



**A qualitative study on diabetic and hypertensive patients in
Cape Town, South Africa: their experiences of primary health
care and their struggles with self-management**

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PREAMBLE

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“If there was **only one truth**, you couldn't
paint a hundred canvases on the same
theme.” – Pablo Picasso

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ABBREVIATIONS

CHC	<i>Community Health Centre</i>
PHC	<i>Primary Health Care</i>
DOTS	<i>Directly Observed Therapy Short-course</i>
NCD	<i>Non-communicable Disease</i>
SA	<i>South Africa</i>
SANHANES-1	<i>South African National Health and Nutrition Examination Survey</i>
SSA	<i>Sub-Saharan Africa</i>
SADHS	<i>South African Demographic and Health Survey</i>
SDT	<i>Self-Determination Theory</i>
SEM	<i>Socio-ecological Models</i>
WHO	<i>World Health Organisation</i>
WHO FCTC	<i>Framework Convention on Tobacco Control</i>
WHO PEN	<i>WHO Package of Essential Non-Communicable Disease Interventions of Primary Health Care in Low-Resource Settings</i>

DISSERTATION ABSTRACT

Background

Non-communicable diseases (NCDs) such as hypertension and diabetes are on the rise and are becoming leading causes of morbidity and preventable mortality in South Africa (SA) (Mahomed, 2011). The World Health Organisation (WHO) estimates the incidence of NCDs in SA to be two to three times higher than that in some developed countries, and similar to some European countries that fall into the highest burden quintile (Mahomed, 2011). The rise in NCDs has been driven by an increase in behavioural risk factors for NCDs in both urban and rural areas as a result of rapid urbanisation and by the nutritional transition that many South Africans are experiencing (Chopra et al., 2007).

Evidence suggests that SA's response to the management of NCDs has had little effect: there is a rising incidence of deaths from NCDs and increasing pressure on health care services from chronic diseases (Mahomed, 2011). Furthermore, several studies have shown that there is poor control of hypertension and diabetes among patients attending public sector primary health care (PHC) facilities in SA, including the Western Cape (Goodman et al., 1997; Steyn et al., 1998; Steyn & Levitt, 2006; Parker et al., 2010; Parker et al., 2012; Mothiba, Malema & Lekhuleni, 2013).

According to the WHO, the effective and equitable management of NCDs should be based on a PHC approach (World Health Organisation [WHO], 2010). The PHC approach includes taking comprehensive services, such as health promotion and disease prevention to communities and emphasising patient-centred care, as well as community participation (WHO, 2010; Mahomed, 2011). A patient-centred approach is particularly important in the management of NCDs, because a significant part of chronic care requires self-management (Beaglehole et al., 2008). Patients with NCDs have to make lifestyle changes such as adopting healthier diets and increasing their physical activity, as well as complying with treatment (Beaglehole et al., 2008).

Self-Determination Theory (SDT) argues that patients who achieve better self-care outcomes are those who feel autonomous, competent and experience a sense of relatedness with their health care providers and family members (Ryan et al., 2008). In addition to individual factors, there are also contextual and structural factors, such as access to quality health care, opportunities for physical activity or the cost of healthy foods, which can either facilitate or impede good self-management (Ahola & Groop, 2013).

The overall aim of this study was to understand how diabetic and hypertensive patients experience PHC in Cape Town, as well as their capacity for self-management of their condition. The specific objectives were: to explore how patients react to existing health care materials/interventions at the health care facility; to identify the needs these patients have for information and behavioural change counselling; to investigate the perceived barriers to lifestyle modification in relation to the patients and to the broader social and economic environment and to investigate the sources of personal motivation to control their illness through lifestyle modification.

Methodology

The study population consisted of patients diagnosed with type 2 diabetes and/or hypertension attending PHC at three community health centres (CHCs) in the Cape Town metropolis: Gugulethu, Retreat and Lady Michaelis. The population attending these public sector facilities is characterised by low socio-economic status and low levels of education (Mash et al., 2012).

A total of 22 patients between the ages of 30 and 77 years were recruited to the study. Participants were a mix of Afrikaans-speaking and Xhosa-speaking patients. Individual in-depth interviews were used to collect data; these were transcribed verbatim. Data was transferred to the ATLAS-TI software programme and analysed using a thematic content analysis approach. The data was coded according to inductive and deductive themes and categories.

Results

The findings of this study suggest that the degree to which an individual is able to manage a chronic condition such as hypertension and/or diabetes is largely dependent upon the interaction of multi-faceted individual and environmental factors, which can either impede or facilitate effective self-management. Individual factors such as motivation (more especially the quality of motivation) and self-efficacy emerged as important factors that impact on self-care. Socio-environmental factors such as the experience of relatedness with health professional and family members also emerged as significant contributors to the adoption of protective health behaviours. It is also evident from the findings of this study that health literacy levels impact on individuals' competence and motivation for behaviour change.

Overall, the findings of this study suggest that diabetic and hypertensive patients who utilise primary health care (PHC) facilities face multiple barriers which make lifestyle change and adherence to treatment the more difficult choice. Participants reported struggling to change their diet from high fat, sugar, and salt diets as a result of cost, taste preferences, misconceptions about "healthy eating" and resistance from family members to eat more healthily. In terms of physical activity, participants reported low levels of physical activity, mainly as a result of ill-health caused by co-morbidities. Participants reported that these problems were exacerbated by the negative experiences of care from health care providers. Participants reported receiving little or no explanation about their conditions, receiving negative attitudes from nurses and experiencing inordinately long waiting periods at health care facilities.

Although this study was qualitative and did not empirically test SDT, the model's constructs of competence, autonomy and relatedness were found to be workable and provided valid concepts in exploring and understanding patients' motivation. Factors such as family support, positive patient-doctor relationships and knowledge about illness were identified as motivators to lifestyle modification and adherence to treatment. Factors that emerged from the analysis as barriers to self-management

were multi-layered, ranging from personal to socio-economic factors. These included poor functional health literacy, lack of family support, lack of support and counselling from health care providers, fear of stigma associated with weight loss, financial constraints and side effects associated with taking medication.

Conclusions

This study gives insight into how health literacy, motivation and socio-ecological factors play a role in how patients respond to a diagnosis of diabetes or hypertension. To that end, the present findings may be used to plan education programmes and interventions that could motivate self-management in diabetic and/or hypertensive patients in other similar settings. Although behaviour change is difficult and individual choices are influenced by broader social, cultural and environmental factors, there is much evidence that shows that health care providers can play a vital role in motivating patients to adhere to treatment and to modify their health behaviours, with a consequent impact on health outcomes.

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CHAPTER 1: OVERVIEW OF THESIS

1.1. INTRODUCTION

Non-communicable diseases are long-term, non-infectious conditions that are caused, to a large extent, by four common behavioural risk factors associated with urbanisation and economic transition: unhealthy diet, harmful use of alcohol, decreased physical activity and tobacco consumption (WHO, 2011). Traditionally, these diseases were considered to be diseases of affluence, as they were initially more prevalent in high-income countries (Schneider et al., 2007). However, there is now abundant evidence to show that the incidence of NCDs has significantly increased in low- and middle-income countries as lifestyle changes and rates of urbanisation increase (Levitt et al., 2011).

In 2008, the World Health Organisation predicted that NCDs will increase by 17% over the next decade, with the greatest increase occurring in the African region (WHO, 2008). Africa is now faced with a triple burden of disease, since a double burden of disease already existed as a result of health problems that are directly related to globalisation and climate change, as well as communicable diseases such as tuberculosis and the HIV/AIDS epidemic (Frenk & Gomez-Dante, 2011; Murray et al., 2013).

Although there is abundant research from developed countries on NCD interventions, there is still a paucity of data on NCDs in developing countries (Miranda et al., 2008). Local research has been deemed necessary since research findings from developed settings are not always appropriate for the development of interventions in the context of developing countries (Miranda et al., 2008). According to the WHO's Action Plan for the Global Strategy for the Prevention and Control of NCDs, member states should invest in epidemiological, behavioural and health systems research as part of their national programmes for the control and prevention of NCDs (WHO, 2008). The Action Plan also urges member states to conduct research on the socio-economic determinants of NCDs, as well as the cost effectiveness of interventions (WHO, 2008).

Other focus areas of research in sub-Saharan Africa that have been suggested in the literature include research on how to improve the primary care services' response to NCDs, how to improve surveillance on NCDs, and how to improve the efficiency and effectiveness of resources currently committed to the care of patients with NCDs (Unwin et al., 2001; Maher et al., 2010). Research on the role of patients in the management of their own chronic conditions such as hypertension, diabetes and heart disease is also needed, since it has become widely recognised that clinical care alone, without patient self-care, is not sufficient to achieve optimal health outcomes (Pruitt & Annandale, 2002). Patients need to change their lifestyles, develop effective self-management skills, and interact with the health care system in order to successfully manage their conditions (Pruitt & Annandale, 2002).

According to the 2002 WHO Global Report on the prevention and management of chronic conditions in health care systems, there is still a lack of data in the current body of health research on patient self-management behaviour (Pruitt & Annandale, 2002). This is despite the fact that patients can play a central role in optimal disease control through lifestyle modification and adherence to treatment (Pruitt & Annandale, 2002).

1.2. RATIONALE AND JUSTIFICATION

As already mentioned in the preceding sections, NCDs are on the rise in SA and are putting considerable pressure on an already overburdened PHC system. Furthermore, the current approach to NCDs is often unstructured and lacking in systematic follow-ups and monitoring of chronic clinical care (Maher et al., 2010). In order to address the rising NCD epidemic, NCD research is needed in order to improve the response of PHC services, which are the main providers of care for people suffering from NCDs (Maher et al., 2010).

Furthermore, a review of the literature has revealed the need for context-appropriate local research in order to generate data that can be used to develop appropriate interventions. The results of this study can contribute to understanding how patients who utilise PHC facilities respond to a diagnosis of diabetes or hypertension, their

experiences of care, their level of health literacy, the extent of their ability and their motivation to make lifestyle changes, as well as perceived barriers to translating this into their daily lives. Identifying and understanding these factors can assist in the development of health education programmes and lifestyle interventions to attempt to influence behaviour at the individual, community or societal level.

1.3. STUDY AIM

The overall aim was to contribute to an understanding of how diabetic and hypertensive patients experience PHC services in Cape Town, as well as their capacity for self-management of NCDs.

