. Approaches to self-management should therefore entail thinking outside of the norm and using health promotion strategies that recognize this complexity. The mainstay of self-management strategies that healthcare workers direct at patients to undertake at home in managing their T2DM include: increasing physical activity, healthy eating to control the blood sugar and weight management. Patients have heard all this before and in fact believe this is business as usual. Strategies that will better motivate patients to engage in healthy behaviour required for controlling their diabetes should be considered and could include marketing the soft benefits of physical activity, healthy eating and weight management that appeal to patient’s psychological reward systems similar to those used by other industries, such as the fast food, tobacco, and the beauty industries, but guided by professional medical ethics. Robinson (26) describes a set of ‘stealth interventions’ whereby behaviour change does

not have to ‘look, feel and taste like health education’, but instead interventions should be motivating in themselves and target identity, values, beliefs and emotions at individual, community or societal level.

In this study, T2DM was defined as a physically and emotionally dangerous disease caused by sociocultural factors and heavily influenced by the sufferers’ food culture and traditional beliefs. Patients did not define diabetes biomedically in terms of blood sugar or glucose metabolism, but as something that one would rather prevent because it changes you as a person, both physically (amputations) and emotionally (sexual dysfunction and loss of libido), and as a disease with a complex aetiology, including witchcraft and unusual eating habits. Similar findings were reported by Awah (27) in Cameroon where culture was a strong influence in patients definition of diabetes and suggested ‘culturally impelling’ and ‘culturally inclusive’ interventions for chronic conditions such as diabetes which are strategies recognized in the WHO innovative care for chronic conditions framework (28). While the main aim of prescribing increased physical activity, healthy diet and weight management as mainstay towards self-management of T2DM is to control blood sugars, this is not the major goal for T2DM patients compared to healthcare workers’ goal. Therefore, to patients, this is a secondary gain while the primary gain is their prevention of changes in their physical appearance and emotional well-being as a result of diabetes. The definition of T2DM, when viewed from a social ontology perspective, shows that T2DM is perceived as a reality by patients based on the morphological and emotional and psychological changes it causes. The definition varies between individuals, suggesting multiple social realities for defining the disease. The prevailing view appears to be inclined to objectivist and constructivist views rather than a pragmatist view. For example, some quotations lean towards a constructivist view that diagnosis of T2DM may not be perceived as a social fact but rather as constructed depending on social factors such as what the parents of a child with diabetes may have done to cause the disease. Others focus on an objectivist view that eating junk food and drinking very cold drinks will result in one becoming a person living with diabetes. The case can hence be made towards adopting a social ontological perspective in the CDSMPs to enhance diabetes self-management and control.

A recurring theme on barriers toward physical activity was noted to be laziness. Laziness as a barrier to physical exercise has been reported among patients attending a diabetes clinic in a teaching hospital in South Africa (29) and in other studies on diabetes patients elsewhere (30). Work on motivational issues is therefore needed to get the community to engage in physical exercise.

The relationship between physical activity and ageing is not only anecdotal but has been documented in the literature and explained in terms of the effect of physical activity on the growth hormone insulin like growth factor axis known to regulate age related changes (31); promoting healthy mitochondrial biogenesis (32) and benefits to the age-related dysfunctional changes in cardiovascular endothelium (33). This is the science behind recommendations for physical exercise for disease prevention. The population in our study, however, comprising of patients living with diabetes or diagnosed with pre-diabetes, are unlikely to internalize this kind of knowledge even if simplified in the plain English or translated to their local language. Therefore, a different approach to making this scientific information more appealing and user-friendly, starting from a basic human need for reward, gratification and self-esteem is needed.

People like to look good because it makes them feel good. Looking good in the study context however could mean either being overweight or not overweight. The community context and cultural undertones on obesity or normal weight will need to be given important consideration when packaging messages for management of overweight and obesity. We propose packaging the message on risk factor management (physical activity, healthy diet, smoking cessation and alcohol in moderation) to appeal to this very simple principle, which can be explained by various psychology theories such as the social cognitive theory (26).

An argument can be made for leveraging on existing social structures and using some of the marketing strategies used by the food and drink industry, tobacco industry or the pharmaceutical industry to appeal to the soft benefits of T2DM risk factor management. The Coca Cola Company have launched a new campaign called ‘taste the feeling’ which aims to ‘bring to life the idea that drinking a Coca-Cola—any Coca-Cola—is a simple pleasure that makes everyday moments more special’ and reflect both the ‘functional and emotional aspects of the Coca-Cola experience’ (34). Given the negative health effects of tobacco, the tobacco industry advertisements target features that the consumer can identify with, such as age, as evidenced by reported doubling of teen smoking uptake within 6 years of Phillip Morris Virginia launching the Slims cigarette targeting young women with the slogan: ‘You Have Come A long Way Baby’ (35). The pharmaceutical industry uses similar approaches to market their products. It is estimated to command a staggering \$131 billion by 2019 and trends show that it has grown exponentially since 2009 from \$12.9 billion to \$15.3 billion despite global economic challenges prevailing during this period (36). The beauty industry reaches out to consumers using targeted specific measurable effects that appeal to the soft side of the consumer such as looking young, vibrant, age defying characteristics of their products (37), which could also be used for advocating healthy lifestyle changes among people living with T2DM or people known to be at risk of T2DM.

Using physical activity and diet as examples, let us look at some of the methods that can be used in advertising physical activity and healthy eating to prevent diabetes.

4.6.1 Physical activity message packaging

Would this kind of marketing health for chronic disease risk factor management be deemed controversial for the health sector or are healthcare professionals missing an opportunity to reach the inner core of our patients through the use of tried and tested methods? Would this be deemed unethical, where will the harm be? If this would be deemed to cause harm, one can argue that perhaps by not adopting these strategies that have been shown to work, we are indeed causing harm to our patients and therefore already violating the principle of non-maleficence. Could healthcare professionals use branded media such as a video showing free, fun ways of exercising other than gym - participants walking with friends for a fun-filled purpose? A randomized controlled study published in *The Journal of Paediatrics*, 2016 done in the USA, showing a vinyl banner attached to the base of the salad trolley displaying vegetable characters; a short television segment next to the trolley with health education delivered by vegetable characters and a combination of the vinyl banner and television segments showed that intake of vegetables increased by 90.5% among children shown the vinyl banner only and 239% among those shown both the banner and the video (38). Using the ‘metshelo’ meetings (local support groups for social events such as weddings and funerals that meet regularly as happens in South Africa and Botswana) for aerobics sessions for

example to promote physical exercise the fun way could be a localized consideration. These sessions could be similar to Zumba fitness but using music that is produced locally and chosen by the patients themselves.

Some of the participants in our study for example suggested shared funeral plans or burial societies as a way of supporting each other and promoting healthy lifestyles among people living with T2DM. The idea being that they use these as support groups where they learn and share experiences about living with T2DM, use the meetings as opportunities to discuss lifestyle modifications supportive of controlled diabetes management, given that such meetings and schemes are popular and tend to be well attended. In addition, the health sector could also team up with religious leaders or organizations to promote the message of keeping fit ('pleasing to the creator') to appeal to the spiritual side of patients.

Likewise, physical activity was also described as a brain and energy booster by study participants. The healthcare sector could be promoting physical activity as a natural fun filled treatment that slows down forgetfulness and increases happiness by learning for example from the coke advert 'open happiness' (39). High levels of drinking have also been associated with marketing through digital media, and especially the use of approaches that encouraged interactivity with young people were deemed attractive (40), resulting in the authors suggesting restriction of such marketing strategies. Could an argument be made that rather than restriction measures which have been shown to be ineffective against the transnational food, alcohol and tobacco industries (41) the same strategies could be used to promote healthy behaviours?

4.6.2 *Weight management message packaging*

Consumers have reported finding health messages on food rather confusing especially where health claims are based on one component out of several other unhealthy ones within the same food item (42). Mechanisms by which marketing of food influences eating habits have been identified in the literature and fall into four categories which are: pricing; marketing communications such as health claims, branding, advertising, promotions and nutritional value; nature of the food product including sensory properties, packaging and composition; the food environment, including availability; and socio-cultural perspectives (21,43). Out of these categories, the food environment has been identified as the least studied but the most influential when it comes to driving actions of consumers through its effect on consumer automatic and volitional control (43).

In our study, affordability, availability and taste were some of the important factors contributing to choice of food. Marketing strategies which target these factors can therefore be considered for this population. Such a marketing strategy could include rebranding of healthy foods on non-health related positive benefits that people can relate to (26). The physiology of food taste, olfaction and reward processes in the brain are well described in the literature (26). Food that smells good tends to taste good and this is due to the convergence of olfactory-taste receptors in the fronto-orbital cortex of the brain (44,45). Our study findings showed that healthy food is perceived to lack taste and appeal. Some ideas to explore would therefore be to harness the science behind the olfactory-taste convergence theory and have 'MasterChef-like' cooking classes for T2DM, which enhance food taste and appeal while preserving essential nutrition, and which persons with T2DM would be encouraged to attend each month when they collect their medications.

Other factors such as portion size which has been shown to lead to increased food intake and potential weight gain (46), and stress mentioned as one of the causes of weight gain in this study and the literature (47), will need to be taken into consideration as part of an overall health promotion package. Another intervention to consider in our study setting would be to engage with street vendors who sell convenience foods. It has been shown that most people will eat convenience food because of proximity to where they are (48). Street vendors act as convenience food take-away for local people and bring food to where the consumer is. They could be trained on serving healthy appetizing convenience food. Making healthy food easier to get on the go has been found to increase consumption of healthy food (49).

While healthy foods tend to be associated with higher prices and unhealthy foods with cheaper sale prices, there is evidence that lowering price of healthy food items can also increase the uptake and consumption of healthy food (43). Pricing policies which lower food commodities can however be subject to socio-economic and political considerations, as well as pressure from the food and beverage industries and unlikely to be well enforced. Health promotion strategists should not be deterred but work with local produce that people can easily access such as samp, beans, spinach and other food items which are more likely to work in our study setting. In addition, public health professionals need to start collaborative research work that explores how best the taste-olfaction-reward system already identified to be operating within the human brain can be harnessed to produce food that is tasty, healthy and nutritious in the local context.

4.7 Study limitations

Findings are based on interpretations of information provided by people living in a township area of Cape Town where majority fall under the low socio-economic stratum of society. Views reflected may therefore be influenced by their psychosocial environment and not generalizable to the South African population as a whole.

4.8 Conclusions

The current status quo needs to be challenged when it comes to promoting healthy eating and physical activity for prevention and self-management of T2DM. This need has been documented in this study using findings from in-depth exploration of factors influencing health seeking behaviours such as the uptake of physical activity, healthy diet and general knowledge about T2DM. T2DM carries a different meaning for the patient compared to the healthcare professionals, and that meaning places significance on the physical, social and psychological changes that results from the diagnosis. Patient literature on T2DM should incorporate this patient definition of T2DM. Self-management of the disease is also interpreted from a social ontological perspective that healthcare workers often pay little attention to. Harnessing the important rewards-based benefits of physical activity and healthy diet that include defying age, brain boosting, energizing and detoxification should be given due consideration as part of health promotion activities for T2DM patients. Public health professionals need to consider use of so-called stealth interventions to promote physical activity and healthy eating among T2DM patients. Further research is recommended using randomized controlled clinical trials and longitudinal studies to evaluate some of the

innovative patient-centred interventions suggested in this article. This will be in keeping with advances in disease prevention and management suggested in the WHO report on innovative care for chronic conditions (28).

4.9 Supplementary data

Supplementary data are available at HEAL online.

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4.12 Conflict of interest statement

None declared.

4.13 References

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Chapter 5: Study 2: Prevalence of Disease Complications and Risk Factor Monitoring Among Diabetes and Hypertension Patients Attending Chronic Disease Management Programmes in a South African Township

Masupe T, De Man J, Onagbiye S, Puoane T, Delobelle P. Prevalence of disease complications and risk factor monitoring amongst diabetes and hypertension patients attending chronic disease management programmes in a South African Township. *Afr J Prim Health Care Fam Med.* 2021 Sep 8;13(1):e1-e7. doi: 10.4102/phcfm.v13i1.2997. PMID: 34636603; PMCID: PMC8517752.

5.1 Abstract

Background: South Africa established chronic disease management programmes (CDMPs) called “clubs” to ensure quality diabetes care. However, the effectiveness of these clubs remains unclear in terms of disease risk factor monitoring and complication prevention.

Aim: We assessed risk factor monitoring, prevalence, and determinants of diabetes related complications among type-2 diabetes (T2D) and hypertension (HTN) patients attending two CDMPs.

Setting: Urban Township in Cape Town, South Africa.

Methods: Cross-sectional survey combined with a ten-year retrospective medical records analysis of adult T2D/HTN patients attending two CDMPs, using a structured survey questionnaire and an audit tool. SPSS version 25 was used to analyse risk factor monitoring and calculate prevalence of complications. Potential determinants of complications were explored through logistic regression.

Results: There were 379 patients in the survey, 372(97.9%) had HTN only while 159(41.9%) had T2D and HTN 361 medical records were reviewed. Blood pressure (87.7%) and weight (86.6%) were the best monitored risk factors. Foot care (0-3.9%) and eye screening (0-1.1%) were least monitored. Nearly 22% of patients reported one complication, while 9.2% reported ≥ 3 complications. Medically recorded complications ranged from 11.1% (1 complication) to 4.2% with ≥ 3 complications. The commonest self-reported and medically recorded complications were eye problems (33%) and peripheral neuropathy (39%), respectively. Complication occurrence was positively associated with age and female gender and negatively associated with perceived illness control.

Conclusions: T2D/HTN patients experienced diabetes related complications and inadequate risk factor monitoring despite attending CDMPs. Increased self-management support is recommended to reduce complication occurrence.

Key words: diabetes complications, hypertension, illness perception, chronic disease management programmes, risk factor monitoring, self-management support

5.2 Introduction

In the 1990-2019 global burden of disease study, high fasting plasma glucose and high BMI were recorded as the most increased risk exposures to health while HTN was the risk factor that showed the largest increase accounting for 10.8 million deaths (1). Most data on NCD prevalence in South Africa comes from national surveys such as the South African National Health and Nutrition Examination Survey (SANHANES-1) conducted in 2012, which revealed an age-standardized prevalence of diabetes in South Africans aged 15 and above of 10.1% (2). Prevalence rates were higher among the people of colour population as well as among women (3). Additionally, an increased mortality from diabetes was reported by the Burden of Disease Research Unit at the South African Medical Research Council (4) probably resulting from lifestyle changes, urbanization and increasing overweight and obesity among South Africans (5). According to WHO data, approximately 27.4% of men and 26.1% of women in South Africa have HTN (6), though a higher prevalence of up to 60% has been reported (7). Studies have estimated a high prevalence of diabetes complications in South Africa including any grade of retinopathy (55.4%), proliferative and pre-proliferative retinopathy (15.6%), cataracts (7.9%), peripheral neuropathy (27.6%), absent foot pulses (8.2%), and amputations (1.4%) (8). Diabetes retinopathy was the most common complication (9). Nearly 80,000 Years Lost to Disability were attributed to diabetes and its complications in South Africa in 2009 (10).