1.4. OBJECTIVES

The specific objectives were:

- to explore how patients react to existing health care materials/interventions at the health care facility;
- to identify the needs these patients have for information and behavioural change counselling;
- to investigate the perceived barriers to lifestyle modification that relate to the patients and to the broader social and economic environment; and
- to investigate the sources of their personal motivation to control their illness through lifestyle modification.

1.5. THESIS OUTLINE

This dissertation has been organised into five chapters. Chapter One provides the dissertation abstract and an introduction to the study, which consists of a broad description of the burden of NCDs and the importance of NCD research in developing countries such as South Africa. This is then followed by the rationale and justification for the study. The study aims and objectives are then presented. Chapter Two contains the literature review, which provides a detailed background to the study. It is divided into four sections. The first part provides an overview of the epidemiology of NCDs, including descriptions of what NCDs are, and of

hypertension and diabetes in particular; descriptions of the disease burden; and the prevalence of NCD risk factors/behaviours. The second part deals with the prevention and control of NCDs and describes the WHO guidelines for comprehensive approaches; SA's response to NCDs; the new strategic plan for SA; and the role of health care services and SA research on this aspect. This is followed by a section that deals with the role of the patient in self-management of NCDs, as well as a review of related research from SA and elsewhere. The last section deals with the theoretical framework underpinning the study, in particular Self-Determination Theory and Socio-Ecological theories.

Chapter Three describes the research methods used in the study. This includes a description of the study population, study design and procedures for data collection and analysis. Ethical considerations are also discussed.

Chapter Four provides a summary of the study results. This includes a description of the demographic characteristics of the study sample; a case study of an individual research participant, which in many respects is a good representation of the salient themes that emerged from the data analysis and finally, a description of the overall results from the analysis of all the interviews.

Chapter Five contains a discussion of how the findings relate to previous studies on a similar topic and the implications of the study findings. Recommendations for how the quality of care for patients with NCDs in South Africa can be improved and how effective self-management can be enhanced are presented. To conclude, there is a discussion on the strengths and limitations of the study.

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CHAPTER 2: LITERATURE REVIEW

LITERATURE REVIEW

2.1. THE EPIDEMIOLOGY OF NON-COMMUNICABLE DISEASES

Non-communicable diseases (NCDs) are on the rise globally, with 36 million of the 57 million deaths that occurred in 2008 due to NCDs, despite these diseases often being preventable (WHO, 2011b). In 2010, the five leading risk factors for the global disease burden were: high blood pressure; tobacco smoking, including second-hand smoke; household air pollution from solid fuels (4.3% of the global DALYs or disability-adjusted life years); dietary risk factors; and physical inactivity (Lim et al., 2013).

In 2010, 54% of all DALYs experienced globally were due to NCDs, compared to 35% of DALYs as a result of communicable, maternal, neonatal and nutritional disorders (Murray et al., 2013). There was also an increase in the YLLs (years of life lost) from premature death as a result of NCDs, particularly cardiovascular diseases, from 33.3% in 1990, to 42.8% in 2010 (Lozano et al., 2013).

Though traditionally considered to be diseases of the wealthy, NCDs are on the rise in Africa, and disproportionately affect the poor (Dalal et al., 2011). Traditionally, infectious diseases and maternal and perinatal conditions accounted for the greatest burden of morbidity and mortality in Africa (Van de Vijver et al., 2013). However, diabetes and hypertension are fast becoming major causes of morbidity and mortality in Africa (Motala & Ramaiya, 2010; Van de Vijver et al., 2013). This growing incidence of NCDs is a result of urbanisation and associated behavioural risk factors, such as reduced physical activity, tobacco use, excessive alcohol consumption, and the adoption of the “western” diet, which is high in sodium, saturated fats and refined sugar (Van de Vijver et al., 2013).

Age-specific levels of diabetes and hypertension in many urban areas of sub-Saharan Africa (SSA) are reported to be as high, if not higher, than in most Western countries (Mbaya & Ramiaya, 2006). These two diseases often coexist. For example, the prevalence of hypertension in diabetic patients has been found to be approximately twice that of the non-diabetic population (Sampanis & Zamboulis, 2008).

Diabetes mellitus is a chronic metabolic disease, characterised by hyperglycaemia resulting from defects in insulin secretion or insulin action in the body (Mbaya & Ramiaya, 2006). Type 1 diabetes, which is commonly found in children, results from auto-immune destruction of insulin-producing cells, leading to the loss of the ability to produce insulin (Mbaya & Ramiaya, 2006). Type 2 diabetes, on the other hand, is characterised by either insulin resistance or by abnormal insulin secretion or both (Mbaya & Ramiaya, 2006). Risk factors associated with the development of type 2 diabetes include excess body weight, physical inactivity and a family history of diabetes (Brancati et al., 2000).

Medical management of diabetes includes a combination of lifestyle and pharmaceutical interventions aimed at preventing and controlling hyperglycaemia (Fowler, 2008), which is a major cause of morbidity and mortality in both type 1 and type 2 diabetes. Complications associated with hyperglycaemia include diabetic nephropathy, retinopathy, neuropathy, peripheral arterial disease and stroke (Fowler, 2008).

Hypertension is the predominant contributor to the morbidity and mortality associated with cardiovascular disease, stroke, renal disease and blindness (Steyn, 2005). Hypertension is usually defined as systolic blood pressure of 140 mm Hg and above or a diastolic blood pressure of 90 mm Hg and above (Roger et al., 2012). Risk factors associated with hypertension include tobacco smoking, high alcohol intake, obesity, and dietary factors such as high intake of saturated fat, animal protein, and increased salt intake (Chobanian et al., 2003).

2.2. THE BURDEN OF NCDs IN SOUTH AFRICA

Like other middle-income countries, SA is experiencing a rise in the incidence of NCDs, which means that SA is now faced with a quadruple burden of disease: maternal and perinatal, NCDs, infectious and injury-related disorders (Puoane et al., 2008). SA has seen a significant rise in NCD-related mortality and morbidity over the past 30 years, particularly in relation to ischaemic heart disease, hypertension, stroke, diabetes and cancer (Steyn & Levitt, 2006).

According to the 2011 WHO's report on member states' NCD profiles, 29% of all deaths that occurred in SA in 2008 were due to NCDs (WHO, 2011). Figure 1.1 shows that in 2008, an estimated 92,400 males and 98,100 females died from NCDs in SA. The proportion of those younger than 60 years who died from NCDs was greater for males (39%) than for females (28%).

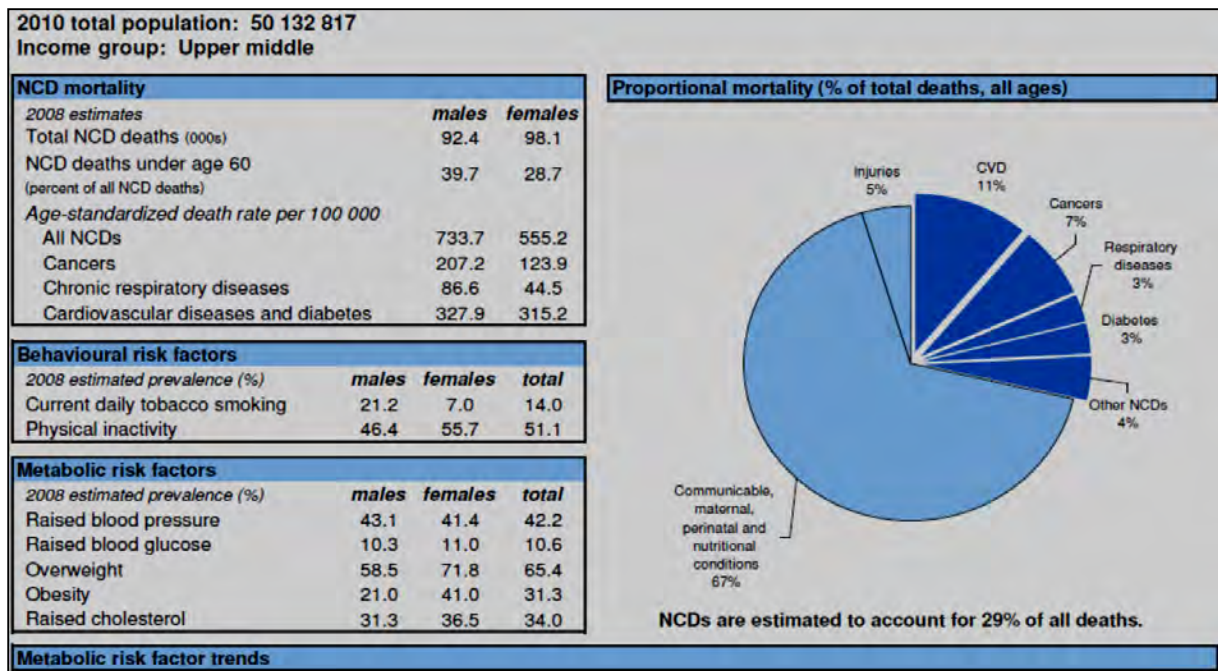


Figure 2.1: South Africa's NCD profile (Reprinted from the World Health Organisation's NCD Country Profiles, 2011)

The results of the South African National Health And Nutrition Examination Survey (SANHANES-1), published in 2013, indicate that the country's NCD burden is escalating. The findings of the survey indicate that the prevalence of pre-hypertension and hypertension is high, despite the presence of cost-effective blood pressure-lowering interventions (Shisana et al., 2013). The results of the survey also show that obesity levels have increased, particularly in women (Shisana et al., 2013).

The International Diabetes Federation (IDF) has estimated the diabetes prevalence rate for South Africa to be 6% for adults between the ages of 20-79 years (Amod et al., 2012). The asymptomatic nature of the disease usually results in 50-85% of cases remaining undiagnosed, especially in rural areas (Amod et al., 2012). The highest prevalence of diabetes has been found among the Indian population, followed by the

coloured, then the black population. There is very limited data on the prevalence of diabetes in the white population¹ (Bradshaw et al., 2007). It has been found that the greatest burden of diabetes is in the Indian community of Durban (15%) and the elderly coloured community of Cape Town (28%) (Rheeder, 2006).

In the Western Cape in particular, the black African isi-Xhosa-speaking group and the coloured group are significantly affected by NCDs. Approximately 23,395 hypertensive and 13,338 diabetic patients attend PHC facilities in Cape Town every month (Parker et al., 2012). Type 2 diabetes and heart disease are highly prevalent in the coloured group, whereas hypertension and stroke are the major causes of mortality in the isi-Xhosa-speaking group (Parker et al., 2012).