South Africa has implemented several policies to guide self-management programmes for quality diabetes care. One such policy was the establishment of chronic disease management programmes (CDMPs) called “clubs,” aimed at equipping patients with the necessary knowledge and self-management skills in order to reduce disease progression and complications (11). In these clubs, stable patients get access to medication, receive monthly blood pressure and glucose monitoring, and health education on self-management of lifestyle disease risk factors. However, the effectiveness of these clubs remains unclear in terms of chronic disease monitoring and halting the progress to complications. The Western Cape NCD audit of 2016/2017 (folder review) which included the two facilities in this study, identified poor adherence to T2D and HTN management (12). However, this audit, did not assess prevalence of disease complications and only reviewed around 45 patient folders per facility. To address this gap, this study assessed yearly monitoring for disease risk factors and estimated the prevalence and determinants of disease complications among T2D/HTN patients attending CDMPs in a Peri-Urban township in Cape Town, between 2018 and 2019.

5.3 Methods

5.3.1 Study design

This was a cross-sectional survey combined with a ten-year retrospective patient records analysis (2009-2018), conducted in March 2018.

5.3.2 Setting

The study took place in two community health centres in Khayelitsha, a predominantly black African (90.5%) township in Cape Town with a recent official population for 2019/2020 estimated at 442721 by

the Western Cape government (13). Patients were attendees of CDMPs where they had medication review, disease control, and risk factor monitoring and health education.

5.3.3 Study population and sampling strategy

The study population consisted of 379 patients with T2D and/or HTN (T2D/HTN) selected from the daily clinic attendance register in both facilities using systematic random sampling. Eligibility criteria included: aged between 18-74 years; diagnosed with T2D/ HTN for at least six months, living in Khayelitsha and attending the CDMP at the selected facility for at least six months; not experiencing acute illness; and able to give informed consent. Eligible patients were asked to participate while waiting for medical consultation. After receiving study information, consenting patients were enrolled.

The prevalence of diabetes retinopathy was used for sample size calculation since it was well documented by a previous study. A minimum sample size of 380 was calculated using Charan & Biswas prevalence estimation formula (14). Each health centre provided half of the required minimum sample size. Additionally, 361 medical records matching survey participants for the period 2009-2018 were audited. The percentage of missing data per variable varied between 0.0 and 2.3%, except for waist circumference (8.1%).

5.3.4 Data collection

A structured survey questionnaire, based on the WHO-STEPS Instrument (15) was used to collect demographic and socioeconomic data; behavioural measures (diet, physical activity, tobacco and alcohol use); medical and medication history; and self-reported complications (eye problems, foot pain, diabetes retinopathy, diminished peripheral pulses, peripheral neuropathy and amputation). Anthropometric measures (height, weight, waist circumference) sitting blood pressure and biochemical measures (FPG, HbA1c) were also collected.

Self-management variables of diabetes knowledge and illness perception were also measured. Knowledge was measured using the Diabetes Knowledge Scale consisting of 13 items from the validated Diabetes Knowledge Questionnaire (DKQ-24), selected based on their contextual relevance (16). Correct answers were scored as 1, and incorrect or 'Don't know' responses as zero, yielding a total score ranging from 0-13. Perceived diabetes and HTN control was measured using three items selected from the Brief Illness Perception Questionnaire (B-IPQ) (17), which is validated across 36 countries, 26 languages, several continents and a variety of illnesses including T2D and cardiovascular diseases among patients aged 8-80 years (18). Selected items included: 'How much control do you feel you have over your diabetes or hypertension?' with responses ranging from 'Absolutely no control' (0), over 'Limited amount of control' (1) and 'Good amounts of control' (2) to 'Complete control' (3). The other items related to the perception of treatment and reported experience of symptoms. Scores ranged from 0 to 9. Factor loadings of this construct were tested using confirmatory factor analysis, ranging from 0.62 to 0.74, and coefficient alpha was 0.72, indicating adequate internal reliability.

To assess risk factor monitoring for disease control and clinician-recorded complications, a retrospective medical audit of patient files was conducted using an audit tool designed by combining variables from

relevant international, national and local guidelines (19–21), and patient facility monitoring cards, used for recording and monitoring of chronic disease care in the Western Cape. The tool captured information on self-care, knowledge, beliefs, and health education on lifestyle risk factor management (diet, exercise, smoking, alcohol use); psychological status; biometric monitoring (annual height, weight, and waist circumference); glucose control and clinical monitoring; cardiovascular risk indicators (blood pressure, total and low-density lipoprotein cholesterol, aspirin use); foot care; eye care (annual screening); renal function and medication management and monitoring.

5.4 Data analysis

Data captured in the audit tools and survey questionnaires was transferred into Redcap software hosted at the University of the Western Cape. Two field workers entered the same participant data independently and then compared their entries, enabling data quality checks during the data collection phase. Field worker supervisor and the research team undertook additional data checks (missing data, data consistency, and deviant entries) before exporting data into an Excel spreadsheet. After cleaning, data was analysed using SPSS statistical software version 25.

The proportion of eligible patients who received risk factor monitoring annually was calculated to assess disease monitoring. Descriptive statistics were produced and the proportion of patients with specific complications was calculated to estimate prevalence rates. Multivariable logistic regression using R software was done to explore associations between the occurrence of complications (binary dependent variable) and socio-demographic characteristics and self-management (independent variables). In a first model, the socio-demographic characteristics included were age, gender, education, married or cohabiting, employment status, and income. In a second model, self-management variables were added, including diabetes knowledge and perceived illness control, while socio-demographic variables and reported intake of oral anti-diabetes medication were included as control variables. The occurrence of complications corresponded to ‘having any self-reported complication’ or ‘having any clinician recorded complication’.



5.5 Ethical Considerations

Health facilities participating in the study also granted permission to access the facilities, patients, and their medical records.

5.6 Results

Most patients (n=372; 98%) had HTN, with 159 patients (42.0%) having T2D/HTN (see Table 3). Most respondents were female (n=308; 81.3%); mean age was 55 (+/-10.4 years). Two fifths (n=160; 42.2%) had no or primary level education, and over half were unemployed (n=210; 55%). Nine in ten (n=336; 88.6%) had a BMI \geq 25. A fifth (n=73; 19.3%) had consumed alcohol while 48(12.7%) had used tobacco products in the last 12 months. Nearly half (n=173; 45.6%) scored above 75% on the T2D/HTN knowledge questionnaire, and 294(78%) reported good to complete control over their T2D/HTN.

Table 4: Background characteristics of the study population (n=379)

Characteristic	N	%
Diagnosis		
HTN	372	98.2
T2D/HTN	159	42.0
Gender		
Male	71	18.7
Female	308	81.3
Age Group (mean 55 +/-10.4)		
20-49	100	26.4
50-64	208	54.9
65+	71	18.7
Marital Status		
Never married /cohabited	72	19.0
Married/cohabiting	173	45.6
Separated/divorced/widowed	134	35.4
Education		
None	24	6.3
Primary	136	35.9
Secondary	142	37.5
Tertiary	77	20.3
Occupation[#]		
Employed	91	24.0
Unemployed	210	55.4
Retired	76	20.1
Average income per household/month		
<ZAR1500	59	15.6
ZAR 1500-ZAR3000	212	55.9
> ZAR3000	108	28.5
Household size		
1-4 members	184	48.5
5 or more members	195	51.5
Body Mass Index (BMI)		
18.5-24.9_(normal)	42	11.4
25-29.9_(overweight)	74	19.5
30-34.9_(class I obesity)	84	22.2
35-39.9_(class II obesity)	79	20.8
≥ 40 (class III obesity)	99	26.1
Current Tobacco use (last 12 months)	48	12.7
Used alcohol in the past 12 months (yes/no)	73	19.3
Physically active (≥ 30 min/day) in the last week		
1-3 days	225	84.3
4-7 days	42	5.7
Diabetes knowledge (correct answers)		
≤50%	53	19.0
51-75%	153	40.4
> 75%	173	45.6

Perceived illness control

No / limited control	85	22.4
Good / complete control	294	77.6

#= 2 petty traders were excluded from analysis as their unemployment status was unclear. ZAR = South African Rand;

Of the 372 available medical records, 361(97.0%) were eligible for review. Most patients (n=351; 97.2%) were prescribed antihypertensive medication in 2009, increasing yearly to 358(99.1%) by 2018. There were 56(35.0%) T2D patients prescribed chronic diabetes medication and/or insulin in 2009, increasing yearly to 150(94.3%) by 2018. Risk factor monitoring was best for weight (86.6%) and blood pressure (87.7%). Patient’s annual weight monitoring increased from 11.9% in 2009 to 86.6% in 2018, and blood pressure monitoring increased from 21.2% in 2009 to 87.7% in 2018. Annual advice on foot care was 1.7% in 2010 (vs. 3.9% in 2018) and eye screening (0% in 2009 vs. 2.0% in 2018) (Figure 7).

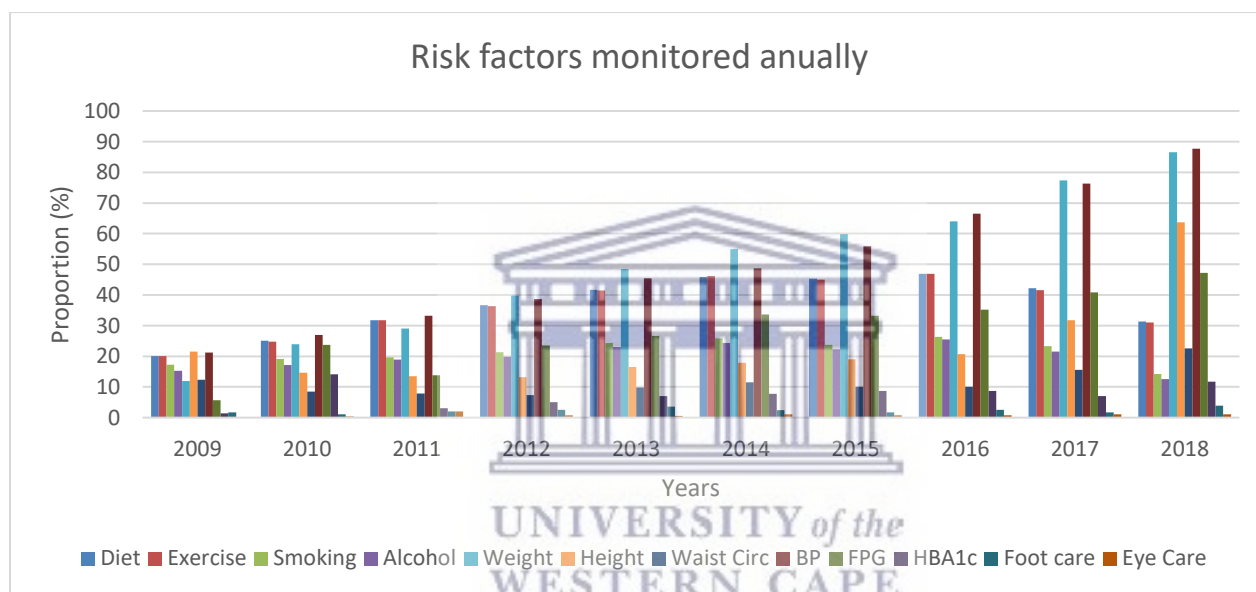


Figure 6: Annual risk factor monitoring (medical records audit 2009-2018)

5.6.1 Self-reported and medically recorded complications

Overall, complications were reported by 172(45.4%) of patients. Nearly one quarter (n=84; 22%) of patients reported one complication, 84(22.2%) reported two complications, and 35(9.2%) reported three or more complications. There were 73(20.2%) patients with a complication documented in their medical records. Medically recorded complications ranged from 11.1% (1 complication) to 4.2% with 3 or more complications (Table 4).

Table 5: Proportion of self-reported / medically recorded complications

Number of complications	Self-reported (N=379)	Medically recorded (N=361)
0	207(54.6)	288(79.7)
1	84(22.2)	40(11.1)
2	53(13.9)	18(5.0)
≥ 3	35(9.2)	15(4.2)

5.6.2 Prevalence and Types of Disease Complications

The most common complications reported by participants were eye problems (n=125; 33%) and poor circulation (n=104; 27.4%), while the least reported was amputation (n=3; 0.8%). From the medical records, peripheral neuropathy (n=62; 16.4%) was the most prevalent complication, while amputation (n=4; 1.1%) was least prevalent (table 6).

Table 6: Prevalence of self-reported / medically recorded complications

Variable	N=379 all	%	N=159 Diabetes only	%
Diabetic retinopathy of any grade				
Yes	33	8.7	33	20.7
No	346	91.3	126	79.2
Diminished peripheral pulses				
Yes	29	7.7	29	18.2
No	350	92.3	130	81.8
Foot ulcers in the past in the year				
Yes	8	2.1	8	5.03
No	371	97.9	151	95
Peripheral neuropathy in the past year				
Yes	62	16.4	62	39
No	317	83.6	97	61
Amputation in the past year				
Yes	4	1.1	4	2.5
No	375	98.9	155	97.5

5.6.3 Determinants of disease complications

Self-reported occurrence of complications was positively associated with age and female gender (Table 7). Education, marital status, employment status and income showed no consistent association. Tertiary education, however, was positively associated with occurrence of self-reported complications. Perceived illness control was negatively associated with occurrence of medically recorded complications. Diabetes knowledge did not show an association with self-reported complications, but a weak positive association with the occurrence of medically recorded complications.