A study conducted in Cape Town among the coloured community showed that there is a high prevalence of diagnosed and undiagnosed type 2 diabetes in this community. Of the 642 people studied, 28% were found to have diagnosed type 2 diabetes and 18% undiagnosed diabetes. Moreover, high rates of obesity were found among women (87.9%) and men (42.2%) in this community (Erasmus et al., 2012).

The prevalence of diabetes has also increased in the black population. A study conducted in 2008/09 in Cape Town in the predominately black townships of Gugulethu, Nyanga, Khayelitsha, Langa and Crossroads examined the prevalence of diabetes among the urban black African population and found that the prevalence of diabetes was significantly higher than it was 20 years ago (Peer et al., 2012).

The study also reported that the overall Impaired Glucose Tolerance (IGT) prevalence found in this population was among the highest found in SSA. This result is indicative of the fact that there may be an increase of diabetes in this

¹ The South African population comprises of four main groups, namely black African, coloured, Indian/Asian and white (Statistics South Africa, 2012). These different classification groups are a legacy of the apartheid Population Registration Act of 1950, which required that every person in South Africa be classified and registered as belonging to a particular racial group (Brown, 2000). Though the Population Registration Act was repealed in 1991, these “racial” categories are still widely used in the classification of the different groups that make up the South African population (Statistics South Africa, 2012). These categories are still relevant analytical tools in South Africa’s efforts to redress the injustices of past discrimination and monitor progress of previously disadvantaged groups.

population in the future, since up to 70% of those with a high IGT may progress to diabetes (Peer et al., 2012).

Hypertension is also a major public health concern in SA (Fehrsen, 1998). A local study by Lambert & Kolbe-Alexander (2006) reported that the greatest prevalence of hypertension in SA has been found in black African populations living in urban and peri-urban areas, with more than 43% of men and over 66% of women reported to have hypertension. Black South Africans have been found to be more prone to complications of high blood pressure, especially strokes, heart failure and hypertensive nephrosclerosis (Rayner, 2010).

A nationally representative survey by Steyn et al. (2008), which aimed to identify groups of patients with high hypertension prevalence and poor control, found that rural black African people had a significantly lower risk of hypertension than urban black African, coloured and white people. The odds of hypertension among urban black African, coloured and white populations were 1.42, 1.54 and 1.84 times higher than among rural black people respectively.

The survey also found that obese/overweight participants had a significantly higher risk of hypertension (OR² 1.37 and 1.97 respectively) when compared with those of normal weight. It was also found that as age increased, the risk of hypertension also increased significantly, for example the above 65 age group had a significantly higher risk of hypertension (OR 20.85) when compared to the 15-24 age groups. Other factors that were found to be associated with a high risk of hypertension included excess use of alcohol and a family history of hypertension and stroke (Steyn et al., 2008).

2.3. BEHAVIOURAL RISK FACTORS FOR NCDs IN SOUTH AFRICA

NCDs such as hypertension and diabetes are usually associated with environmental and lifestyle factors, rather than with genetics (van de Vijver et al., 2013). The main risk factors that will be discussed are: unhealthy diets, physical inactivity, overweight and obesity, tobacco use and excessive alcohol consumption. Where

² Odds Ratio

possible, the findings of the South African National Health And Nutrition Examination Survey (SANHANES-1) will be highlighted, since this depicts the most current data on the magnitude of, and trends in, NCD-related risk behaviours (Shisana et al.,2013).

2.3.1 Unhealthy diets

South African studies on dietary intake have shown that the black African population, which forms the majority of the SA population, is undergoing a nutritional transition. The transition is from a traditional diet, comprised of high fibre and carbohydrate intake, to a westernised diet, which typically includes refined foods and foods which are high in saturated fats, salt and sugar (Chopra et al., 2007). SA studies indicate that the coloured, white and Indian populations already follow this westernised diet (Steyn, 2006).

National surveys have indicated that unhealthy dietary patterns are becoming increasingly prevalent among children and adolescents. The first National Food Consumption Survey (NFCS) in SA, which was conducted in 1999 among 1-9 year-old children, showed that urban children consumed a diet with a higher energy intake, with more fat and more sugar than their rural counterparts (Steyn & Labadarios, 2011). In 2005, another NFCS was conducted; the results showed that 10% of children were overweight and 4% were obese (Labadarios et al., 2008). The results of the Youth Risk Behaviour Survey (YRBS), conducted in 2002, showed that over 17% of adolescents were overweight and 4.2% were obese (Labadarios et al., 2008).

In terms of the latest findings, the SANHANES-1 survey revealed that 39.7% of the participants consumed a diet low in diversity, indicative of a diet of poor nutritional quality. The study revealed that almost one out of five participants consumed a diet with a high fat score (18%). Overall, participants who resided in urban areas had a significantly higher fat intake than participants who lived in rural areas.

2.3.2 Physical inactivity

The 2003 National Demographic and Health Survey found that 63% of women and 48% of men were insufficiently active (Department of Health [DoH] et al., 2007). Evidence suggests that 30% of ischaemic heart disease cases, 27% of colon cancer cases and 20% of diabetes cases in SA can be attributed to physical inactivity (Kolbe-Alexander, Bull & Lambert, 2012). Black South African women have been identified as the highest risk group, having the country's highest levels of physical inactivity, obesity and overweight (Walter, du Randt & Venter, 2011). Physical inactivity is also a big problem among the youth. The 2002 Youth Risk Behaviour Survey (YRBS) found that 29% of learners had no physical education classes in schools, and that 25% watched television for over three hours per day.

The second YRBS was conducted in 2008, in which an even higher proportion of learners reported that they had no physical education classes in schools (34%) in comparison to the 2002 study. Moreover, the proportion of learners who watched TV for more than three hours per day (29%) was also higher when compared with the 2002 YRBS (25%) (Reddy et al., 2010).

2.3.3 Overweight and obesity

According to the results of the South African Demographic and Health Survey (SADHS), women and men have high levels of overweight/obesity, but in comparison to men, more women are overweight/obese (Steyn et al., 2006). More than 70% of women above the age of 35 years are overweight or obese, compared to 45% of men of the same age range (Bradshaw et al., 2011). In terms of ethnic groups, the highest levels of overweight or obesity are found among black African women and in white men (Steyn et al., 2006). The rising prevalence of obesity is a problem because obesity is a risk factor for type 2 diabetes, hypertension, ischaemic heart disease and ischaemic stroke (Bradshaw et al., 2011).

Similarly, more recent data provided by the SANHANES-1 study revealed that the prevalence of overweight and obesity was still significantly higher in females (39%)

than in males (24%). The study found that 20% of males and 68% of females have a waist circumference which placed them at risk of metabolic complications.

In terms of children, the SANHANES-1 study found a significant proportion of girls to be obese and overweight (22%), when compared to boys (10%). According to Shisana et al. (2013), regional and international comparisons show that South Africa's preschool aged children have a major problem with overweight and obesity, with a prevalence of 22% - twice that of Morocco, Swaziland, Botswana and Nigeria.

2.3.4 Tobacco smoking

The tobacco consumption pattern in SA shows that there was a peak in the use of tobacco products in the 1990s and then a decline (Peer et al., 2009). This decline has been attributed to tobacco control legislation, introduced in 1993, which led to health warnings on cigarette packets and advertisements (Steyn et al., 2006; Peer et al., 2009). After the amendment of the Act in 1999, all advertisements of tobacco products and their sale to minors were banned (Steyn et al., 2006).

The results of the 1998 SADHS showed that more than 39% of black African, white and Indian adult males smoked daily or occasionally (Steyn et al., 2006). Females have been found to have lower prevalence rates of daily smoking, with the overall prevalence rate lowest in black African females (5%) and highest among white females (27%) (Steyn et al., 2006).

A study, which compared the prevalence and patterns of tobacco use in the 2003 SADHS with the 1998 SADHS, found that the smoking prevalence for women remained unchanged, whereas it decreased in men (from 42% to 35%) (Peer et al., 2009). The greatest decline in tobacco use was found among the poorest males and those aged 25-44 years (Peer et al., 2009). Despite this positive decline in smoking among males, smoking rates in SA are still higher than those of other African countries (Peer et al., 2009).

The SANHANES-1 study found that overall, 16% of the nationally representative sample were daily smokers. Higher tobacco smoking prevalence rates were found

among men (76%) compared to women (62%). The study also revealed that exposure to environmental tobacco smoke is of great concern in this country. Although only 16% of adults were daily smokers, 29% of adults revealed exposure to environmental tobacco smoke. Smoking and exposure to environmental tobacco smoke causes, amongst other things, lung cancer and lower respiratory tract infections (Öberg et al., 2011).

2.3.5 Excessive consumption of alcohol

Excessive consumption of alcohol is a risk factor for strokes, diabetes and some cancers (Steyn et al., 2006). A study by Peltzer, Davids & Njuho (2011) on national alcohol use showed an increase in the rates of binge and hazardous drinking between 2005 and 2008. A multistage random population sample of 15,828 persons aged 15 years or older participated in the survey. Alcohol use was reported by 41.5% of the men and 17.1% of the women who participated in the study. Risky or hazardous drinking was defined in the study as a pattern of alcohol consumption that places the individual at risk for adverse health events, and was reported by 17% of the men and 2.9% of the women.

The self-reported data of the 2003 SADHS and the 2008 YRBS indicate that South African youth also engage in excessive drinking. The 2003 SADHS showed that the highest drinking levels occur in adolescents (both male and female) aged between 15-19 years, with the highest rates of drinking among adolescents reported in the Western Cape, North West, and Eastern Cape provinces (Department of Health [DoH] et al., 2007). In the 2008 YRBS, 29% of learners reported engaging in binge drinking in the past month prior to the survey (Reddy et al., 2010). Binge drinking is heavy episodic drinking and usually occurs during weekends, holidays and at month end. Binge drinking is a major contributor to injury, disease and death (WHO, 2011a).

According to the most current data from the SANHANES-1 study, more than half of the households (54%) reported that no one in the household drank alcohol, whereas 46% of the households reported alcohol consumption. Of the households that

reported alcohol consumption, the majority did not perceive this as a problem of alcohol misuse. Moreover, 20% did not perceive alcohol misuse to be serious. Conversely, a significant minority (16%) perceived alcohol misuse in their households as either serious or very serious. The study also indicated that binge drinking was common especially among black African and coloured households.