Table 7: Determinants of self-reported and medically recorded disease complications

	self-reported complications				medically recorded complications			
	Model 1		Model 2		Model 1		Model 2	
	Est.	SE	Est.	SE	Est.	SE	Est.	SE
Female gender	0.62*	0.30	0.52\$	0.31	0.62	0.38	0.81*	0.41
Age	0.04***	0.01	0.05***	0.01	0.03*	0.01	0.02	0.02
Primary education	0.46	0.50	0.54	0.51	0.18	0.67	0.28	0.69
Secondary education	0.64	0.50	0.70	0.40	0.58	0.66	0.78	0.67
Tertiary education	0.99\$	0.53	1.09*	0.53	0.76	0.69	0.81	0.70
Married or	-0.12	0.24	-0.19	0.24	0.59*	0.29	0.52\$	0.30
Unemployed	-0.43	0.28	-0.42	0.28	-0.07	0.35	-0.12	0.36
Income	-0.00008	0.0002	-	0.0002	-0.0005	0.0003	-0.0005	0.0003
Oral T2D medication			-0.60**	0.23			-0.15	0.28
Perceived illness			-0.02	0.06			-	0.08
Diabetes knowledge ^a			0.13	0.10			0.23\$	0.13

Legend: Logit estimates of socio-demographic characteristics (model 1); and socio-demographic characteristics and self-management variables (model2). ^a Diabetes knowledge was only estimated for people with T2D. P-value codes < 0.001 ‘***’ < 0.01 ‘**’ < 0.05 ‘*’ < 0.1 ‘\$’

5.7 Discussion

5.7.1 Key findings

This study assessed the process of monitoring for disease risk factors and estimated the prevalence and factors associated with disease complications among T2D/HTN patients attending two CDMPs in an urban township in South Africa. A significant proportion (45%) of patients reported at least one disease complication while medically recorded complications were at one fifth (20%). Age, gender and perception of control over disease were associated with disease complications in this population. There was overall, poor yearly monitoring for disease risk factors in the CDMPs but showing a gradual increase between 2009 and 2018. In this study, the best monitored risk factors were weight and blood pressure, similar to a study evaluating lifestyle care process among T2D patients in South Africa (22) Despite that, nearly 90% of the patients were overweight/obese, a known risk factor for insulin resistance and diabetes complications, indicating that monitoring needs to be complemented with appropriate interventions when risk factors are identified. Foot care was poorly monitored despite its importance in preventing amputation, one of the most feared diabetes complications contributing to delayed health seeking according to T2D patients in another township in South Africa (23). Despite the high prevalence of eye problems, eye screening was also poor in these CDMPs. Similar findings were observed in the Western Cape NCD audit (12) attributed to possible infrastructural and human resource challenges. We recommend that eye and foot care monitoring should be given more attention and suggest additional research to identify the barriers explaining this poor monitoring.

5.7.2 Discussion of key findings

Other studies have recorded a higher prevalence of some complications than ours, including a similar study done in patients attending clinics in Cape Town in 1997 which recorded a prevalence of any grade

of retinopathy of 55.4%, compared to 20.7% in ours, but lower peripheral neuropathy (27.6%) compared to 39% in our study (8). The differences could be due to their complications rates being measured in real time by study physicians rather than retrospectively reported by patients or based on medical records. It is also noteworthy that in absolute numbers, the number of participants reporting eye problems and the number of participants with medically recorded diabetic retinopathy was exactly the same at 33 each. This could give us some level of confidence that eye problems are investigated when patients report them. Despite that, an important limitation of using self-reported measure is the tendency towards under-reporting which could potentially lead to under-estimation of prevalence measures hence the use of both self-reporting and medical records measures. Complication rates in our study are also lower than those from a Tanzanian study, which reported 49.6% (95% CI 28.6–70.7) ophthalmic, and 28.8% (95% CI 8.0–65.1) neurological abnormalities (24), possibly reflecting health system differences, as the latter study did not report complication rates among patients attending CDMPs.

The positive association between female gender and having a complication remaining even after controlling for BMI was unexpected and warrants further investigation. The positive association between tertiary education and occurrence of self-reported complications was unexpected but could be explained by more adequate reporting by this subgroup. In terms of self-management, perceived control over illness was negatively associated with medically recorded disease complications, underlying the importance of adequate self-management support. Similar findings were reported in other studies (25,26) which assessed illness perceptions, self-care behaviours and their relationship in recently diagnosed T2D patients with and without diabetes-related complications. A possible explanation of the inconsistent association between diabetes knowledge and the number of complications could be that patients with a better knowledge are more vigilant for disease complications and more likely to report complications or seek care when a complication occurs.

5.7.3 *Strengths and limitations*

The limitations associated with a cross-sectional survey include the lack of identification of causal relationships. Data collection was based on self-reported information and medical records. Both methods are prone to several types of measurement error (e.g. recall bias, social desirability bias, incomplete registration, etc.). Despite complications, patients may also refrain from seeking care or seek care in other facilities which may have resulted in an underestimation of the medically registered complications, especially since screening of complications was poor.

However, including information on complications from two different sources provides the option of triangulation as both sources have an added value, despite being prone to a substantial measurement error. As such, we encourage readers to look at these figures through different lenses while on the one hand taking into account measurement error but including the patient and health workers' perspective on the other hand. The association between diabetes knowledge and outcomes of interest could also have been influenced by other factors not measured in this study, such as adherence to treatment regimens.

5.7.4 Implications or recommendations

We hypothesise that using innovative strategies towards capacitating patients to control their disease during care provision could assist with reduction of disease complications in our setting. Suggested strategies for enhancing patient self-management and control of T2D/HTN include healthcare worker capacitation to provide optimal self-management support to patients and identifying patient success stories of self-management in real life settings to encourage other patients (27). Examples include the use of drawings made by patients to assess their illness perception (28), extended engagement with patients beyond the clinical setting using interventions that include peer-led support groups, psycho-behavioural support, community based lifestyle programmes for patients and their families, and cooking classes (29).

We recommend a re-orientation of CDMPs to meet actual patient needs whereby the clubs focus on providing individualised self-management support to patients (11) consistent with their illness experience. Risk factors identified during yearly CMDP attendance should be adequately addressed through tailored self-management interventions and subsequent audits to assess the effect of the interventions.

5.8 Conclusion

In this study, patients with co-morbid T2D/HTN experienced disease complications despite attending CDMPs. Important risk factors related to feet and eyes were poorly monitored. Weight control was well monitored but poorly managed. Illness perception in terms of having control over the disease was negatively associated with prevalence of disease complications. To provide optimal care, CDMPs should make patient self-management a core of their strategies, strengthen risk factor monitoring and effectively address identified risk factors. An evaluation component such as facility based clinical audits should be added to the CDMPs to monitor implementation of interventions.

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5.10 Competing interests

The authors have no relevant financial or non-financial interests to disclose.

5.11 Author contributions

[information redacted to maintain the integrity of the review process]. All authors provided critical feedback and helped shape the research, analysis, and manuscript.

5.12 Funding

[information redacted to maintain the integrity of the review process]

5.13 Availability of data and material

The data that support the findings of this study are available from the corresponding author, [information redacted to maintain the integrity of the review process], upon reasonable request

5.14 Disclaimer

The views expressed in this article are those of the authors and are not a position of the author institutions.

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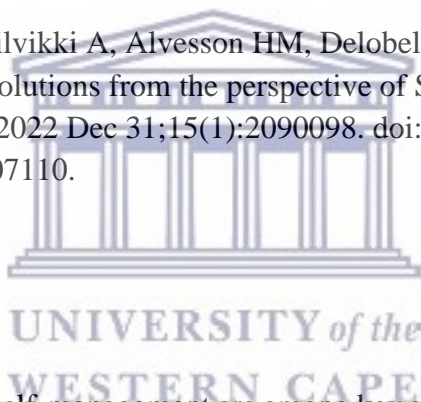
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Chapter 6: Study 3: Diabetes Self-Management: A Qualitative Study on Challenges and Solutions from the Perspective of South African Patients and Healthcare Providers

Masupe T, Onagbiye S, Puoane T, Pilvikki A, Alvesson HM, Delobelle P. Diabetes self-management: a qualitative study on challenges and solutions from the perspective of South African patients and health care providers. *Glob Health Action*. 2022 Dec 31;15(1):2090098. doi: 10.1080/16549716.2022.2090098. PMID: 35856773; PMCID: PMC9307110.



6.1 Abstract

Background: Health education and self-management are among key strategies for managing diabetes and hypertension (HTN) to reduce morbidity and mortality. Inappropriate self-management support can potentially worsen chronic diseases outcomes if relevant barriers are not identified, and self-management solutions are not contextualised. Few studies deliberately solicit suggestions for enhancing self-management from patients and their providers.

Objective: This qualitative study aimed to unravel experiences, identify self-management barriers, and solicit solutions for enhancing self-management from patients and their healthcare providers.

Methods: Eight IDIs were conducted with healthcare providers. These were followed by four FGDs among patients with type-2- diabetes (T2D) and or HTN receiving chronic disease care from two health facilities in a Peri-Urban township in Cape Town, South Africa. The Self-Management framework described by Lorig and Holman, based on work done by Corbin and Strauss was used to analyse the data.

Results: Patients experienced challenges across all three self-management tasks of behavioural/ medical management, role management, and emotional management. Main challenges included poor patient self-control towards lifestyle modification, sub-optimal patient- provider and family partnerships, and post-diagnosis grief-reactions by patients. Barriers experienced were stigma, socio-economic and cultural

influences, provider-patient communication gaps, disconnect between facility-based services and patients' lived experiences, and inadequate community care services. Patients suggested empowering community-based solutions to strengthen their disease self-management, including dedicated multidisciplinary diabetes services, counselling services; strengthened family support; patient buddies; patient led community projects, and advocacy. Providers suggested contextualised communication using audio-visual technologies and patient-centred provider consultations.

Conclusions: Community-based dedicated multidisciplinary chronic disease healthcare teams, chronic disease counselling services, patient-driven projects and advocacy are needed to improve patient self-management.

6.2 Background

Type 2 diabetes (T2D) and hypertension (HTN) lead to morbidity and mortality due to their complications (1) and higher health services utilization (2). The World Health Organization (WHO) estimates that diabetes was directly responsible for 1.5 million deaths globally in 2019 (3). The highest contributors to global mortality and disability-adjusted life years (DALYs) due to diabetes included increased Body Mass Index (BMI) and behavioural risk factors, with SSA recording the second-highest age standardized mortality (4). The Burden of Disease Research Unit at the South African Medical Research Council also reported increased mortality from diabetes between 1997 and 2010 due to population growth and change in age structure (5). Diabetes is estimated to affect 10.1% of South Africans aged 15 years and above (6).

Health education and self-management are among key strategies for T2D and HTN management according to the WHO (7), aimed at reducing disease complications. self-management, however, is considered poor in SSA (8) and challenging 65 in South Africa (9). Physiological benefits to patients in self-management programmes are documented but harm can occur if self-management is not patient-specific (10). With the advent of COVID-19, the importance of self-management has become even more pronounced, especially among diabetes patients. A study in India showed that the usual patient-centred care for diabetes patients needed to adapt to more self-management (11) techniques at home where patients have to apply the self-management principles, showing that self-management remains critical even for infectious diseases.

Self-management is described based on tasks that fall within three categories: medical/behavioural management, role management, and emotional management (12). The medical/behavioural role entails proper use of medication for disease control and adopting positive health behaviours geared towards slowing down disease progression. Role management defines new long-term partnerships between patients and healthcare professionals where the patient plays a role of a partner, accurately and truthfully reporting any changes in symptoms. The emotional role consists of the patient's emotional reactions to chronic disease.

While self-management support is effective in improving clinical outcomes, it can potentially worsen chronic disease outcomes when barriers are not identified, and self-management solutions are not population-specific (13). Few studies however deliberately solicit suggestions for optimizing self-management from patients and their providers (14). This qualitative study aimed to unravel experiences,

identify self-management barriers, and solicit solutions for enhancing self-management of T2D/HTN from patients and their healthcare providers.

6.3 Methods

6.3.1 Study setting

This study was part of the formative phase of a larger study (A people-centred approach to Self-Management And Reciprocal Learning for the prevention and management of Type 2 Diabetes – SMART2D) which aimed to strengthen capacity for T2D care and self-management among people at risk of or diagnosed with T2D in three different income settings in Uganda, Sweden and South Africa (15). The study was conducted in two community health centres providing chronic disease care for T2D/HTN in a predominantly black African township (99.5%) in Cape Town, South Africa. The township had an estimated population of 400,000 in 2011 (nearly 96.5% speaking isiXhosa) with high rates of unemployment (est. 35.7% in 2017), 19% having no income and over half of the 118,000 households living in informal dwellings (16), 23% living in dwellings without piped water, and around 62% of residents being rural to urban migrants (17), mostly originating from the Eastern Cape. The township has seven government-run public healthcare facilities, with previous studies indicating a high prevalence of HTN (88.6%) and T2D (12.5%) among adults aged 18 and above (17,18). The health system is typically low-resourced with nurses being responsible for day-to-day management of these patients and doctors seeing mainly difficult cases. Following initial diagnosis and treatment, non-communicable disease (NCD) patients with a stable disease typically receive care from nurses in chronic disease clubs at facility level. All health services are free at the point of access, including medications for diabetes and HTN. The role of the private sector in this setting is negligible if any, but there are non-governmental organizations (NGOs) which run some chronic disease services, including collection and delivery of medications.

In 2013, the National Department of Health embarked on a primary healthcare re-engineering process in line with the call for Universal Health Coverage, which aimed, among others, to strengthen the management and control of chronic diseases at primary healthcare level. The chronic disease clubs came about as part of implementation of this process (18), with the aim of empowering patients with diabetes with skills and knowledge to manage their diabetes. The model was expanded to include other chronic diseases such as HTN, asthma, and epilepsy. In the clubs, patients with chronic diseases are monitored for risk factor management, anthropometric measurement, biomarkers such as glucose and cholesterol, and health education for self-management. The clubs are free to attend and operate on a monthly basis.

6.3.2 Study design and population

The study involved conducting eight IDIs with healthcare workers and four mixed FGDs with male and female patients diagnosed with T2D/HTN attending the two study facilities. In our study, we used the Self-management framework by Lorig and Holman to situate our study and analyse the findings. We ended the study with a recommendation for a contextualised framework for self-management by looking at other self-management theories. Creswell (19) alludes to the inductive approach, whereby information is collected from participants using interviews or field notes, data is analysed to form themes or categories, broad patterns or generalizations are identified, and finally compared with the literature. The essence of

the patients' experience with self-management starting from the day of diagnosis; the emotional reactions to the diagnosis; and subsequent experiences when engaging with the healthcare providers and health system in the chronic disease clubs which led participants to identify potential solutions to address challenges with their self-management. In this paper, we focus on their suggestions for improving self-management, based on their lived experience.