It is clear from the results of the various surveys undertaken in SA that there is a high prevalence of NCD behavioural risk factors, which has grave implications for the future burden of disease. The changes in lifestyle patterns in the SA population can be traced to underlying social, economic, political, environmental and cultural changes over the last few decades (United Nations Development Programme [UNDP], 2013). Individual behaviour does not occur in a vacuum (UNDP, 2013). In order to address the health and developmental burdens of NCDs effectively, efforts to change health behaviour at the level of the individual are not sufficient: interventions are also needed at the level of the social, economic and cultural contexts in which individuals live and work.

2.4. SOCIAL DETERMINANTS OF NON-COMMUNICABLE DISEASES

The social determinants of health are the underlying causes of health problems such as environmental factors, socio-cultural and socio-economic factors that directly or indirectly affect the health of the population (Puoane et al., 2008).

2.4.1 Environmental factors

Globalisation, with its associated free trade agreements, has afforded transnational food companies opportunities to sell their products in developing countries. South Africa is considered to be the leading sub-Saharan African country for multi-national fast food chains (Chopra et al., 2007). The increased availability and accessibility of these foodstuffs has contributed significantly to the nutrition transition in SA. For example, the sales of snack bars and ready-made meals rose by 40% between 2005 and 2010 (Igumbor et al., 2012).

Fast food consumption negatively impacts on the effective management of NCDs such as diabetes and hypertension since it is associated with a higher dietary intake of energy and saturated fat, and a lower intake of fruit and vegetables, which can result in obesity (Steyn & Labadarios, 2011). Obesity has been shown to affect effective management of type 2 diabetes by increasing insulin resistance and blood glucose concentrations (Klein et al., 2004).

The consumption of street foods by South Africans is also on the increase (Steyn & Labadarios, 2011). Street vendors are an important group of food retailers for certain sub-groups of the population, such as men without families, who move from rural areas into urban areas in search of work, and for impoverished families without kitchens (Chopra et al., 2007). According to a recent survey, 11.3% of the national population reported buying food from street vendors and 6.8% reported buying food from fast foods outlets at least twice a week, which indicates that more South Africans buy street foods than fast foods (Steyn & Labadarios, 2011).

The cooked foods that are usually sold on the street are deep fried, for example fat cakes, fried chicken and fried meat (Steyn & Labadarios, 2011). These cooked foods are frequently energy dense, high in saturated fat and low in micronutrients. This makes them unsuitable for hypertensive and diabetic patients, who require low calorie diets which are low in sodium and saturated fat, and high in fibre (Ganesh & Viswanathan, 2011).

The increase in advertising and marketing of fast foods through the mass media has also been an important factor in the changing patterns to greater consumption of processed and take-away foods. It is reported that in 2007 alone, the advertising expenditure for big companies in SA was R23 billion; of that amount, R1.4 billion was spent on beverage advertisements and R875 million was spent on food advertisements (Cassim, 2010). Food and beverage marketing particularly targeted at children has been linked with high rates of child obesity in the USA and now in developing countries (Cassim, 2010). A US review conducted by the Institution of Medicine in 2006 noted strong statistical evidence linking exposure to television advertising and obesity among children aged 2-11 years (Cassim, 2010). These

developments have all significantly contributed to the creation of an environment that is not conducive to people making healthy food choices.

Social environments at family, work, or community level can also influence a person's level of physical activity (Dishman, Sallis & Orenstein, 1985; Micklesfield et al., 2013). For example, in terms of family support, studies have found that physical activity modelling and encouragement by mothers are particularly strong predictors of later exercise participation by their daughters (Dishman, Sallis & Orenstein, 1985).

In terms of the built physical environment, it has been found that factors such as safe pavements, public parks and proximity to recreational facilities facilitate participation in physical activity (Frantz & Ngambare, 2013). In South Africa, one study found that black African women in South African townships did not engage in sufficient physical activity as a result of a lack of exercise facilities, lack of parks, and a fear of violence and crime (Puoane et al., 2008).

2.4.2 Socio-cultural factors

Socio-cultural factors also play an important role in influencing health behaviour. A study conducted in Rwanda found that culturally, Rwandan women were not allowed to participate in physical activity (Frantz & Ngambare, 2013). Conversely, a study which examined the components of self-efficacy and social support as mediators between culturally specific dance and physical activity in African American women, found that participation in culturally specific dance, related to traditional practices or connectedness, can increase lifestyle physical activity (Murrock & Madigan, 2008).

Socio-cultural factors also play an important role in the management of NCDs. For example, studies have shown that black South African women do not maintain an ideal body weight because of the weight loss stigma associated with the HIV/AIDS wasting syndrome (Puoane et al., 2008; Devanathan et al., 2013).

2.4.3 Socio-economic factors

People's food choices are strongly influenced by socio-economic factors. A study conducted on supermarkets in rural South Africa found that healthier foods typically cost between 10% and 60% more than unhealthy foods, when compared on a weight basis (R per 100g) and between 30% and 110% more, when compared on the cost of food energy (R per 100KJ) (Temple et al., 2011). People with few financial resources will thus choose high fat, energy-dense foods over the healthier options because of affordability (Puoane et al., 2008). Other socio-economic factors including inequalities in income, education, and health care influence people's vulnerability to NCDs and their consequences ((Puoane et al., 2008; Stuckler & Basu, 2011).

2.5. IMPLICATIONS OF THE RISING BURDEN OF NON-COMMUNICABLE DISEASES

The rising burden of morbidity and mortality related to NCDs in SA has major implications. SA is currently in the midst of a demographic transition, which means there is a significant increase in the working-age population (Chopra et al., 2007). As a result, more people of working age will be affected by the deaths and disabilities associated with NCDs, which has serious consequences for productivity and health costs. It has been estimated that by 2030, 41% of deaths due to cardiovascular disease will occur among the working age group (ages 35-64). This may result in the reduction of productive labour and earning capacity, which stifles economic development and perpetuates poverty (Chopra et al., 2007).

In terms of the SA health system, NCDs are adding an extra burden on the already scarce health care resources as a result of increasing patient numbers and shortage of staff (Puoane, Bradley & Hughes, 2005; Goudge et al., 2009). The rising level of NCDs also exacerbates health financing challenges due to the fact that people suffering from NCDs require multiple interactions with health care services, as well as long-term care (Nikolic, Stanciole & Zaydman, 2011).

2.6. THE WHO GUIDELINES ON THE PREVENTION AND MANAGEMENT OF NON-COMMUNICABLE DISEASES

2.6.1 Prevention and control of NCDs

Strong scientific evidence has indicated that preventative strategies that focus on the key underlying risk factors of NCDs, such as dietary habits and physical activity, can powerfully influence risk factors in populations (Waxman, 2003). Primary prevention strategies involve targeting people who have an increased risk for developing an NCD, with the intention of treating and modifying the risk factors in cost-effective ways at a population level (Steyn, 2005; Lusamba-Dikassa, 2008).

The WHO has compiled a list of cost-effective interventions, which it calls “best buys” and “good buys” interventions, as these produce accelerated results in cutting down costs and saving lives (Zarocostas, 2011). “Best buys” are interventions which have been proven to be highly cost effective and highly feasible in low-, middle- and high-income countries (WHO, 2011b).

“Good buys” are other interventions which may cost more, or generate less health gain, but are still considered feasible and good value for money. For instance, a best buy for reducing tobacco smoking would be increasing taxes on cigarettes and banning tobacco advertising, promotion and sponsorship. A good buy, on the other hand, would be the provision of behavioural and pharmacological therapies for tobacco dependence as part of PHC (WHO, 2011b). Table 2.1 below is a summary of the WHO’s best buy and good buy interventions.

Table 2.1: Best buys for the prevention and control of NCDs (Adapted from: The WHO, Global Status Report on NCDs, 2011)

Risk Factor	Effective Interventions
Tobacco smoking	<p>Best buys</p> <ul style="list-style-type: none"> • Tax increases • Smoke-free indoor workplaces and public spaces • Health warnings and information <p>Good buys</p> <ul style="list-style-type: none"> • Treatment for tobacco dependence and behavioural therapies as part of primary health care
Harmful use of Alcohol	<p>Best Buys</p> <ul style="list-style-type: none"> • Tax increases • Restricted access to retailed alcohol • Ban on alcohol advertising <p>Good buys</p> <ul style="list-style-type: none"> • Treatment of alcohol use disorders • Brief counselling interventions for harmful drinking • Drinking-driving laws
Unhealthy diets	<p>Best buys</p> <ul style="list-style-type: none"> • Reduced salt intake in food • Replacement of trans fat with polyunsaturated fat <p>Good buys</p> <ul style="list-style-type: none"> • Restrictions in marketing of foods high in salt, sugar and fats to children • Increased taxation on unhealthy foods and price subsidies • Production incentives for foods that are healthier
Physical activity	<p>Best buys</p> <ul style="list-style-type: none"> • Public awareness through mass media on diet and physical activity <p>Good buys</p> <ul style="list-style-type: none"> • Multi-targeted approaches to encourage physical activity • Provision of safe spaces for walking and engaging in sport, and active play for children

2.6.2. South Africa's response to NCDs

Since 1994, the Directorate of Chronic Disease, Disability and Geriatrics in the national Department of Health has led government's response to the emerging NCD epidemic (Everett-Murphy, Mash and Malan, 2013). Many clinical practice guidelines and standards of care have been issued (Strategic Plan for NCDs, 2012a). There have been several significant NCD-related interventions at a national level, the most successful being the implementation of a comprehensive piece of tobacco legislation as a result of the obligations imposed on UN member states by the 2004 Framework Convention on Tobacco Control (WHO FCTC). The WHO FCTC was developed in response to the globalisation of the tobacco epidemic (WHO, 2004). The South African Tobacco Products Act of 1993 was amended in 1999, 2007 and 2008 to create what has been deemed as one of the most effective tobacco control policies in the world (Puoane et al., 2008). This Act governs many aspects of tobacco control, including, but not limited to, public smoking restrictions; packaging and labelling of tobacco products; and tobacco advertising, promotion and sponsorship.

In contrast, the development of an alcohol policy has been piecemeal and slow, in part due to the conflicting values and interests of different stakeholders. On the one hand, the alcohol industry makes a large contribution to employment and to the domestic GDP through taxation and export earnings, hence resistance from powerful lobbies (Fieldgate & Jordaan, 2013). On the other hand, the cost to the fiscus that relates to poor productivity, absenteeism, interpersonal conflict and injuries as a result of alcohol abuse is estimated to be around R9 billion per year, which is equivalent to 1% of our GDP (Seggie, 2012). Further, there is a strong link between alcohol and NCDs, particularly cancer, cardiovascular disease, liver disease, pancreatitis and diabetes (Parry et al., 2011).

In 2007, after a protracted campaign by civil society groups, legislation was successfully passed banning the sale of cheap, bulk wine (papsakke) in an effort to curtail alcohol abuse by farm workers (Everett-Murphy, Mash and Malan, 2013). Since 2003, there has also been a consistent increase in alcohol price to reflect

exercise duty increases legislated by the National Treasury (Ramsoomar & Morojele, 2012). In 2013 cabinet approved a draft Bill banning the advertising of alcohol.

In relation to the local food environment, National Food-Based Dietary Guidelines were first promulgated in 2001; in 2010, food labelling regulations were promulgated (DoH, 2012b). In March 2013, the Minister of Health, Aaron Motsoeledi, announced mandatory regulations to reduce salt in bread and several other commonly consumed foodstuffs. These regulations apply to both local and imported food products, and set salt reduction targets for food manufacturers which have to be achieved by 2016 and 2018 respectively (Public Health Association of South Africa, 2012). On the basis of evidence that shows that industrially produced trans-fatty acids increase the risks of diabetes, cardiovascular disease and cancer, the government has also introduced mandatory restrictions on trans-fatty acids to less than 2% in manufactured food products (Everett-Murphy, Mash and Malan, 2013).

At a community level, there have been various government and non-governmental initiatives to promote healthy lifestyles in SA. Some examples of community-based and school-based interventions for chronic disease prevention are provided in Table 2.2.

Table 2.2: Community-based and school-based interventions for chronic disease prevention

Programme	Description	Programme Outcome
Vuka SA: Move for your health	Aimed at achieving increased population-level participation in health-enhancing physical activity over the long term. ³	Monitoring and measuring of Vuka SA activities have not been systematic and there are no current measures of national or regional react impact. ⁴
Community Health Intervention Programmes (CHIPs)	Launched by the Sports Science Institute of South Africa in response to the growing burden of NCDs. The aim is to promote health in various age groups through regular physical activity. Five programmes were designed to respond to needs of individuals across the different age groups. Each programme has a two-fold strategy: educate to increase awareness regarding the risk for developing NCDs; and regular physical activity to encourage adherence and self-efficacy in making healthier lifestyle choices. ⁵	A retrospective evaluation of CHIPs showed that it positively impacts on the quality of life, perceptions of the role of physical activity in health, and on personal responsibility for health for those involved in its programmes. ⁶

³ Kolbe-Alexander, Bull & Lambert, 2012.

⁴ Ibid.

⁵ Puoane et al., 2008.

⁶ Draper, Kolbe-Alexander & Lambert, 2010.

... continued

Community- based and school –based interventions for chronic disease prevention

Programme	Description	Programme Outcome
Soul City Health Promotion Programme	A multi-media edutainment programme which consisted of a 13 part prime time television drama, a 45 part radio drama in 9 languages, and 3 full colour information booklets. It was aimed at impacting positively on health and social outcomes by addressing the social and individual determinants of health. ⁷	An extensive evaluation of the Soul City programme showed that it resulted in increased knowledge and awareness of high blood pressure, and adopting a healthy lifestyle to prevent and treat hypertension. ⁸
Making the Difference Programme	A private-public sector initiative in South African primary schools, focused on promoting healthy lifestyles, especially nutrition, among learners. ⁹	A small but significant improvement was demonstrated with regard to self-reported behaviour in relation to nutrition (eating vegetables). ¹⁰
Community Health Workers' Intervention Programme for Primary Prevention of NCDs in Khayelitsha	A community–based project to increase community awareness about primary prevention of NCDs by using community health workers as change agents in their community ¹¹	The community health workers intervention successfully managed to increase awareness of NCDs among people living in Khayelitsha ¹²

⁷ Steyn et al., 2006.

⁸ Ibid.

⁹ Jacobs and Mash, 2013.

¹⁰ Ibid.

¹¹ Puoane et al., 2013.

¹² Ibid.

2.6.3 South Africa's Strategic Plan for the Prevention and Control of NCDs

In 2013, the national Department of Health presented a Strategic Plan for the Prevention and Control of NCDs to curb the rising rates of NCDs (DoH, 2013). The strategic plan is built on a foundation of action over the last 15–20 years, in which numerous legislative and policy initiatives, as well as guidelines and standards, have been developed by the national Department of Health to address risk factors and improve control of NCDs (DoH, 2013). It is closely aligned to the UN/WHO recommendations and places a strong emphasis on intervention in three distinct areas, which evidence shows, can produce rapid gains in reversing the epidemic:

- **Prevent NCDs and promote health and wellness at population, community and individual levels.** The plan advocates for stronger inter-sectoral collaboration in addressing the broader determinants of health. Proposed interventions include establishing a national NCD stakeholder forum; introducing multi-sectoral policies, laws and regulations to create sustainable, health promoting environments and reduce modifiable risk factors for NCDs.
- **Improve control of NCDs through strengthening the health system.** The plan commits to strengthening primary health care services to cater for the growing numbers of patients with NCDs. Important strategies for secondary prevention and increasing life expectancy include: proactively identifying individuals at risk; providing early medical treatment and assisting in lifestyle modifications; establishing a patient-centred chronic care service for people already diagnosed with a non-communicable disease, to help them adhere to treatment and sustain lifestyle changes.
- **Comprehensive monitoring of NCDs and their main risk factors and conducting innovative research.** The plan emphasises the importance of establishing more effective and reliable national surveillance mechanisms, health information systems and dissemination processes to assist with policy, planning and management; and to enable the evaluation of NCD prevention and control interventions (DoH, 2013).

2.6.4 Management of NCDs

According to the WHO, the effective and equitable management of NCDs should be based on a PHC approach (WHO, 2010). This is due to the fact that NCDs require long-term care that is proactive, patient centred and community based (Beaglehole et al., 2008). The key features of a PHC approach include a person focus across the lifespan, as opposed to a disease focus, accessibility with no out-of-pocket costs and the availability of comprehensive services (Beaglehole et al., 2008).

In 2002, the WHO produced a framework for the management of chronic conditions, The Innovative Care for Chronic Conditions Framework (see Figure 2.2 overleaf), which gives greater emphasis to the role of patients and the community in chronic care. This is because a significant part of chronic care is self-management (Beaglehole et al., 2008). It is recommended that health care professionals use communication styles that allow for patients to be actively involved in the decision-making process of their own treatment (Levitt et al., 2011). One such style of communication is brief Motivational Interviewing (MI), which has been shown to be effective in changing risk behaviours and improving self-management practices (Rollnick, Miller & Butler, 2008). The framework also gives emphasis to policy features that can help improve health care such as supportive legislative frameworks, consistent funding, and development and allocation of human resources (Beaglehole et al., 2008).

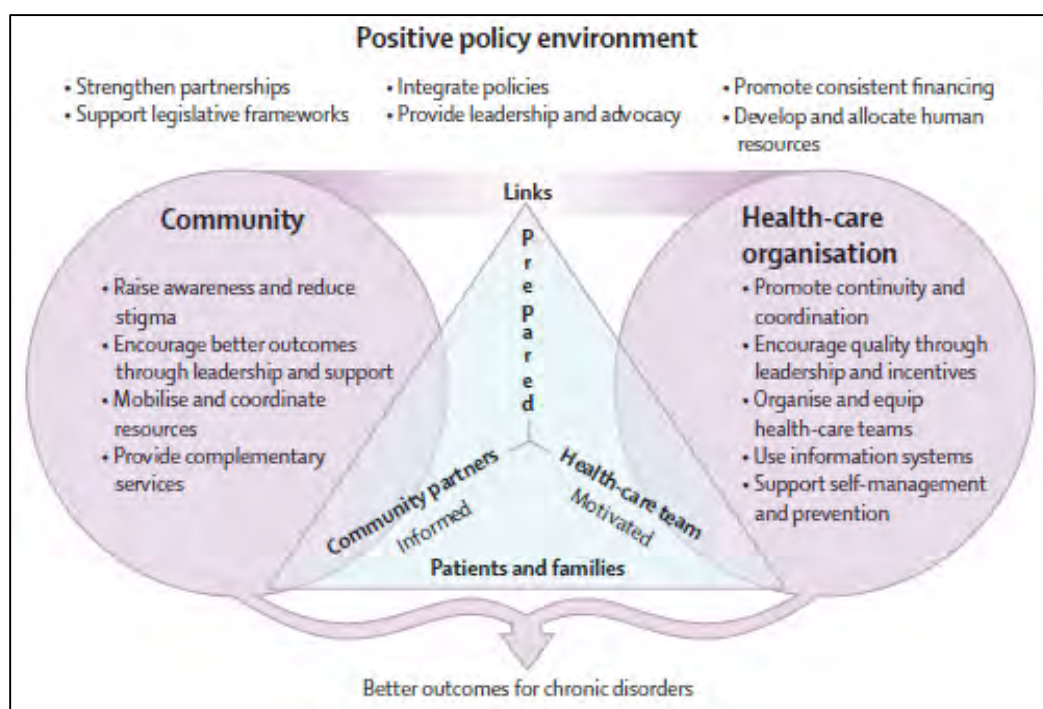


Figure 2.2: WHO Innovative Care for Chronic Conditions Framework (Reproduced from Beaglehole et al., 2008)

Another WHO tool of great importance for the integration of NCDs into PHC level is the WHO Package of Essential Non-Communicable Disease Interventions of Primary Health Care in Low Resource Settings (WHO PEN), which was published in 2010 (WHO, 2010). The WHO PEN includes evidence-based clinical protocols for the early identification of people with NCDs, management of NCD emergencies, monitoring of complications and application of evidence-based interventions in NCD prevention and management (Beaglehole et al., 2008).

Other recommendations on how to manage NCDs at the PHC level include adopting the Directly Observed Therapy Short-course (DOTS) framework for NCDs (Harries et al., 2008). The DOTS model was developed by the WHO to combat tuberculosis (TB). It is a five-point policy package which incorporates political commitment, passive case finding, standardised drug treatment, a standardised monitoring and evaluation system and uninterrupted drug supply to combat TB. The authors argue that the DOTS model can be used to tackle the issue of unstructured and unmonitored NCD clinical care (Harries et al., 2008).

In contrast, Levitt et al. (2011) and Nigatu (2012) argue for the integration of NCDs on the basis that chronic diseases share similarities in their progression and management. For example, both NCDs and HIV infection develop progressively over time; the management of both requires continuous follow-up, patient involvement, and a focus on positive health behaviours (Nigatu, 2012). The authors however argue that before such integration can take place, pilot projects will have to be designed and implemented in order to concretise the concept of integrated care for patients with NCDs and HIV/AIDS in order to inform policy change (Levitt et al., 2011).