Participants were selected purposively to ensure the provision of rich information on self-management for T2D/HTN and care provision. Selection of patients for the FGDs used purposive sampling for maximum variation, with inclusion criteria being over 18 years, diagnosed with T2DM/HTN for at least six months to ensure self-management experience, and using healthcare services in the selected facility for more than six months prior to enrolment. Patients without diabetes and or HTN, patients with type 1 were excluded. Variability within the group was enhanced by encouraging participation of younger (<40 years) and older (>60 years) patients. Attempts were made to include both males and females; patients with both well controlled diabetes (HbA1c <7%) and poorly controlled diabetes (HbA1c >8%); and patients with well-controlled blood pressure of <130/90 mmHg and poorly controlled blood pressure (>130/90 mmHg). This information was obtained from the HCWs who assisted with patient recruitment during T2DM/HTN 'club' days (when patients attended the clubs for their monthly reviews). The sister in charge of the clinic and the health promoter were informed of the study and its objectives. The sister then addressed the patients waiting for consultation and briefed them on the study.

The study population for IDIs consisted of all HCWs caring for T2D/HTN patients at the facilities, except doctors who were unavailable for interviews. All healthcare providers interviewed were over the age of 18, with the youngest being the dietician, followed by the health promoter, and the oldest being a clinical nurse practitioner 1. Three clinical nurse practitioners (CPNs), one dietician, and one health promoter were interviewed in Facility A. In Facility B, three interviews were conducted with two CPNs and one social worker. The staff complement was slightly different among both sites. The dietician in Facility A also serviced Facility B, and the health promoter in Facility B did not consent to be interviewed (Table 6).

Table 8: Characteristics of HCWs in the In-depth interviews

Facility	Cadre	Gender	Years of Work
Facility A	Health promoter	Male	8
Facility A	Dietician	Female	2
Facility A	Clinical nurse practitioner 1	Female	>20
Facility A	Clinical nurse practitioner 2	Female	>20
Facility A	Clinical nurse practitioner 3	Female	10
Facility B	Facility manager/ clinical nurse practitioner	Female	>20
Facility B	Clinical nurse practitioner 4	Female	>20
Facility B	Social worker	Female	11

For patient FGDs, purposive sampling was used with inclusion criteria being over 18 years of age, at least six months of T2D/HTN diagnosis, and using healthcare services in the selected facility before enrolment. Four FGDs were conducted (two per facility) with 43 participants, mainly including females (only eight males). The patient age range was 38-75 years, and patients had been diagnosed with T2DM/HTN between six months and 21 years prior to data collection.

Table 9: Composition of the FGDs

Group number	Number of participants per group	Facility	Gender	
			Femal	Male
1	13	Facility B	9	4
2	10	Facility B	10	0
3	8	Facility A	6	2
4	12	Facility A	10	2

HCWs at each facility assisted with patient recruitment during monthly review visits, and a quiet room was used for consenting patients meeting the inclusion criteria before conducting the FGD.

6.3.3 Data collection

Data collection for the IDIs and the FGDs occurred between March and April 2018 and was preceded by two pilot FGDs done at one of the study facilities (Facility A). The pilot patients were excluded from the final study sample. Interview guides used for data collection from both HCWs and patients were informed by the literature (12,20) and pre-tested (see appendix) . The research team consisted of three trained fieldworkers: KH (male), BC and BB (females) in the presence of the researcher TM (a female medical doctor practicing public health in Botswana who is not fluent in isiXhosa). Interviews took place in designated rooms at each study site. They were conducted in isiXhosa. Field workers added additional probes as necessary. KH and BC managed the consent process, TM took field notes of non-verbal cues during the interviews to augment interpretation of the interview transcripts and enhance familiarity with the data. Patients and HCWs were not known to any member of the research team. Fieldworkers were non-practicing HCWs who had worked as field workers for at least 3 years and were able to practice the concept of bracketing and were sensitized to cultural norms when speaking to participants in this setting, especially older people. They were trained in T2D management, the study protocol, and data collection tools. Their qualifications as HCWs were not observed to influence participants away from talking freely. Rather the fact that the field workers lived locally, spoke local language made participants feel that they understood their challenges with self-management especially when it comes to managing diet and physical activity encouraged uninhibited contribution from participants. For example, when discussing unhealthy foods and using local herbs such as Aloe vera, participants were able to freely share their experiences. The lead researcher was present in the room during interviews and made field notes of interactions between fieldworkers and participants. The lead researcher also applied bracketing during data analysis and during interviews with CHWs.

6.4 Data analysis

Data analysis was done using the self-management framework described by Lorig & Holman (12), based on work done by Corbin & Strauss (20) and guided by the seven-steps framework approach described by Gale et al., 2013 (21). Recorded IDIs and FGDs were transcribed verbatim and translated into English by a fieldworker fluent in isiXhosa. Following familiarization, open coding of transcripts was done independently by two coders (TM) and (SO) using ATLAS.ti software version 7. SO (male) was not a member of the research team at the time of data collection. This initial inductive coding allowed for the unexpected; gave rise to memo creation; and gave researchers a holistic view of the data. Open codes developed from quotations were compared between the coders, agreed upon, and applied into an analytical framework informed by the three self-management tasks of self-management. This was followed by applying framework codes to each transcript (closed coding) and data interpretation. The analysis was augmented with feedback from the supervisors (PD and TP) and field workers through debrief sessions.

6.5 Ethical considerations

Ethics clearance was received from the University of the Western Cape biomedical ethics review board (BMREC Nb 130416-050). Local authorities granted permission to access the study sites (permit WC_2017RP50_730). Consent was administered to all participants. Confidentiality was ensured and maintained through anonymizing participant identifiers. In the FGDs, patients introduced themselves by their “clan” names, which identify that one belongs to a certain grouping or family line in the community. For patients who wanted to use their real names, the information was removed during transcription and translation. Participants were treated with respect and continuously reminded that participation was voluntary, and that they could withdraw consent at any time. Those who did not consent were not coerced to participate, and their lack of consent did not in any way affect their access to healthcare. The interviews were conducted after the patients had received healthcare. No harm was done to participants, and they were made aware of where to go in case of concerns or complaints.

6.6 Results

Findings are presented under five themes: i) behavioural/medical management; ii) role management; iii) emotional management; iv) barriers to self-management; and v) solutions for enhancing self-management. Themes are summarized in Table 8 below:

Table 10: Summary of themes derived from the data

Themes	Categories	Subcategories
Behavioural and medical (self)-management	Patient internal behavioural mediators	Lack of understanding Low health literacy Poor self-control
	External behavioural mediators	Marketing of unhealthy food Cultural Influences Affordability of healthy food

Role management	Interaction with healthcare professionals	Feeling disrespected by HCWs Fear appeals Dishonest behaviour
	Family support	Feeling unsupported
	Perceived stigma	Fear of disclosure Self-isolation
Emotional management	Reactions to diagnosis	Shock/disbelief Fear and depression
	Coping with diagnosis	Rationalization of diagnosis Lack of acceptance Seeking divine help Non-adherence
Barriers to self-management	Patient-related mediators	Treatment side effects Lack of education Poor decision-making Entitlement mentality
	External factors	HCW attitude Television advertising Inadequate community services Travel and migration Staff shortage
Solutions for enhancing self-management	Patient-centred approaches	Individual consultations Contextualised communication Use of audio-visual material Family support Use available resources
	Community engagement	Community projects Empowerment of street vendors Patient advocacy
	Strengthened diabetes care services	Designated counselling services Dedicated healthcare team Treatment buddy Community health worker capacitation

6.6.1 Behavioural and medical management

In this study, behavioural management is described in terms of patient-internal mediators (PIMs), external mediators (EMs), and disease control strategies. PIMs influenced how the patient engaged with the diagnosis, including lack of understanding of disease pathogenesis, lack of knowledge, and poor self-control. Poor self-control is illustrated by the quotes below from both a patient and HCW perspective:

I am part of a group who is just greedy. I was always going for the braai (barbecue) meat (P3:FGD1)

Ah patients are very stubborn as well when it comes to their diet (Int: giggles) they want to eat meat, they want to eat umphokoqo [starchy porridge]....with too much starch (P4 HCW female)

External mediators included the marketing of unhealthy foods, the cost of healthy food, and cultural influences. Some patients described feeling pressure to eat food considered not healthy when they attended cultural ceremonies such as funerals and weddings. Additionally, the belief that being overweight is a sign of good living had an influence on their eating habits. Marketing of unhealthy foods affected patients' decision-making skills towards healthy food choices as perceived by healthcare workers, while patients had a common perception that healthy food was unaffordable. This in turn influenced patients' ability to identify and use appropriate and available resources to support disease management through diet.

6.6.2 Role management

This task requires patients to maintain or create new meaningful behaviours towards disease control, characterized by good relationships with their HCWs and good self-regulation (12). Partnerships between patients and HCWs appeared negatively influenced by patients' feeling disrespected by HCWs. This sometimes led to patients withholding important information, such as the use of herbal medicines and a lack of adherence to lifestyle modification from the HCWs.

I just drink a spoon of aloe extract and mix it with that metformin, and they find it at 8", I just drink when I come to the clinic to fool the nurses.... (P1 FGD2)

Then I always tell them you must be honest with me now, tell me exactly: have you followed it (lifestyle advice)... (P 2: HCW female)

Role management also requires HCWs to change their behaviours and attitudes and recognize the importance of the long-term partnership required for patients with long-term disease. To enhance patient adherence to their advice, some HCWs used fear appeals rather than motivational approaches during patient consultations:

But I always scare them that is my weapon, especially with diabetes I ask them ...do you want to have just one leg? Do you want to be blind, do what is right so that you avoid these things so the scaring them to me works (P1 female HCW)

These did not always work for patients, however. Another important partnership influencing role management was family support, which significantly influenced how patients managed their disease. Some patients described poor family support, driven by a lack of understanding of T2D and its complications and criticism from some family members around dietary adherence:

They shout at me daily – dad you have not even tasted the food but want salt (P11 FGD4)

Forming strong partnerships was also influenced by perceived stigma and fear of being judged by others, such as intimate partners. This led to non-disclosure of the diagnosis and patient self-isolation from others, including family members:

And even at home, you are judged by your disease. So you see I stay alone and they always used to ask me, why would you stay alone when you have diabetes... because I do not want to be judged for my disease (P7 FGD3)

6.6.3 Emotional management

This task recognizes the significant emotional impact of being diagnosed with a chronic disease on patients. Two categories were identified, including initial reactions to and coping with the diagnosis. Initial reactions to a diagnosis of T2D/HTN included those of shock, disbelief, and fear, which were expressed by participants across all FGDs:

I was shocked and I asked myself if the doctor tested me correctly, maybe he is making a mistake, I thought that he made a mistake.... (P2 FGD1)

Various coping mechanisms were used, including finding explanations for why they would have the disease, e.g., hereditary, seeking divine guidance, not accepting the diagnosis, and non-adherence to medication. Sometimes patients failed to cope, leading to unresolved emotions for several years after diagnosis. These emotions were described, especially among the older population, and included stress and depression :

The elderly people get scared and you will see that they are scared and stressed, they get down and depressed (P6 Female HCW)

The three themes described above demonstrate that patients diagnosed with T2D/HTN experience important challenges and barriers to self-management.

6.6.4 Barriers to self-management

Two types of barriers were identified, including patient-related barriers and external barriers. The patient-related barriers included adverse treatment effects, lack of education reported by patients, poor decision-making, and entitlement mentality perceived by healthcare workers. This entitlement mentality seemed to affect patients' abilities towards problem-solving and resource identification and utilization, as illustrated below:

My people have that belief in their minds that the government must do everything for them, they don't want to do anything for themselves (P2 female HCW)

For example, it was thought by healthcare workers that patients spent some of their money on expensive commodities such as meat, alcohol, and cigarettes instead of healthy foods.

External barriers included HCW attitudes experienced by patients, television advertising, inadequate community services, travel and migration between service delivery points and patients' residence, and staff shortages noted by healthcare workers. HCW's attitude was a major concern for patients, who decried the disrespectful treatment by HCWs across the FGDs:

So do you understand I am here to get advice from her and then the way she responded to me it was as if I could just leave there and get smashed by a train.....(P8 FGD3)

In contrast, HCWs believed that telemarketing of unhealthy foods was a more important barrier to patients adopting a healthy lifestyle:

It is very difficult. What matters currently is commercials and what is seen on TV matters more than what we tell people in our institutions... (P2 female HCW)

Additionally, seeing patients at the facility and not being familiar with their home circumstances, travel or migration from the Eastern Cape to access treatment, and staff shortages were other important barriers noted by HCWs.

6.6.5 Solutions to enhancing self-management

Three types of solutions for enhancing patients' self-management were found: patient-centred approaches, community engagement, and strengthened diabetes care services.

6.6.5.1 Patient-centred approaches

Patient-centred solutions were mainly suggested by HCWs. They included individually tailored consultations for struggling patients, contextualized communication, encouraging patients to use available and affordable local food resources for dietary requirements and family support. An example of contextualized communication was using an analogy that patients can understand e.g., the three-legged pot:

That pot must have those three legs in order for it to stand, if one leg breaks, it is no longer a pot...so we make that example into managing their HTN (P1 HCW female)

Using movies as an audio-visual communication tool was suggested by HCWs who noted that even patients with low literacy watched movies and understood the storylines. They could therefore understand health messaging communicated using similar platforms.

You realize that wow, they actually understand what is happening in the movies.....because mostly even people who are not educated are good at watching things (P6 female HCW)

This solution would allow HCWs to use this type of media to influence health behaviour through health marketing during TV programmes mostly watched by patients and their families. As families tend to watch television or movies together, this could also strengthen family support. Additionally, patients attending

consultations accompanied by family members would also enhance family support and facilitate concurrent health education sessions.

6.6.5.2 Community engagement approaches

Patients and HCW suggested community-oriented and patient empowering self-management enhancing solutions. Community engagement solutions included empowering street (food) vendors, engaging patients in community projects and advocacy, and capacitating community health workers (CHWs).

Street vendors sell mostly unhealthy convenience food, including hot dogs, braai meat, and fat cakes near health facilities. Empowering these street vendors towards selling healthy food to patients was considered an important solution:

It needs to be changed there first, and then also these little shops on the side, these Spaza shops (street vendors) and if we can go to these people also and see what they're actually selling and giving them healthy alternatives (P2 female HCW)

The empowerment could be extended to patients through community projects such as youth-run vegetable gardens, to be self-sufficient in healthy food production and create employment:

I would like to agree with this lady, there is a lot of unemployed youth out on the street so if the government could develop a big project where each section has a garden planted by the youth for the elderly that would be very helpful. (P10 FGD3)

Patient-led advocacy through community campaigns to reduce the feeling of disempowerment was also suggested by patients:

Also, for campaigns to finally take place, for people living with diabetes to finally stand up and even the ones in wheelchairs to push their chairs, and for us to not be under the table but on top of it. (P4 FGD2)

6.6.5.3 Strengthened diabetes care services

Under this category, suggested solutions included designated diabetes counselling services and a dedicated T2D healthcare team.