Currently, NCDs are poorly managed in PHC settings. When SA transitioned to a constitutional democracy in 1994, it inherited a two-tier health care system from the apartheid era; a public health care system that served the majority of the population (about 80%) and which was financed through taxes, and a private health sector that was primarily funded through medical aid schemes for a historically privileged white minority (about 20%) (Flood & Gross, 2014). The current health system remains largely structured on this basis, with the vast majority of poorer South Africans attending public sector services and a relatively privileged minority, both black and white, having access to private, better quality health care through medical aids (Flood & Gross, 2014).

During apartheid, the public health care system was characterised by fragmented service delivery for different racial groups, gross inequities, and insufficient rural facilities. Tertiary hospital care was disproportionately favoured over primary care (Flood & Gross, 2014). However, soon after 1994, health care reforms were initiated and a PHC approach was adopted in an effort to strengthen the health care system and to achieve public health outcomes through disease prevention and health promotion (Bam et al., 2013).

The principles of primary health care include achieving equity in health service delivery, access to affordable services, sustainability of service provision and improving the quality of care (Dookie & Singh, 2012). PHC in the public sector is

therefore offered free of charge and most PHC facilities are located in communities so as to be easily accessible (Peltzer, 2009).

Notwithstanding the good intentions behind this policy, the implementation of PHC in SA has encountered numerous challenges. These include the continued disparities between urban and rural health services and dominance of a hospital-centric and acute care-orientated health system, as well as increased pressure on health services as a result of the emerging NCDs epidemic (Bam et al., 2013)

Several studies have investigated the management of NCDs in the public health sector in SA, and suggest that NCDs, particularly hypertension and type 2 diabetes, are poorly managed in this country. This is unsettling, particularly because approximately 17 million visits to health centres are related to hypertension and diabetes (DoH, 2013).

A cross-sectional descriptive study conducted in Limpopo province in 2002 revealed poor management of hypertension at the PHC level. The study revealed that there was inadequate knowledge among nurses regarding hypertension management, a shortage of staff and of anti-hypertensive medication, and a lack of functional equipment, such as sphygmomanometers or broad BP cuffs (Sekokotla et al., 2003).

A similar study on NCD management was also conducted in 22 clinics in the Eastern Cape, which focused on the quality of diabetic care among the nursing staff (Steyn & Levitt, 2006). The study found poor knowledge among the nurses on diabetes management. The study also revealed that regular examination of diabetic patients was inadequate, especially with respect to examination of the feet, which is important in preventing the development of foot ulcers and eventual leg amputations (Steyn & Levitt, 2006).

A number of studies carried out in Cape Town also confirm poor management of NCDs at the PHC level. A cross-sectional study by Steyn et al. (2008), conducted in 18 CHCs around Cape Town, reported that primary care for patients with hypertension and diabetes at public sector CHCs is suboptimal. The data showed that prescriptions for drugs were not recorded in 22.6% of diabetic patients' records

and 11.4% of hypertensive patients' records. Special investigations, co-morbid conditions and clinical signs of target organ damage were seldom noted in patients' records.

The study further reported poor condition control among the study participants, as well as poor knowledge regarding their condition. Of the 923 hypertensive patients who participated in the study, 63% did not know the consequences of untreated hypertension and less than 1% knew that renal failure could result from poor treatment. This finding suggests that patients at these facilities receive little or no information about self-management of NCDs. A possible limitation for this study was that patients who could not speak Xhosa or Afrikaans were excluded. This can introduce selection bias, since the study population will not be a true representation of the source population (Steyn et al., 2008).

Two qualitative studies were conducted in 2003 to gain insight into the determinants of hypertension and diabetes care delivered to patients in the public health care sector. The studies were conducted by Stollman (2004, cited in Steyn & Levitt, 2006:230) and Carpay (2004, cited in Steyn & Levitt, 2006:230) respectively. The studies reported suboptimal care for these two conditions in the public health care sector. Staff shortages, an increase in patient numbers and dramatic budget cuts were identified as barriers to using the diabetes and hypertension guidelines, investing time in educating patients and screening for complications. However, a potential limitation of both these studies, as with all qualitative studies, is that the results cannot be generalised to other settings (Steyn & Levitt, 2006).

A more recent cross-sectional descriptive quantitative study evaluated the knowledge and practices of PHC health professionals and final-year nursing and medical students regarding lifestyle modification in the management of NCDs within the public health care sector in the Cape Town metropolis (Parker et al., 2010). The results of the study showed that the majority of health professionals overestimated their actual knowledge of lifestyle modification, which indicated that misconceptions and misinformation about lifestyle modification are high among health professionals (Parker et al., 2010).

The poorest knowledge test scores, as compared with their perceived ratings, were found among the nursing staff and nursing students. This is disconcerting, considering that nurses are expected to be the main providers of lifestyle modification education and counselling in PHC (Parker et al., 2010). The lack of knowledge by health care professionals on the basics of how to diagnose and manage common diseases has also been identified as a serious problem in other developing countries, particularly in Africa (Pakenham-Walsh & Bukachi, 2009). Other challenges include poor staff motivation, low levels of appropriate skills, limited resources and lack of managerial capacity (Dookie & Singh, 2012).

2.6.3 Self-management of NCDs

Another important aspect of NCD management is self-management, which is the ability of the patient to deal with all the aspects of a chronic illness such as symptoms, treatment, physical and social consequences, as well as lifestyle changes (Coleman & Newton, 2005). Interventions that target self-management have been suggested as an integral part of improving the quality of chronic disease care (Powers et al., 2009).

Unlike traditional patient education, which generally refers to knowledge-based instructions, self-management education seeks to motivate patient behaviour change and provide problem-solving skills (Bodenheimer et al., 2002; Powers et al., 2009). A central feature of self-management education is promoting self-efficacy, which is the confidence in oneself to carry out behaviour necessary to reach a desired goal (Bodenheimer et al., 2002; Powers et al., 2009).

Reviews on the literature of self-management approaches for people with chronic conditions found that self-management interventions are associated with improved disease outcomes (Barlow et al., 2002; Norris et al., 2002). According to a review by Barlow (2002), randomised controlled studies in the field of diabetes show that self-management approaches are effective in increasing the use of behaviours such as adherence to medication and making lifestyle changes.

A review of the effectiveness of self-management interventions in type 2 diabetes found that educational sessions which actively involved patients were more effective in generating positive self-management outcomes than those where education was didactic (Norris et al., 2002). Health professionals can therefore encourage efforts in effective self-management through collaborative care (Coleman & Newton, 2005). This entails identifying problems from the patient's perspective, linking patients with community-based self-management resources and providing patients with problem-solving strategies to overcome barriers based on the patient's immediate concerns (Coleman & Newton, 2005).

Various South African studies have provided insight into how patients manage their self-care, as well as insight into their experiences and perspectives. Kagee, Le Roux and Dick (2007) conducted a qualitative study to examine the experiences of hypertensive and/or diabetic patients attending four PHC clinics within the Stellenbosch municipality in the Western Cape.¹³ The narratives that emerged were of three discernable types: experience of the illness, concerns related to adherence to treatment and psychosocial issues related to illness and adherence. The experiences that were shared included interactions with the clinic staff, in particular nurses. The participants felt that the service they received was mechanical rather than empathetic and caring. The participants also shared their concerns regarding adherence to changing their diets. They revealed that changing their diets as a result of their illness meant that they would not be able to share meals with their families (Kagee, Le Roux & Dick, 2007).

It was also clear that the participants understood their illness and the consequences of poor adherence to treatment. However, they revealed that they struggled with adherence as a result of, among other things, financial difficulties, and concerns that the medication might be addictive and could cause side effects, such as frequent urination. On a more positive note, the participants revealed that social support and

¹³ The Western Cape is one of the nine provinces in South Africa, and Cape Town is the provincial capital.

advice from family members regarding management of illness played a very important role in their efforts to adhere to treatment (Kagee, Le Roux & Dick, 2007).

Another insightful qualitative study was conducted by Matwa (2001) in an effort to explore the experiences and foot-care practices of diabetic patients who attended a tertiary hospital in the Eastern Cape.¹⁴ Though participants shared their own unique experiences, it was clear that there were some common underlying social, cultural, economic and institutional factors which influenced their understanding and management of their illness. For instance, cultural values were found to influence attitudes towards adherence to medical recommendations. Participants who viewed diabetes as a disease caused by witchcraft or ancestral spirits did not believe that western medicines could help them. Some participants revealed that they relied on both traditional and medical remedies to manage their illness (Matwa, 2001).

Participants' concerns about their illness included possible loss of employment; discrimination and labelling by employers, for example some participants revealed that they had been referred to as "the sickly staff" by their employers and the fear of complications, such as blindness and amputations. In terms of foot-care practices, the study revealed that foot-care knowledge among the participants was limited. Overall, the study revealed that participants struggled with adherence, despite their efforts to follow medical recommendations, such as taking their medication and changing their diets. Poor adherence was linked to a lack of knowledge about self-management practices, poor health care services in PHC facilities, as well as poor coping skills (Matwa, 2001).

It is clear from the studies discussed above that diabetic and hypertensive patients who utilise the public health sector face many challenges which extend beyond the health care system. It is evident that health behaviour is complex and influenced by various factors. The authors of these studies argue that more local studies are needed in order to more fully understand the challenges faced by NCD patients in SA and that such findings can be used locally to inform policymakers and health

¹⁴ The Eastern Cape is one of the nine provinces in South Africa.

professionals on the key factors which influence or impede health-seeking and health-related behaviours by NCD patients.

The next section presents the theoretical framework underpinning this study.

2.7. THEORETICAL FRAMEWORK

2.7.1 Introduction

In the previous section, the literature dealing with NCDs was reviewed, providing insight into the burgeoning burden of NCDs, their behavioural risk factors and social determinants, and the available prevention and management strategies. Furthermore, the local literature was reviewed to give insight into the management of NCDs in SA. This section presents the theoretical framework underpinning this study. Finally, the link between the theoretical framework and the research question will be clarified.

2.7.2 Health behaviour theories

Health promotion interventions or health education programmes, aimed at the prevention of NCDs or at better management of a chronic NCD condition, are more likely to succeed if they are guided by a theory of health behaviour (Glanz, Rimer & Viswanath, 2008). Behavioural theories provide a platform for understanding why people engage in health risks or why they adopt healthy protective behaviours (DiClemente, Crosby & Kegler, 2009).

Theories on health behaviour first emerged in the discipline of psychology and other health-related disciplines in an attempt to describe, explain and predict health related behaviours (Conner & Norman, 2005). Health theories are also widely used to design interventions that target behaviour change (Conner & Norman, 2005). This is because they provide conceptual frameworks on which to build and test health promotion interventions (Glanz, Rimer & Viswanath, 2008). Theory-driven interventions attempt to impact on the constructs which have been identified through research as important in predicting change in particular health behaviours (Rothman, 2004).

No single theory dominates the research or practice of health education/promotion, so effective interventions depend on selecting the most appropriate theories and methods for a particular situation (Gielen & Sleet, 2003; Glanz, Rimer & Viswanath, 2008). Multiple theories currently exist and often have conceptually overlapping constructs (French et al., 2012). Commonly used behaviour change theories include: the Health Belief Model (HBM) (Rosenstock, 1974); the Theory of Reasoned Action (TRA) (Fishbein & Ajzen, 1975); the Theory of Planned Behaviour (TPB) (Ajzen, 1985); Bandura's Social Cognitive Theory (SCT) (Bandura, 1986) and the Transtheoretical Model (TTM) (Prochaska and DiClemente, 1983). These theories share the assumption that beliefs, attitudes and expectations of future outcomes are major determinants of health behaviour (Munro et al., 2007). Often health promotion research and interventions will employ a range of behaviour change methods and approaches drawn from more than one theory.

Self-Determination Theory (SDT) was chosen to guide the aspect of this investigation which focused on patients' motivation and competency for self-management. SDT is particularly suited to this line of investigation because it focuses on the processes through which a person acquires the motivation to initiate new health-related behaviours and maintain them over time.

2.8. SELF-DETERMINATION THEORY

SDT emerged in the late 1970s and early 1980s; its main focus is on how to facilitate lasting motivation in the context of health behaviour, most particularly in nutrition and physical activity (Deci & Ryan 2002; Patrick & Williams, 2012). SDT represented an advance on the social cognitive tradition, which emphasised expected outcomes and enhanced patients' sense of confidence (quantity of motivation) by focusing on the quality of motivation, sense of autonomy and locus of causality (Patrick & Williams, 2012).

Health education programmes informed by this theory of behaviour change focus not only on enhancing knowledge, but also on exploring values; changing beliefs and attitudes; and on assisting people to develop the confidence and personal skills

to implement positive health choices, facilitating intrinsic, self-regulated motivation to maintain change (Nutbeam, 2000; Silva et al., 2008). Motivation is considered by SDT to be a critical factor in supporting and sustaining health-related behaviours such as exercise adherence, weight control and medication adherence, which are all relevant to the self-management of NCDs (Silva et al., 2008; Williams et al., 2009; Teixeira et al., 2012). As a result, SDT was selected to guide this study's line of enquiry.

Over the past 10-15 years, a growing body of research has emerged testing the applicability of SDT to health care environments, health behaviour change and health interventions (Patrick & Williams, 2012). There have been a number of large field studies and randomised controlled trials interventions based on SDT. For example, studies such as that conducted by William et al. (1998) have shown that long-term medication adherence is substantially a function of patient autonomy. Similarly, maintained weight loss has been linked to autonomy support and the internalisation of treatment goals (Williams et al., 1996).

Randomised controlled clinical trials, testing the efficacy of SDT-based interventions, have also been conducted. These include interventions concerning tobacco dependence (Williams et al., 2006); diet and glycaemic control (Williams, Freedman & Deci, 1998; Williams et al., 2004; Williams et al., 2005); exercise (Fortier et al., 2007; Fortier et al., 2012); and adherence to medication (Kennedy, Goggin & Nollen, 2004). Together, the findings of these studies have demonstrated the role of autonomous motivation in a variety of mental and physical health outcomes.

2.8.1 The construct of motivation under SDT

SDT draws a distinction between intrinsic motivation and extrinsic forms of motivation. Intrinsic motivation involves doing something willingly because it aligns with personal values, whereas extrinsic motivation entails doing something for its instrumental value or for tangible rewards (Fortier et al., 2012). Behaviour that is extrinsically motivated is therefore externally regulated (Deci & Ryan, 2012a). SDT proposes that individuals who are intrinsically motivated are more likely to adopt and maintain health-conducive behaviours (Ryan & Deci, 2000). The theory argues

that in order to facilitate intrinsic motivation, which is considered to be the ideal motivation for long-term behaviour change, the three inherent psychological needs of autonomy, competence and relatedness have to be satisfied (Ng et al., 2012). These three concepts are discussed below.

The concept of *autonomy* within SDT is used to refer to the sense of volition and experience of willingness in doing something as a result of integration of values into self (Deci & Ryan, 2002). According to the theory, people have to be autonomously motivated in order to internalise behaviour and maintain it over a prolonged period of time (Ryan et al., 2008). The concept of *competence* refers to feeling confident and capable of achieving desired outcomes (Patrick & Williams, 2012). This is essentially the same as the concept of self-efficacy in social cognitive theory, which involves a judgement of one's ability to successfully perform a behaviour required to produce an outcome (Bandura, 1997).

Finally, *relatedness* refers to the need to feel connected to others, as well as to have a sense of belonging to other individuals and to one's community (Deci & Ryan, 2002). Although autonomy and competence have been found to be the most powerful influences of intrinsic motivation, relatedness has also been found to be important in the maintenance of intrinsic motivation (Deci & Ryan, 2000).

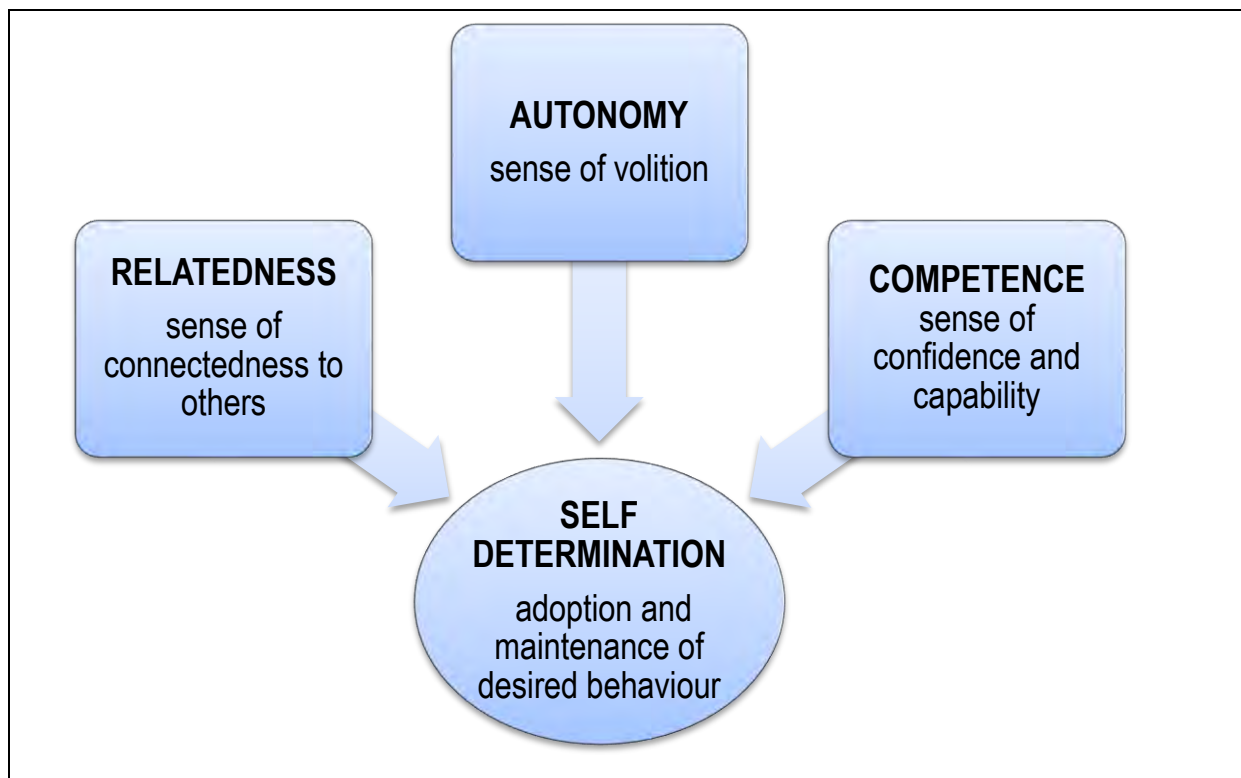


Figure 2.3: Schematic representation of the Self-Determination Framework

2.8.2 The influence of social contexts

SDT also recognises that individuals exist within social contexts, which vary in how they support or undermine intrinsic motivation, which forms the basis of autonomous behaviour (Deci & Ryan, 2012a). Both proximal interpersonal contexts (the behaviour of friends, family, health care providers) and distal contexts (cultural norms and economic and physical structures of society) are considered to be important influences on motivation (Deci & Ryan, 2012a).

According to SDT, in order for social contexts to be supportive of intrinsic motivation, they have to be supportive of autonomy, competence and relatedness (Deci & Ryan, 2012a). Autonomy-supportive social contexts are ones in which the individual's perspective is acknowledged, often by an authority. In autonomy-supportive contexts, individuals are given choice and the use of controlling language is minimised (Deci & Ryan, 2012a).

In contrast, controlling contexts are those which pressure people to behave or think in specific ways through the use of coercion or manipulation (Deci & Ryan, 2012a).

In a health care setting, autonomy support can be achieved through eliciting and acknowledging patients' perspectives and emotions before making recommendations, by minimising control and judgement and by being supportive of patients' initiatives (Patrick & Williams, 2012).

There are several studies that show a relationship between autonomy-supportive contexts and motivation. For instance, Deci et al. (1981 cited by Deci & Ryan, 1985: 55) conducted a study in which they asked elementary school teachers to report the degree of their own autonomy supportive vs. controlling classroom styles. The teachers' self-reports were then compared with their students' self-reports of experiences of intrinsic motivation, perceived competence, and self-esteem. The study found that when teachers were more autonomy supportive, their students became more intrinsically motivated and perceived themselves more positively.

In health care settings, studies have shown that patients who perceive their health care providers as more autonomy supportive tend to have better health outcomes (Deci & Ryan, 2012a). For instance, when health providers were found to be more autonomy supportive, their patients tended to have better glucose control (Williams, Freedman & Deci, 1998), stop smoking (Williams et al., 2006) and increased physical activity (Teixeira et al., 2012). Autonomy-supportive contexts have also been found to support the other two basic psychological needs – the need for relatedness and competence (Deci & Ryan, 2012a).