Measures to strengthen diabetes care such as designated counselling services like those provided for HIV patients were suggested by patients in this study.

"You are there to test if you have HIV, so if they found that you are positive, they first counsel you but with this thing, it just comes out... and it needs treatment immediately, do you understand? So where is the time for counselling? There is no time, right! (P11 FGD4)

A treatment buddy, similar to an HIV buddy was also suggested. These solutions would enable patients to cope with psychological emotions evoked by diagnosis of T2D/HTN and fear of their complications:

I think for people with fears of amputation should their diabetes go up, counselling would help like in the case of that lady so that her worries are not so dependent on that (P6 FGD1)

Types of counselling suggested included pre-test counselling, continuing counselling, and family counselling to enhance understanding of the implications of T2D diagnosis for patient self-management. Community healthcare teams dedicated to T2D/HTN consisting of a counsellor, a dietician, a health educator, a nutritionist, and nurses committed to providing quality care were recommended.

People from the club should have a team in the club like a dietician, counsellor, educator, nurses that love clubs..... (P6 female HCW)

6.7 Discussion

In this study, we explored experiences, identified self-management barriers and solicited solutions for enhancing self-management of T2D/HTN from patients and their healthcare providers.

Behavioural/medical management was challenging for patients, mediated by factors internal and external to the patient. Poor patient self-control was the main internal challenge, driven by a lack of understanding and poor disease knowledge. This relationship between diabetes knowledge and poor self-management has been demonstrated in quantitative studies (22,23), including a positive association between diabetes education and self-management behaviours (24).

External influencers of behavioural/medical management included the marketing of unhealthy food and the perceived unaffordability of healthy food. Patients' self-management challenges were particularly around diet-related lifestyle modification. A US-based study among adults aged 18 years and above showed that advertising food through television strongly affects individual food choices (25). This includes evidence from a study in Mexico which showed that consumption of advertised foods among mothers and their children is associated with frequency of broadcasted advertising, number of hours of watching television, and BMI (26). However, evidence of the effect of advertising on adult T2D/HTN is lacking.

Role management also challenged patients, particularly the creation and maintenance of healthy behaviours and meaningful partnerships. Key contributors to these challenges were perceptions of disrespect by HCWs, lack of family support, and stigma. HCWs observed that patients remained non-adherent to medications and lifestyle advice. Different approaches were used to improve adherence, including the use of metaphoric and fear appeals, which are considered effective in positive behaviour change (27). While HCWs believed that fear appeals enhanced role management, patients' perceptions were contrary to this notion. Research suggests that fear appeals are effective when recipients have high self-efficacy but are ineffective or could even backlash when self-efficacy is low (28), even leading to maladaptive behaviours such as those shown in this study. A meta-analysis of qualitative and quantitative

studies has shown that positive emotional appeals might prove more effective than cognitive appeals or negative emotional appeals (29), which supports experiences from our study participants.

Role management in this study was negatively affected by patients' experiences of disrespectful HCW attitudes and poor communication. Feeling disrespected by healthcare providers was reported as a major reason for not honouring outpatients' clinic appointments in a qualitative US study (30), which resonates with patients in this study. These challenges could be addressed by using a more patient-centred participatory and appreciative approach (31) that addresses the patient agenda, a priority neglected by HCWs but valued by patients (32).

Family support was considered important to role management by both patients and HCWs. The importance of family support in diabetes care and management is well captured in a commentary by Ahmed & Yeasmeen (33), who argue that "better health can be provided if the family is considered central to the management of diabetes". Empirical evidence from South Africa has demonstrated a positive association between family support and following a diabetes meal plan, foot care, physical activity, and emotional management of T2D diagnosis, underscoring the importance of family support in T2D self-management (34).

Emotional management was a challenge for patients having to deal with the grief-reaction evoked by a T2D diagnosis, ranging from initial shock and denial to acceptance and coping with future disease complications. Grief reactions among T2D patients were described even three decades ago (35) and recently (36), highlighting the importance of acknowledging the emotional management of coping with the diagnosis.

Patients experienced several barriers due to internal and external factors. Patients and HCWs identified possible solutions to enhance self-management. The SMART2D Self-Management framework (9) is considered a useful model for guiding the implementation of such solutions. The framework encapsulates four core self-management tasks (medical, emotional, role, and lifestyle management); five self-management skills (decision-making, resource mobilization, taking action, problem-solving, and forming partnerships); and five mediators (perceived autonomy, perceived relatedness, self-efficacy, illness perception, and learning of self-management strategies). The framework embeds these requirements within the patient's proximal environment. The barriers and solutions for optimal self-management suggested in our study speak directly to all these factors.

6.8 Study strengths and limitations

The study ensured trustworthiness as defined by Lincoln & Guba (37), encompassing transferability, credibility, dependability, and confirmability. The thick description of the study context, methods, and use of quotations from participants enhanced confirmability, while dependability is demonstrated through literature citations showing consistency with our findings. Credibility was shown through triangulation using data from patients and HCWs, collecting data at different times of the year, week and day to cater for the influence of seasonal migration, using two interviewers per recording session and different coders,

which enhanced interpretation of the data. Field notes and personal reflections by the researcher enhanced reflexivity, reducing being judgemental.

While findings from this study are based on information provided by HCWs and patients in a specific locality and used a small number of participants, which may not reflect the views, experiences, and opinions of all HCWs and patients in this setting, the facilities where this study was conducted are among the largest provider of chronic disease management programmes for T2D/HTN patients in this area.

6.9 Conclusion

In this study, both patients and providers found self-management to be complex in real life. Patients experienced challenges across three self-management tasks of behavioural and medical management, role management, and emotional management. Main challenges included lifestyle modification for disease self-management, poor partnerships with HCWs and family members, and post-diagnosis grief-reaction, cultural norms, poor HCW-patient communication, and disconnect between facility-based HCWs and patients' lived experiences. Barriers to self-management included stigma, entitlement mentality, inadequate community services, and human resource shortages. Patients want empowering, predominantly community-based solutions to strengthen their self-management. Suggested solutions included dedicated diabetes/HTN services with multidisciplinary teams, counselling services, increased family support, patient advocacy, and contextualised communication using audio-visual technologies. A contextualized self-management framework that covers the essence of these solutions is recommended as an ideal multi-pronged approach to self-management in this setting.

6.10 Policy Recommendations

- Dedicated community-based multi-disciplinary healthcare team using well-trained CHWs
- Healthcare workers' capacitation to use patient-centred consultation models such as motivational interviewing
- Provision of pre- and post-counselling services in the community for patients and families
- Introduction of a chronic disease buddy-system similar to the HIV buddy system to further strengthen patient self-management
- Chronic disease care programmes that feature patient-driven community projects and supports patient-led advocacy.

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6.12 Author contributions

T.M., P.D., and T.P. conceived and planned the project and supervised data collection. T.M, S.O., and P.D. carried out the analysis. T.M., S.O., P.A, H.A., P.D., and T.P. contributed to the interpretation of the results. P.A. and H.A. provided critical guidance on qualitative methodology. T.M. led the writing of the manuscript. All authors reviewed several versions of the manuscript and provided critical feedback and helped shape the research, analysis, and manuscript. All authors approved the final manuscript before submission.

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6.13 Ethics and consent

Ethics clearance was received from the University Biomedical Ethics Review Board (BMREC Nb 130416-050). Local authorities granted permission to access the study sites (permit WC_2017RP50_730). Health facilities participating in the study also granted permission to access the facilities and patients. Written informed consent was obtained from all participants in the study.

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6.15 Paper context

Patients attending chronic disease clubs in South Africa are expected to practice self-management of their diseases, but they face significant challenges. We unravelled their experiences, challenges, and barriers to practising optimal self-management. They have previously not been asked to provide their voice on solutions to these. This study went a step further and solicited solutions to improve self-management from these patients and their providers experiencing self-management in one of the largest townships in South Africa.

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Chapter 7: Developing the 3-3-3 Self-Management Package

This chapter addresses the last objective of this body of work which was to develop a contextualised care package for the Peri Urban Townships in the Western Cape. Based on the findings from the first four objectives of this body of work, we developed a self-management care package for T2D and HTN patients attending CDMPs in the Townships, which will be proposed to policymakers. The package development was guided by the adapted TDF (1). This framework provides four critical steps in development of any guidelines or recommendations. It consists of four steps which answer the following questions: i) who needs to do what, differently? ii) Using a theoretical framework, which barriers and enablers need to be addressed? Which theory or theories are likely to inform the pathways of change? iii) Which behaviour change techniques and mode(s) of delivery) could overcome the modifiable barriers and enhance the enablers? iv) What is likely to be feasible, locally relevant, and acceptable and combine selected components into an acceptable intervention?

7.1 STEP 1: Who needs to do what, differently?

This step identifies a target group for intervention and behaviour change needed to reduce the practice gap. In this study, optimal self-management is the practice gap while patients and healthcare workers are the targets for the proposed intervention (the 3-3-3 self-management care package). The two qualitative studies in this thesis enabled identification of key behavioural changes that are needed to close the self-management practice gap. Key factors needing to change under the four self-management management tasks were identified in the qualitative studies. Partnerships between patients and their healthcare providers were found to be sub-optimal. There was lack of trust between the two which affected patient adherence to medications and lifestyle advice. The partnerships were also affected by perception of poor family support and negative healthcare provider attitudes with some providers using scare tactics during health promotion activities. Patients perceived the health services that were provided to them as inadequate, poor quality, not meeting their needs and expectations and too focused in the health facility. From the provider perspective, the way that healthcare professionals market health to clients was considered inadequate and ineffective. Using technology such as audio-visuals and adding patient-centredness into the consultations including use of motivational interviewing, were some of the ideas suggested to facilitate better uptake of health promotion information by patients. These are summarized diagrammatically below:

Step 1: Who needs to do what, differently?

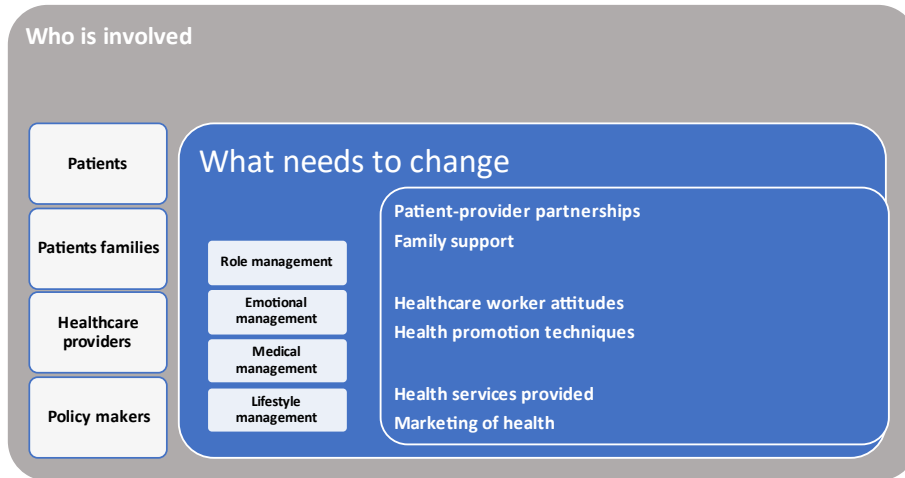


Figure 7: Who needs to do what, differently

7.2 STEP 2: Addressing barriers and enablers using a theoretical framework

This step answers the question: which theory or theories are likely to inform the pathways of change? The SMART2D self-management framework (2) was applied here to identify barriers and challenges that need to be addressed for the proposed intervention to succeed.

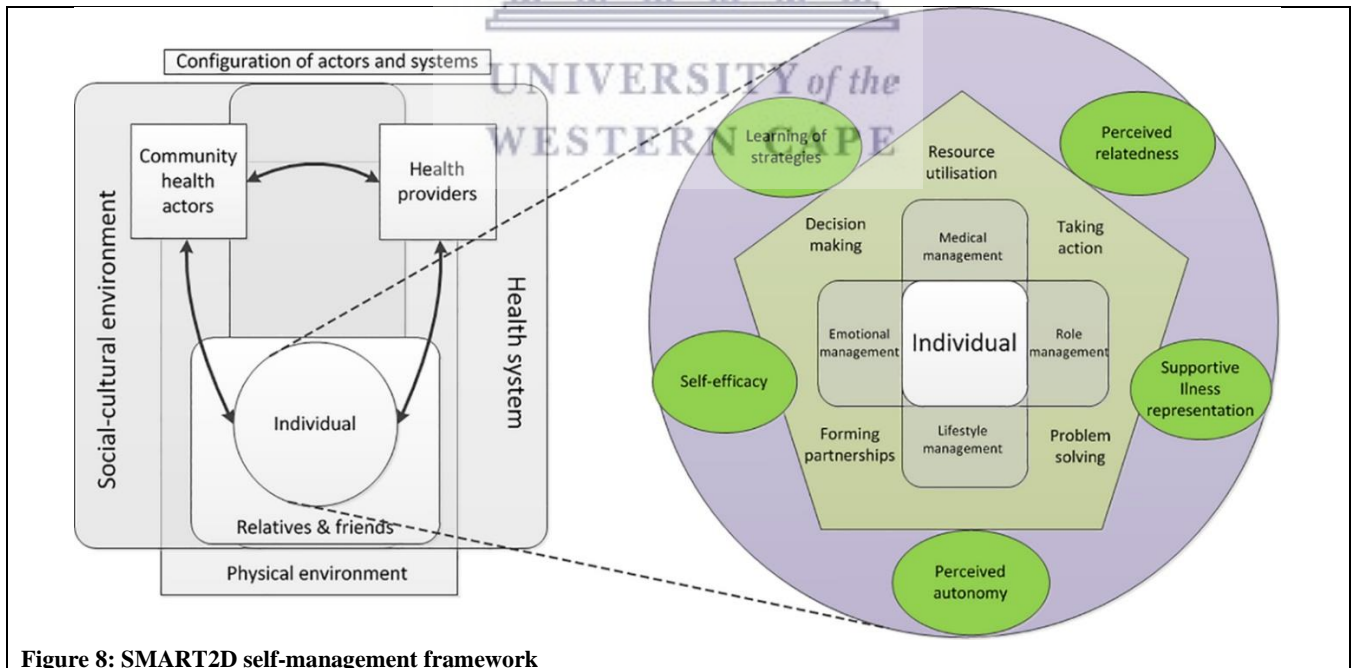


Figure 8: SMART2D self-management framework

Using the above framework and findings from the three studies constituting this body of work, the following barriers to change are identified:

7.2.1 Socio-cultural environment

The findings indicate that there were important socio-cultural factors in the patient's environment that heavily influenced their ability to practice self-management effectively. These included: (i) food environment that encourages unhealthy eating, especially availability and advertising of junk food; (ii) perceived cost of healthy food, and (iii) religious beliefs, and cultural norms, which were found to influence dietary patterns and weight management.

7.2.2 Physical environment

In this component, a safe environment to undertake physical activity that is required for self-management was considered lacking, partly due to inadequate resources to support such an environment.

7.2.3 Health system barriers

The main health system barriers identified included perceived negative healthcare provider attitudes, lack of healthcare providers with relevant skills and training on T2D and HTN, long waiting times at facilities when patients seek healthcare, and unavailability of a patient defaulter tracking system.

7.2.4 Individual barriers

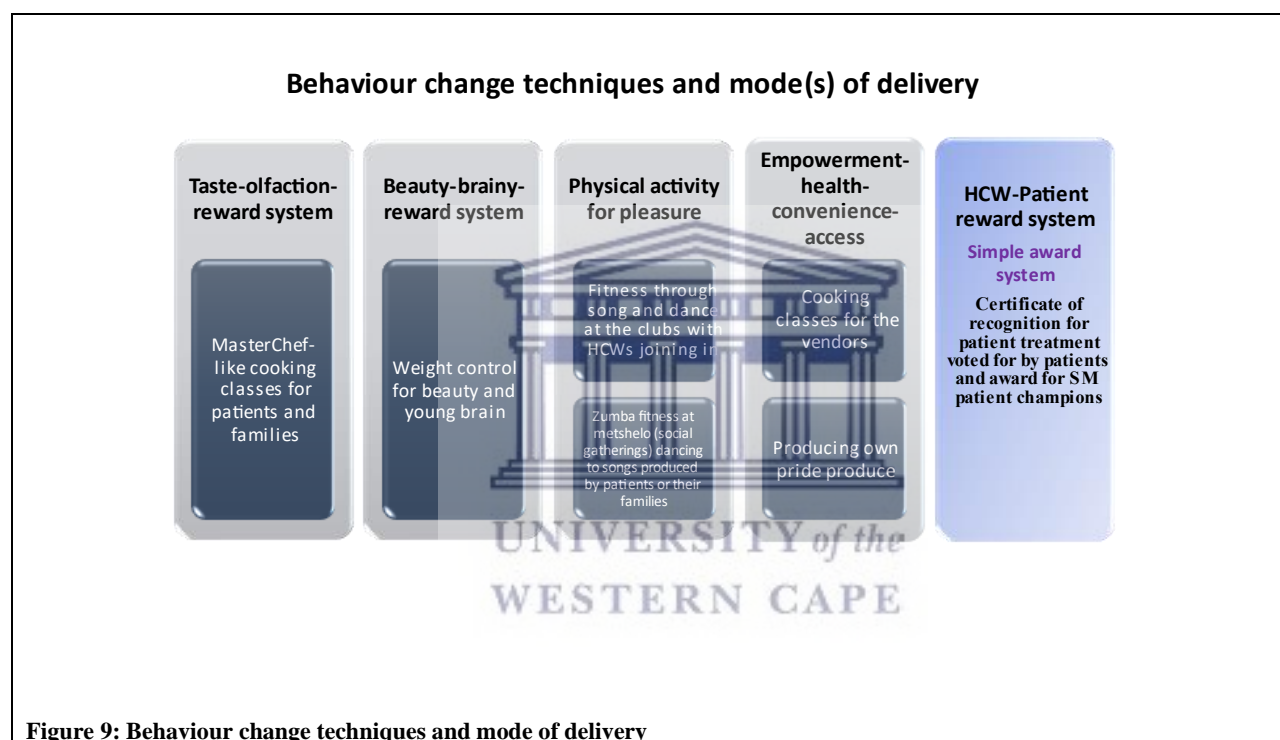
Several barriers at individual patient level were identified. These were mainly around the patients' health seeking behaviours and what patients perceived to be beneficial to them. There were important observations by healthcare providers and patients about the patient's laziness, lack of knowledge, and personal beliefs around illness causation.

7.3 STEP 3: Behaviour change techniques and mode(s) of delivery

Which behaviour change techniques and mode(s) of delivery could overcome the modifiable barriers and enhance enablers? This was informed by findings from the first four objectives of this study and complemented by the literature.

Behaviour change techniques likely to have a positive effect have to be those that show thinking outside the box. These included adapting some of the strategies employed by the alcohol, tobacco and food industries which use gratification appeals to encourage uptake and consumption of their products. Stealth interventions that promote uptake of healthy behaviours are therefore recommended. The behaviour change techniques considered good to adopt for this study are use of the taste-olfaction reward system, beauty-brainy reward system, physical activity for pleasure, using empowerment-health convenience-access and a provider-patient reward system. The taste-olfaction reward system recognizes the importance of food that tastes and smells good to the patients. Healthy food therefore needs to taste and smell good to make patients want to consume it. This comes from findings in this study. Evidence also suggests that the combination of bio-sensory-emotional responses can be a cue for how the individual views food as a form of reward (3). The beauty-brainy reward system is also informed by findings in this body of work where patients described the positive effects of exercise which can motivate them to engage in it. An important theme was that exercise helps with brain activity and keeps people looking young. Physical activity for pleasure describes doing exercise in a way that does not feel like it is a chore. Weaving in

exercise into physical activity that combines song and dance is considered as one of the ways to motivate patients into undertaking more exercise. Empowerment-health-convenience-access refers to enabling patients to access healthy food convenient to where they are through patient empowerment schemes where they are part of the solution. They could be empowered to run small businesses which sell healthy convenience food using local products that they produce. This combines solutions suggested by patients (empowering community-based solutions through patient led businesses) and healthcare providers (capacity building for those selling convenience foods to patients in the tuck shops around health facilities) in this study. The Healthcare worker-patient reward system recognizes the sub-optimal partnerships between patients and their providers. This solution aims at closing this gap. Patients would be able to “vote” for their best healthcare provider in terms of service delivery, while healthcare providers would also vote for the “model” patient when it comes to effective self-management behaviours that lead to physiological improvement of their T2D and HTN. These behaviours change techniques are captured in Figure 11 below:



7.4 STEP 4: Combining components to design the intervention

This step requires researchers to identify what is likely to be feasible, locally relevant, and acceptable and combine selected components into an acceptable intervention that can be piloted by policymakers. This information was also based on findings from the three studies in this thesis. Here the three steps described above are combined to form the simple self-management care package for T2D/HTN patients in Western Cape Townships. Study two demonstrated that current methods of monitoring disease risk factors in the facilities and promoting self-management were inadequate. Patients are experiencing disease complications despite attending the clubs. The feeling of having control over their disease and its management was significantly associated with protection from experiencing complications. This package shifts the focus to strengthening self-management using different, innovative and yet achievable solutions

suggested by both patients and their healthcare providers. The suggested package here may appear radical but the current business as usual model cannot continue as is as we have argued in the preceding chapters.

7.5 Introducing the 3-3-3 Self-Management Care Package

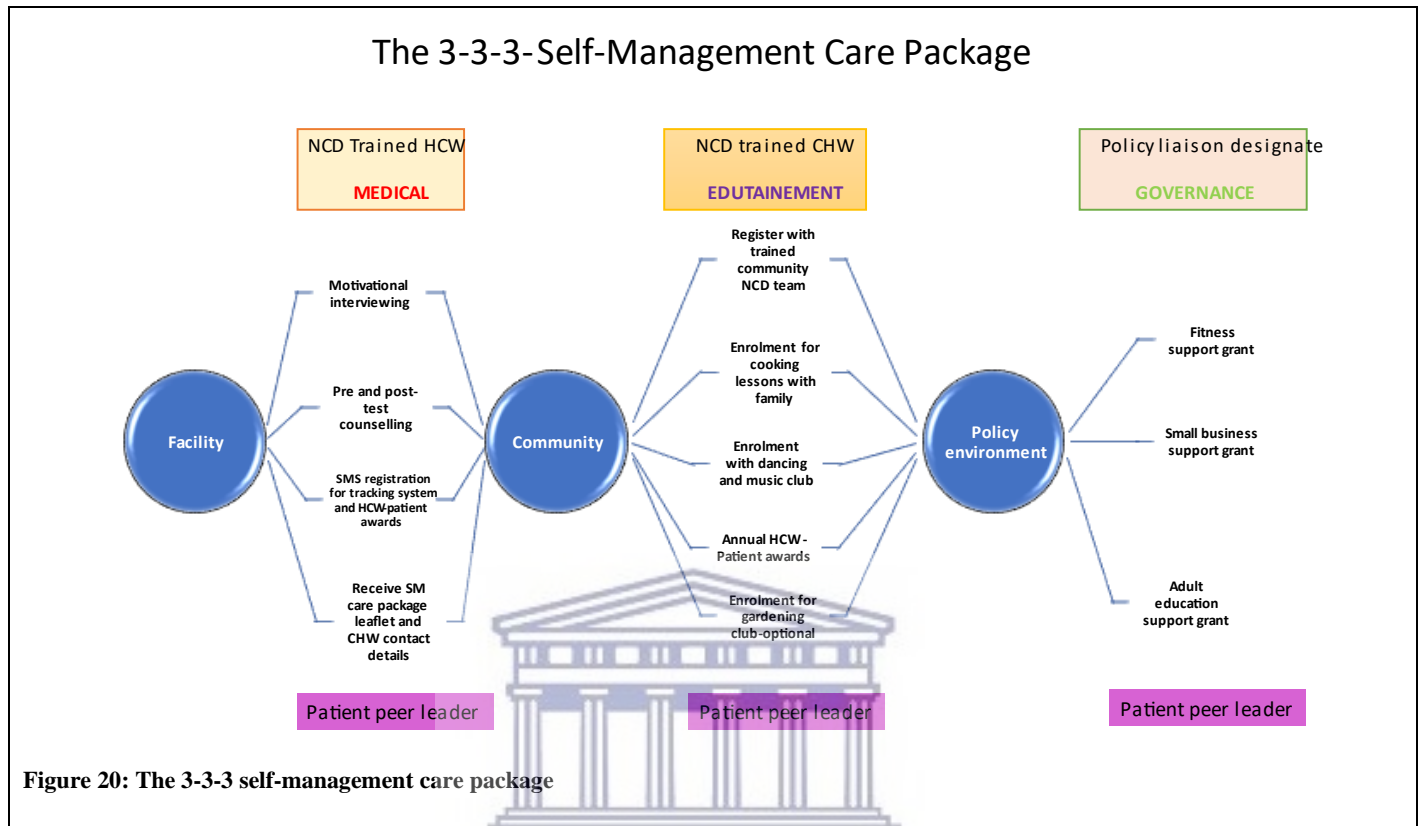


Figure 20: The 3-3-3 self-management care package

Based on our study findings a simple 3-3-3 self-management package is recommended for enhancing self-management of chronic diseases among T2D/HTN patients in the Peri-Urban Townships. The package ensures that there is a set structure for patients to follow at facility, community, and policy level.

7.5.1 The three layers making up the package

7.5.1.1 Layer 1: the three environments

This layer consists of three environments that impact patient self-management. These are facility, community, and policy environments. In the facility, patients interact with healthcare providers as they receive services. While family members play a key role in the facility as they accompany the patient during consultation, Family support becomes even more critical in the community during the edutainment aspect. Family provides the support system for patients as the patients engage with edutainment activities. The edutainment activities address the lifestyle behaviour changes by applying the taste-olfaction reward system, beauty-brainy reward system and physical activity for pleasure. The policy environment provides a governance support system to ensure that resources needed to drive the initiatives are available. A continuous feed-back loop between these environments is recommended.

7.5.1.2 *Layer 2: The three components: medical, edutainment & governance*

This layer consists of the components of each environment aimed at enhancing patient self-management. These are the medical, the edutainment and the governance. The individual constituents under each component are as follows:

Medical- focused on disease detection and medical management. Those at risk of disease such as pre-diabetes or early HTN, or patients presenting with suggestive symptoms but not yet diagnosed or attending for routine checks e.g. people at risk or with pre-diabetes or hypertension, first get pre-test counselling for T2D/HTN. Then they undergo the relevant medical test, followed by post-test counselling, which will include topics pertinent to medical management, drug adherence, disclosure of diagnosis, and managing emotions. Additionally, patients receive a brief leaflet about the 3-3-3 self-management package, get registered for tracking purposes and for annual healthcare worker-patient awards, which take place under the edutainment component. Although these awards take place in the next environment, it is important for patients to be registered at this stage so that they do not feel as if the only interest in them is for tracking purposes. The tracking system should not be difficult to implement given the already existing Single Patient Viewer (SPV) system. This is a web-based electronic patient health record system that enables patient level clinical data from multiple sources to be integrated and viewed by clinicians for ease of managing patients. It also has a tracking through voice call and messaging service facilities. Although still at prototype level, it has been found to have good usage among the clinicians (4). SPV is also ideal to support self-management because it has inter-operability with other databases managed by the Western Cape Provincial Health Data Centre (PHDC). The PHDC merges individual level data from across various organs of the Western Cape government, which also enhances patient tracking and follow up (5). This is important because it will facilitate patient follow up at community level.

Edutainment- This is the health promotion arm of the package. It reinforces self-management practice in the patient setting by providing health promotion messages for lifestyle behaviour change using entertainment as education, using the stealth interventions suggested in study 1. It will be expected that every patient enrolls in at least one edutainment activity. Family members can join the patient during cooking classes, accompany them to the awards and partake in gardening activities as part of the community support structure. The edutainment is to be coordinated by a team of healthcare workers coordinated by a CHW. Participants in this study considered CHWs as a key resource for enhancing patient self-management as practiced by patients in the community. According to Mash et al (6) The Western Cape Province in South Africa, where this body of work was done, has adopted the Community Oriented Primary Care framework as one of the key policy measures to guide provision of primary care services in the Western Cape up to the year 2030. The framework recognizes both facility and community-based teamwork as key to better coordination of service provision. It also defines the ideal primary care team composition and scope of work as well as a health information system for use by CHWs in care coordination and follow up of patients (6). The model puts the CHW at the centre of primary care, which would lend support to this proposed care package. Based on solutions suggested by participants in this study, the team could be strengthened by addition of a health promoter, counsellor or psychologist, dietician, chef, gardener, musicians, poets, sports personalities, pastors, and other skilled professionals

who can contribute to the edutainment. These individuals could be other patients with T2D/HTN or their friends and families, creating an ecosystem for self-management.

Governance- In this component, a designated policy coordinator at local level will be driving the monitoring and evaluation aspect in collaboration with teams from the other two components. Their role is to advocate for patient empowerment at policy level. Some of the suggested support activities they would consider include a fitness support grant to replace the disability grant. The policy coordinator would also facilitate resources for sponsorship of the annual patient-provider awards and small business grants to support cooperative societies of patients with NCDs to afford healthy food while earning a small income from their businesses. Other income generating activities could include strengthening the local stokvels which are popular within communities but have the potential to create disharmony if not well managed. Stokvels have documented benefits including income generation for members to meet their basic needs, opportunity for savings and investment, creating social capital, empowerment of women and providing moral support, including mutual assistance, during family emergencies (7). Simple financial management training could be provided as part of patient empowerment strategies as suggested by participants in this study. Additionally, these support measures should be tied to patient engagement and meeting of agreed targets for measuring the performance of the care package.

7.5.1.3 Layer 3: The people- chronic disease peer leaders or patient buddies

This is the simplest and yet most important layer. It consists of peer support for patients within each environment. It is aimed at ensuring that at every level, the patient is not lost. They have a go-to person for guidance, they have a representative who is a member of the team at each level and importantly a representative who plays an advocacy role at local policy level. The peer leader would play the role of a health system navigator. Having a health system navigator has been found to contribute towards improved patient experience with the health system in other settings such as Denmark for chronic conditions such as cancer (8), and mental health, cancer and other chronic conditions in the National Health Service, UK (9). HIV programmes have also effectively used peer support for people living with HIV and with good patient outcomes especially retention in care (10). The peer leader would be identified by other patients guided by the primary care team at each level and ideally should be diagnosed with the relevant NCD, in this instance T2D and or HTN. A healthcare worker with T2D/HTN could also be a peer leader.

7.5.2 Assumptions of the package

The package assumes that training for healthcare workers and provision of a CHW at community level can be done within the confines of the healthcare system. It also assumes that the different components of the package can be implemented in one sitting or over a period of time. Another assumption is that the health system in the Western Cape is able to adjust to the suggested changes similar to the adjustments that were seen during primary health care (PHC) service delivery at the height of COVID-19 in South Africa (11,12). Where literacy is a challenge, use of other technologies such as voice notes, drawing of pictures by patients and healthcare workers to allow for collective learning (13), may be considered.

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Chapter 8: Conclusion

8.1 Summary of the studies done

This thesis is composed of three studies followed by designing of a self-management care package for patients with T2D/HTN receiving chronic disease care in Khayelitsha.

8.1.1 Study 1: Contextual and environmental factors influencing diabetes self-management

The first study was a qualitative study conducted in Langa, a Peri-Urban Township near Cape Town, South Africa which identified and facilitated in-depth understanding of contextual and environmental factors pertinent to the patient that could influence Type 2-diabetes mellitus (T2D) self-management. The study led to a new definition of diabetes from a patient's perspective. Patients defined T2D as a physically and emotionally dangerous disease caused by socio-cultural factors, influenced by the sufferers' food and socio-cultural environment with significance placed on physical, social and emotional effects of T2D diagnosis. This study also showed that this definition of T2D is key to enhancing T2D self-management. Patients suggested that personally rewarding benefits of physical activity and healthy diet such as anti-ageing, brain boosting, energy boosting which are commonly harnessed by food, tobacco and beauty industry should be considered in T2D self-management strategies.

8.1.2 Study 2-Assessment of health service provision within CDMPs to prevent disease complications

We assessed the process of risk factor monitoring, prevalence and determinants of diabetes related complications among T2D and HTN patients attending two CDMPs or "clubs" using a cross-sectional survey combined with a ten-year retrospective medical records analysis of adult T2D/HTN patients attending two CDMPs, using a structured survey questionnaire and an audit tool. This study found that blood pressure (87.7%) and weight (86.6%) were the best monitored risk factors while foot care (0-3.9%) and eye screening (0-1.1%) were least monitored. Nearly 22% of patients reported one complication, while 9.2% reported ≥ 3 complications. Medically recorded complications ranged from 11.1% (1 complication) to 4.2% with ≥ 3 complications. The commonest self-reported and medically recorded complications were eye problems (33%) and peripheral neuropathy (16.4%), respectively. Complication occurrence was positively associated with age and female gender and negatively associated with perceived illness control. T2D/HTN patients experienced diabetes related complications and inadequate risk factor monitoring despite attending CDMPs. Increased self-management support is recommended to reduce complication occurrence.

8.1.3 Study 3- Diabetes self-management: challenges and solutions from South African patients and healthcare providers: A qualitative study

This was a qualitative phenomenological study that aimed to unravel experiences, identify barriers to self-management, and solicit solutions for enhancing self-management from patients and their care providers. The study findings were that patient's experienced challenges across all three self-management tasks of behavioural and medical management, role management and emotional management described by Lorig and Holman (1). The main challenges were poor patient self-regulation leading to non-adherence to lifestyle behaviours, sub-optimal patient-provider and patient-family partnerships and post-diagnosis

grief-reaction experienced by patients. Identified barriers to self-management were fear-based stigma, socio-economic and cultural factors, provider-patient communication gaps, disconnect between facility-based services and patients' lived experiences and inadequate community care services. Solutions suggested in the study were dedicated multi-disciplinary diabetes services, dedicated diabetes counselling services; strengthened family support including patient buddies; patient-led community projects and advocacy. Providers suggested contextualised communication using audio-visual technologies and provider consultations tailored to each patient's needs.

8.2 Conclusion

The current status quo needs to be challenged when it comes to promoting healthy eating and physical activity for prevention and self-management of T2D and HTN. This need has been documented in this study using findings from in-depth exploration of factors influencing health seeking behaviours such as the uptake of physical activity, healthy diet and general knowledge about T2D. Diabetes carries a different meaning for the patient compared to healthcare professionals and that meaning places significance on the physical, social and psychological changes that results from the diagnosis. Patient literature on T2D should incorporate this patient definition of T2D. Self-management of the disease is also interpreted from a social ontological perspective that healthcare workers often pay little attention to. Harnessing the important rewards-based benefits of physical activity and healthy diet that include defying age, brain boosting, energizing and detoxification should be given due consideration as part of health promotion activities for T2D patients. Public health professionals need to consider the use of so-called stealth interventions to promote physical activity and healthy eating among T2D patients. Further research is recommended using implementation science studies to evaluate some of the innovative patient-centred interventions suggested in this study. This will be in keeping with advances in disease prevention and management suggested in the WHO report on innovative care for chronic conditions (2).

Patients experienced multiple complications from T2D/HTN despite attending the CDMPs which provides services aimed at early detection and prevention of these complications. Important determinants of complications included non-modifiable factors of age and sex as well as modifiable risk factors of education, disease knowledge and perceived disease control. These are self-management behaviours that can be strengthened. The SMART2D self-management framework was used to situate the study and also guide development of the contextualized self-management care package for T2D/HTN patients attending public sector primary healthcare services in this township. The framework guided a structured identification of socio-cultural, environmental, physical, health system, and personal factors affecting patient self-management as well as barriers to self-management. Self-management was found to be complex in real life with patients experiencing several challenges and barriers to self-management. On a positive note, solutions for optimizing self-management and therefore disease control were elicited from patients and HCWs. They expressed the need for empowering community-based rather than facility-based solutions to strengthen patient self-management behaviours supported by an advocacy strategy for patients' empowerment.

8.3 Contributions to new knowledge

The PhD has contributed to new knowledge as follows:

1. Focus groups discussions with patients and interviews with HCWs contributed towards an understanding of how patients and healthcare workers experience self-management in the context of low resourced healthcare services and African culture. Contextual factors influencing self-management and their interactions were elucidated.
2. Barriers preventing optimal self-management of T2D/HTN among patients attending the CDMPs in Khayelitsha were identified and explored.
3. A new definition of T2D was coined based on the meaning of diabetes from a patient perspective.
4. The study identified and recommended a new way of promoting behaviour changes for maintaining a healthy lifestyle as part of self-management of patients with T2D and HTN. Innovative strategies borrowing from other industries which have been successful at marketing their products were suggested in the form of stealth interventions that do not break ethical codes.
5. The study provided information on performance of the two clinics in providing quality care for T2D and HTN through the clinical audit of service provision which has not been independently done. The study identified gaps in risk factor monitoring for prevention of disease complications among the patients attending the CDMPs.
6. The cross-sectional survey provided much needed information on the prevalence of disease complications among patients with T2D / HTN, which the annual audit by the Western Cape government has not been able to establish (the Western Cape Government audits have focused on processes rather than outcomes and the impact of the services they provided remains unclear).
7. The study has contributed to new knowledge through the development of the 3-3-3 self-management care package that enhances self-management, informed by local research.

8.4 Implications of the findings

Based on the findings from this study, the following policy implications are identified

1. Upgrading of chronic disease care models based on findings from robust monitoring and evaluation systems that are embedded within the CDMPs.
2. Capacity building initiatives for healthcare workers at facility level that take into account the need for multi-disciplinary teams in the community.
3. Resource implications for new models of care that includes pre and post-test counselling for T2D patients and edutainment for health promotion.
4. New models of care that are driven through stronger patient-healthcare worker partnerships required for self-management.
5. Reward systems that are non-monetary but that motivate both healthcare providers and patients practicing self-management.
6. Change of mindset from disease focused healthcare management at health facilities to making health in the community.

8.5 Limitations

Findings are based on interpretations of information provided by people living in a township in Cape Town where most people fall under the low socio-economic stratum of society. Views reflected may therefore be influenced by their psychosocial environment and not generalizable to the South African population as a whole. The limitations associated with a cross-sectional survey include the lack of potential to identify any causal relationships. Data collection was based on self-reported information and medical records which are prone to several types of measurement error (e.g., recall bias, social desirability bias, incomplete registration, etc.). Despite complications, patients may also refrain from seeking care or seek care in other facilities which may have resulted in an underestimation of the medically registered complications, especially since screening of complications was poor. However, including information on complications from two different sources provides the option of triangulation as both sources add their value, despite being prone to substantial measurement error. The sample size estimation was done using prevalence of diabetic retinopathy from other studies in South Africa. However, the number of patients with diabetes who were included in the study was only 159 out of 374. Most patients turned out to have hypertension. This limitation could have affected the findings by recording lower prevalence of disease complications. As such, we encourage readers to look at these figures through different lenses: while taking into account measurement error but also the richness of patient and health workers' perspectives. The association between diabetes knowledge and outcomes of interest could also have been influenced by other factors not measured in this study, such as adherence to treatment regimens. The qualitative studies provide information which was obtained from healthcare providers and patients in a specific locality and setting. The number of participants was small, and their views and experiences may not necessarily reflect those of other patients diagnosed with T2D/HTN.

8.6 Recommendations for further research

One of the major findings from this study is the gap in research that tracks performance of chronic disease management clubs in the Khayelitsha setting. This gap could be addressed through implementation science research using programme evaluation methods. Additionally, research that tracks incidence and prevalence of risk factors, and adherence to self-management principles among patients and healthcare providers is needed to inform practice. Considerations for research to develop new models of care that are forward looking as well as reflect prevailing contextual and environmental factors influencing chronic disease self-management are suggested.

A major finding from this study was patient suggested solutions for enhancing self-management. Some of these solutions are incorporated in the 3-3-3 self-management care package designed from the findings of this study. Further research on outcomes and implementation research is needed. Shortcomings on healthcare worker attitudes towards patients attending the CDMPs were identified. Studies that investigate interventions to address these shortcomings, such as motivational interviewing, will be critical. These could be coupled with patient satisfaction surveys given the feedback from patient FGDs in this study. Longitudinal studies with controlled research designs including pre- and post-evaluation or other quasi-experimental designs are also recommended.

A research agenda that includes patient empowerment principles, other sectors that influence self-management such as health economics, entrepreneurship and patient literacy and leadership is also recommended.

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Chapter 9: Appendices

9.1. Appendix 1: Ethics approvals

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Ethics Reference Number: BM/17/1/2

Project Title: Early detection, prevention and self-management of type 2 diabetes and hypertension in an urban township in the Western Cape, South Africa.

Approval Period: 15 December 2016 – 15 December 2017

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval. Please remember to submit a progress report in good time for annual renewal.

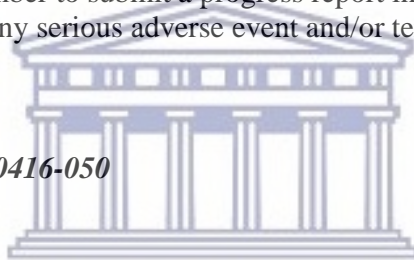
The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias

Research Ethics Committee Officer

University of the Western Cape

PROVISIONAL REC NUMBER -130416-050



**UNIVERSITY OF THE WESTERN CAPE
BIOMEDICAL RESEARCH ETHICS COMMITTEE**

Re: Extension of ethics permit Reference Number: BM/17/1/2

Dear BMREC Chairperson

This letter serves to confirm that I would like to apply for an extension of my research ethics permit which was granted for the period 15/12/16 to 15/12/17

The following progress has been made since the permit was granted

1. Phase 1-qualitative phase a. All in-depth interviews with healthcare workers have been completed at Site B, transcribed and currently being analysed
- b. All FGDs with patients at both site B and Michael M are completed and are currently being transcribed
- c. 2 in-depth interviews with healthcare workers done at Michael M with 2 more planned which will complete the qualitative phase
- d. 1st manuscript has been published in health education research journal

2. Phase 2- quantitative phase a. 50% of the new patient files have been reviewed at Site B
- b. Rest of phase 2 to continue after Easter holidays

I would like to request for an extension to enable me to complete the remainder of data collection and analysis. Please find enclosed original permit and study proposal documents

Yours sincerely

Dr Tiny Masupe (student no 3166940)

SIGNATURE:**DATE:**

OFFICE OF THE DIRECTOR: RESEARCH AND INNOVATION DIVISION

Private Bag X17, Bellville 7535 South Africa T: +27 21 959 4111/2948 F: +27 21 959 3170 E: research-ethics@uwc.ac.za www.uwc.ac.za

25 July 2018

MS T Masupe

School of Public Health

Faculty of Community and Health Sciences

Ethics Reference Number: BM17/1/5

Project Title: Early detection, prevention and self-management of type 2 diabetes and hypertension in an urban township in the Western Cape.

Approval Period: 23 May 2018 – 23 May 2019

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the extension of the research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias

Research Ethics Committee Officer

University of the Western Cape

PROVISIONAL REC NUMBER -130416-050



REFERENCE: WC_201/RP50_/30
ENQUIRIES: Ms Charlene Roderick

University of Western Cape

Robert Sobukwe Road

Bellville

Cape Town

77007

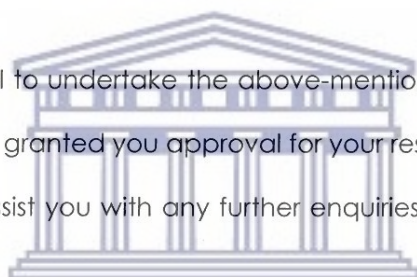
For attention: Dr Tiny Masupe, Dr Peter Delobelle, Prof Thandi Puoane, Dr Hanani Tabana

Title: Early detection, prevention and self-management of type 2 diabetes and hypertension in an urban township in the Western Cape, South Africa..

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact following people to assist you with any further enquiries in accessing the following facilities:

Hayelitsha (Site B)CHC



David Binza UNIVERSITY of the WESTERN CAPE 021 360 5207

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final feedback (**annexure 9**) within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).

3. In the event where the research project goes beyond the *estimated completion* date which was submitted, researchers are expected to complete and submit a progress report (**Annexure 8**) to the provincial Research Co-ordinator (Health.Research@westerncape.gov.za).
4. The reference number above should be quoted in all future correspondence.

Yours sincerely

 AD HAWKRIDGE.

DR A HAWKRIDGE

DIRECTOR: HEALTH IMPACT ASSESSMENT

DATE: 10/3/2017.



UNIVERSITY of the
WESTERN CAPE

9.2 Appendix 2: supplementary materials: FGD interview guide

ANNEX 2 Focus group discussion guide for patients

STUDY TITLE: EARLY DETECTION, PREVENTION AND SELF-MANAGEMENT OF T2DM AND HYPERTENSION IN LIMITED RESOURCE SETTINGS:

Patient barriers to self-efficacy and self-management

We are going to talk about your experiences and challenges with managing your blood pressure or diabetes at home, taking the prescribed medications, following advice on which behaviours to avoid and managing your emotions towards diabetes and high blood pressure.

Self-management

Self-management is composed of three tasks: managing the disease through conventional medicines from healthcare practitioners, managing behaviours that can lead to poor control of the disease and management of your emotions and reactions towards the disease

Managing emotions

1. How long have you been living with diabetes and or high blood pressure?
2. Tell us your experiences on how you reacted emotionally after being told that you have diabetes or high blood pressure
3. How have your emotions changed over time since you were told you have the disease?
4. What assistance if any did you receive towards helping you manage your emotions?
5. If you felt challenged to manage your emotions, why do you think that was the case?
6. What can be done to help people in your position to manage their emotional reactions towards being told they have diabetes or high blood pressure?

Managing medications and medical treatment

1. What treatments do you have to take to manage your diabetes or high blood pressure?
2. What are some of the challenges that you have experienced with your treatment and interactions with healthcare professionals who manage your condition?
3. What can be done to address those challenges?
4. Do you mix western medicines for diabetes and high blood pressure with traditional medicines? If so why?

Managing behaviours

1. What are some of the things that you have been advised to start doing because of having diabetes or high blood pressure?
2. What are some of the things that you have been advised to stop doing because of having diabetes or high blood pressure?
3. Have you come across any challenges with those behaviours?
4. If so, what have been the challenges that you have experienced?
5. What can be done to assist people with diabetes or high blood pressure to follow the correct behaviours as advised by healthcare professionals?

Self-efficacy

Self-efficacy describes the degree to which an individual believes in their own ability to perform specific behaviours in order to meet a specific goal. In this case the specific behaviours will be eating healthy diet, engaging in physical activities regularly, avoiding excess alcohol intake and not smoking. Given the above:

1. Do you think you have skills or power to control your diabetes or blood pressure as directed by healthcare professionals?
2. Share examples of how well you are able to control the condition through eating healthy diet, engaging in physical activities and avoiding other behaviours such as smoking and excess alcohol
3. What are the challenges that you face which affect your ability to follow good behaviours which help you to control your condition?
4. What do you think can be done to help you with the challenges that you have identified?

Thank you very much for your time

9.3 Appendix 3: supplementary materials: In-depth interview guide

ANNEX 1: Interview guide for healthcare workers

STUDY TITLE: EARLY DETECTION, PREVENTION AND SELF-MANAGEMENT OF TYPE 2 DIABETES AND HYPERTENSION IN A RESOURCE LIMITED TOWNSHIP IN WESTERN CAPE

We are going to talk about your experiences and challenges with managing patients with diabetes and high blood pressure focusing on your skills to empower them to manage their hypertension or diabetes at home, taking the prescribed medications, following advice on which behaviours to avoid and managing their emotions towards diabetes and high blood pressure

1. How long have you been practising as a healthcare worker
2. How many patients do you see on average a day, week, and month?
3. What is your profession?

Self-efficacy

4. Have you heard of the term chronic disease?
5. Have you ever heard of the term self-efficacy?
6. What is your understanding of the meaning of the term self-efficacy?

Self-efficacy describes the degree to which an individual believes in their own ability to perform specific behaviours in order to meet a specific goal. In this case the specific behaviours will be eating healthy diet, engaging in physical activities regularly, avoiding excess alcohol intake and not smoking. Given the above:

7. Do you think you have the skills to empower your patients to control their diabetes or blood pressure independently?
8. Share examples of how well you are able to empower your patients to control their diabetes or high blood pressure through
 - a. eating healthy diet
 - b. engaging in physical activities
 - c. avoiding other behaviours such as smoking and excess alcohol
 - d. managing their emotions towards living with the disease
9. What are the challenges that you face which affect your ability to empower your patients to follow good behaviours which help them to control their condition?
10. What do you think can be done to help you with the challenges that you have identified? (social, religious, cultural myths for example)

Self-management

1. Have you ever heard of the term Self-management?
2. What is your understanding of the meaning of the term Self-management?
3. How does this term apply to patients with chronic diseases such as diabetes and high blood pressure?
4. What is challenging about self-management in real life for patients with chronic diseases like diabetes and blood pressure?

Self-management is composed of three tasks: managing **the disease** through conventional medicines from healthcare practitioners, **managing behaviours** that can lead to poor control of the disease and **management of emotions** and reactions towards the disease

Managing emotions

7. Tell us your experiences on how patients have reacted emotionally after being told that they have diabetes or high blood pressure (positive and negative)
8. Why do you think patients reacted the way they did?
9. How did you handle such emotions (positive and negative)
10. What assistance did you provide towards helping patients to manage their emotions?
11. What can be done to help people in your position to manage their patients' emotional reactions towards being told they have diabetes or high blood pressure?

Managing medications and medical treatment

5. Tell us about the treatments that your patients have to take to manage diabetes or high blood pressure?
6. Do you think they are able to manage their treatment at home? Explain your thoughts
7. What are some of the challenges that your patients have experienced with treatment?
8. Do you think they mix western medicines for diabetes and high blood pressure with traditional medicines? If so why?

9. What can be done to address those challenges? (dealing with myths, spiritual & religious beliefs for example)

Managing behaviours

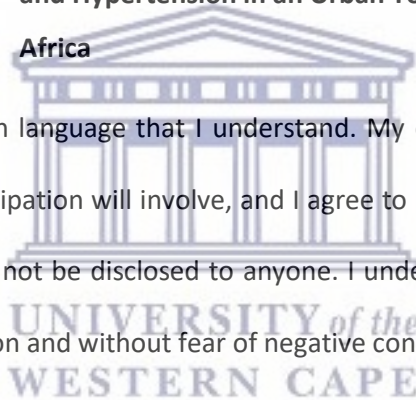
6. What are some of the things that you have advised patients to start doing because of having diabetes or high blood pressure?
7. What are some of the things that you have advised patients to stop doing because of having diabetes or high blood pressure?
8. Have you come across any challenges with those behaviours among your patients?
9. If so, what have been the challenges that you have experienced?
10. What can be done to assist people with diabetes or high blood pressure to follow the correct behaviours as advised by healthcare professionals?

9.4 Appendix 4: supplementary materials: Consent forms

CONSENT FORM (surveys)

Title of Research Project: **Early Detection, Prevention and Self-Management of Type 2 Diabetes and Hypertension in an Urban Township in the Western Cape, South Africa**

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve, and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.



Participant's name.....

Participant's signature.....

Date.....

UXWEBHU LWESIVUMELWANO (Kuphando)

Isihloko sophando: *Early Detection, Prevention and Self-Management of Type 2 Diabetes and Hypertension in an Urban Township in the Western Cape, South Africa*

Oluphando lucacisiwe kum ngolwimi endiluqondayo. Imibuzo yam ngoluphando iphendulekile. Ndiyayiqonda into yokuba ukuthabatha kwam inxaxheba koluphando kubandakanya ntoni, kwaye ndiyavuma ukuba ndithabathe inxaxheba koluphando ngokuzikhethela nangaphandle kwesinyanzeliso. Ndiyayiqonda into yokuba iinkcukacha zam aziyi kutyhilwa mntwini, ziyakugcinwa ziyimfihlo. Ndiyayiqonda into yokuba ndingarhoxa nangaliphi na ixesha ngaphandle kokunika isizathu kunye nangaphandle koloyiko lokuphulukana namalungelo wam okanye ukufumana imiphumela emibi.

Igama lomthabathi nxaxheba.....

Utyikityo lomthabathi nxaxheba.....

Umhla.....



Revised: 05/062018

INFORMATION SHEET

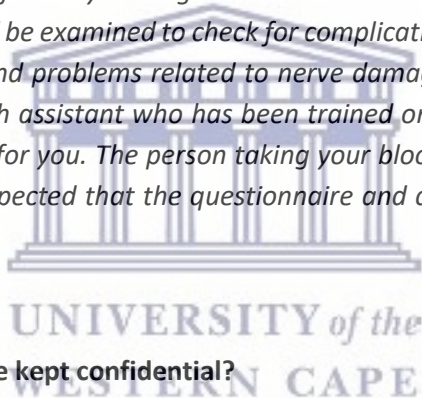
Project Title: Early Detection, Prevention and Self-Management of Type 2 Diabetes and Hypertension in an Urban Township in the Western Cape, South Africa

What is this study about?

This is a research project being conducted by **Dr Tiny Masupe** at the University of the Western Cape. We are inviting you to participate in this research project because you meet the study criteria of an adult who is either living with diabetes or at high risk of diabetes, an adult who is either suffering from high blood pressure or at increased risk of high blood pressure living and using healthcare services in Khayelitsha. The purpose of this research project is to gain a deeper understanding of how patients with diabetes and high blood pressure manage their conditions at home, what challenges they come across and how they can be assisted. We also aim to see how many healthcare workers assisting the patients also understand how patients should be managing their conditions of blood pressure and diabetes more effectively. With the information that we will gather, we hope to produce guidelines which will help improve patients and healthcare workers ability to manage diabetes and blood pressure more effectively. The gaps identified and lessons learnt will be used to inform policy on catching diabetes and high blood pressure early to prevent many people getting complications. You were selected as a possible participant in this study because you meet the research criteria. Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

What will I be asked to do if I agree to participate?

If you decide to participate, you will be invited to complete a questionnaire which one of our study team members will help you to fill. The questionnaire has a series of questions about your background, knowledge about diabetes and high blood pressure and how to effectively manage these conditions. We will also ask to check your blood sugar levels, blood pressure and you will be examined to check for complications of diabetes or high blood pressure such as eye problems, foot problems and problems related to nerve damage that can occur as a result of these diseases. The researcher or the research assistant who has been trained on this questionnaire will be asking the questions and completing the answers for you. The person taking your blood pressure and blood sugars will also be a trained healthcare worker. It is expected that the questionnaire and clinical examination will take no more than 45 minutes of your time



Would my participation in this study be kept confidential?

The researchers undertake to protect your identity and the nature of your contribution. To ensure your anonymity, **“the survey questionnaires are anonymous and will not contain information that may personally identify you”**. (1) **your name will not be included on the surveys and other collected data;** (2) **a code will be placed on the survey questionnaire and other collected data;** (3) **through the use of an identification key, the researcher will be able to link your survey to your identity;** and (4) **only the researcher will have access to the identification key.**

To ensure your confidentiality, **the data from this investigation will be handled confidentially and all efforts shall be made to ensure that your privacy is maintained. Your name shall only be recorded on the consent form. All other documents used during this study shall have your allocated number for the study. Only the researchers involved in this study will know your identity from the numbers allocated. All records from this study shall be kept safely and securely in lockable cabinets, and information entered in any computer used for**

this research will be password protected. None of these will be used for commercial purposes. If we write a report or article about this research project, your identity will be protected.

What are the risks of this research?

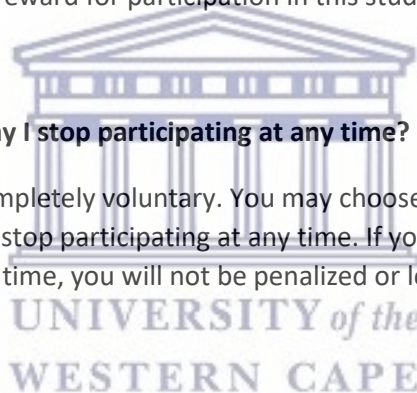
All human interactions and talking about self or others carry some amount of risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

There are no personal benefits for participating in this study. However, we anticipate that the results from the research project will help in informing policy prevention of diabetes and high blood pressure through empowerment of the general population. The findings from this study will help us to recognize and address existing gaps on how we can improve prevention and self-management of diabetes and high blood pressure. Taking part in this study might be a platform to have any questions you might have about these diseases answered. There shall be no monetary reward for participation in this study

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify



What if I have questions?

This research is being conducted by Dr Tiny Masupe from The School of Public health at the University of the Western Cape. If you have any questions about the research study itself, please contact Dr Tiny Masupe at: University of Botswana Faculty of Medicine, Corner Notwane and Mobuto road, Gaborone, Botswana. Phone: +267 3554839 or +26771812082. Email: tiny.masupe@mopipi.ub.bw

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Prof Thandi Puoane

School of Public Health

University of the Western Cape

Private Bag X17

Bellville 7535

tpuoane@gmail.com

Prof Anthea Rhoda

Dean of the Faculty of Community and Health Sciences

University of the Western Cape

Private Bag X17

Bellville 7535

chs-deansoffice@uwc.ac.za

This research has been approved by the University of the Western Cape's Research Ethics Committee.

(REFERENCE NO: WC_2017RP50_730: iyakufakwa xa kuthe kwafunyanwa isiliphu Research Ethics Committee)



UNIVERSITY *of the*
WESTERN CAPE