2.8.3 The continuum of motivation for behaviour change

Another central concept within SDT is the distinction between various types of motivation or behavioural regulations (Deci & Ryan, 2012b). These are illustrated in Table 2.3 below. The nature and focus of motivation depends on the underlying reasons for action (Deci & Ryan, 2012b). SDT views motivation as lying along a continuum from non-autonomous to completely autonomous behavioural regulations (Deci & Ryan, 2012b) As indicated in Table 2.3, at one extreme end of the continuum is *amotivation* and at the other end is *intrinsic motivation* (Deci & Ryan, 2012b).

Amotivation is a state of lacking an intention to act; it is usually a result of not personally valuing an activity, not feeling competent to carry it out or not believing that it will yield a desired outcome (Deci & Ryan, 2012b). *Intrinsic motivation*, as already discussed, is acting because the task is seen as inherently interesting or rewarding, rather than for some separable outcome of instrumental value (Deci & Ryan, 2012b).

In between the two extremes is *extrinsic motivation* (Deci & Ryan, 2008). Extrinsic motivation falls on a continuum, ranging from the least autonomous form of extrinsic motivation to the most autonomous form of extrinsic motivation. The least autonomous form of extrinsic motivation is called *external regulation*; behaviour that is *externally regulated* is performed to satisfy an external demand or to obtain an externally imposed reward contingency (Deci & Ryan, 2000). The second type of extrinsic motivation is *introjected regulation*, which is a type of regulation that is still controlled because actions are performed under pressure in order to avoid guilt, anxiety or for attainment of ego enhancements. A more autonomous form of extrinsic motivation is *identification*, which results from identification with the personal importance of a behaviour (Deci & Ryan, 2000).

Finally, the most autonomous form of extrinsic motivation is *integrated regulation*. This type of regulation occurs through self-examination and bringing new regulations into congruence with one's other values and needs. The more a person internalises the reasons for action, and assimilates them into the self, the more one's extrinsically motivated actions become self-determined or autonomous (Deci & Ryan, 2000).

TABLE 2.3: Self-Determination Theory: continuum of motivation for behaviour change(Adapted from Deci & Ryan, 2000)

Motivation differs in terms of both level and orientation. The nature and focus of motivation depends on the underlying reasons for action. The quality of the experience and performance can be very different, depending on what type of motivation the person has.

REGULATORY STYLES	AMOTIVATION Lacking in any intention to act. Passive	EXTRINSIC MOTIVATION Acting in order to attain some separable outcome of instrumental value. Can vary in the extent to which they represent self-determination. Internalisation and integration are the processes through which extrinsically motivated behaviours can become more self-determined.				INTRINSIC MOTIVATION Acting because the task is seen as inherently interesting, rewarding, rather than for some separate consequence. Acting out of free choice. Emerging from natural human tendency to expand one's abilities, creatively apply one's skills and explore the world.
		External regulation Performance to satisfy an external demand or externally imposed reward contingency	Introjection Performance under pressure to avoid anxiety or for affirmation	Identification Personally identifying with the importance or value of the behaviour	Integration Internalising the reasons for action, full assimilation of the value and utility of the task	
ASSOCIATED PROCESSES	Not valuing the activity or seeing its relevance, feeling incompetent, not believing the action will yield the desired outcome, unwilling, not seeing behaviour as representing one's self	Mere compliance - can be resentful or disinterested	Focus is on the approval of others, ego involvement	Conscious valuing of activity, self-endorsement of goals, therefore can be adopted with sense of volition and responsibility	Congruence with personal values and needs, fully transforming the regulation into one's own so that it emanates from sense of self	Exploratory, curiosity driven, appreciation of aesthetic value, novelty or challenge. Strong personal endorsement, willingness. Goal of personal satisfaction.
LOCUS OF CAUSALITY	External, little chance of formulation of intention and action	External	Somewhat external	Somewhat internal	Internal (however, still extrinsic as behaviour is motivated by presumed instrumental value of task)	Internal, resulting in high quality learning and creativity. More behavioural effectiveness.

2.8.4 Limitations of SDT

As is the case with other health theories, SDT is not without its limitations. SDT has a history of experimental work on motivational factors, but more intervention and translational studies are needed to adequately model, implement and evaluate key components of autonomy, competence, and relatedness supports (Deci & Ryan, 2008; Teixeira et al., 2012). Further, Patrick & Williams (2012) found that SDT researchers often find it challenging to translate the theoretical concepts of autonomy, competence and relatedness into clinical techniques to be used in interventions. In order to overcome some of these limitations, some scholars have integrated Motivational Interviewing (MI) techniques into SDT interventions. This is due to the consistency between the spirit of MI and its techniques and SDT's basic psychological needs of autonomy, relatedness and competence (Patrick & Williams, 2012).

Motivational Interviewing (MI) is a client-directed therapeutic style to enhance readiness for change by helping clients explore and resolve ambivalence (Hettema, Steele & Miller, 2005). Even though MI is a technique grounded in social-psychological theories and various social cognitive approaches, and SDT is a theory, the two are conceptually similar (Deci & Ryan, 2012b). Both SDT and MI are person-centred, supportive, non-judgemental, and emphasise patients' autonomy and a need to promote patients taking responsibility for their own health (Deci & Ryan, 2012b). As a result of the similarities, many SDT-based interventions have used MI counselling techniques (Deci & Ryan, 2012b).

2.9. SOCIO-ECOLOGICAL MODELS

The basic premise of socio-ecological approaches is that health, behaviour and their determinants of health are interrelated (Townsend & Foster, 2011). The socio-ecological models (SEM) emphasise the interaction between, and interdependence of, factors within and across all levels of health behaviour, recognising that most public health challenges are too complex to be adequately understood and addressed from single-level analyses (Townsend & Foster, 2011).

Most of the systematic theory building on the ecological perspective has been done by Bronfenbrenner, a psychologist who is well known in the field of child development. Bronfenbrenner argued that in order to understand human development one must consider the entire ecological system in which growth occurs (Bronfenbrenner, 1979). Bronfenbrenner suggested that the fit between the person and the environment influences successful development. He identifies four important system levels: microsystem, mesosystem, exosystem, and macrosystem (Bronfenbrenner, 1979). Table 2.4 provides a description of these four environmental systems.

Table 2.4: Outline of Bronfenbrenner’s ecological levels (Adapted from Stokols, 1996)

Ecological Level	Description	Example
Microsystem	This level refers to the immediate environment in which a person is operating; it is a dynamic system in which the person is affected and in turn affects the environment.	Family, classroom, peer group, neighbourhood.
Mesosystem	This level refers to the interaction of two microsystem environments.	Family affecting an adolescent’s peer group.
Exosystem	This level refers to aspects of the environment in which an individual is not directly involved, which is external to his or her experience, but nonetheless affects him or her.	Parents’ workplace, economic state of community, parents’ marriage.
Macrosystem	This level refers to the larger cultural context, including issues of cultural values and expectations, in which the other systems function.	Values, laws, resources, customs of a particular culture.

In the 1980s, McLeroy et al. (1988) proposed a variation on Bronfenbrenner’s conceptual framework in the form of a social ecological model for health promotion.

According to this model, behaviour is influenced by five factors, namely intrapersonal factors (personal traits, knowledge, beliefs and attitudes); interpersonal processes and primary social groups (including family, friends and close networks); institutional factors (schools and health facilities); community factors (including relationships among organisations, institutions and informal networks); and public policy (national laws and policies) (McLeroy et al., 1988).

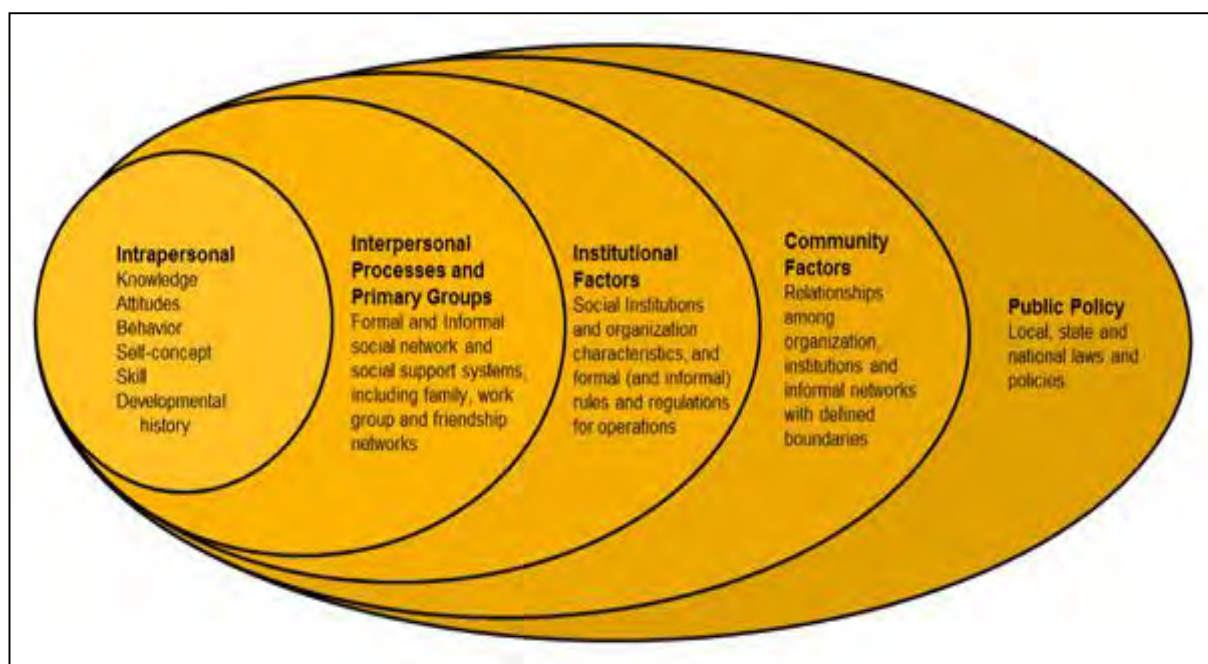


Figure 2.4: The Socio-ecological Framework (Reproduced from McLeroy et al., 1988).

In the field of health promotion, such models help us realise that people's health behaviours can be profoundly influenced by their social and material circumstances. Factors such as place of residence, level of income, educational opportunities, and type of employment or racial discrimination can have a direct or indirect effect on health status and on people's ability to change or modify their health behaviour (Westmaas et al, 2007). Structural interventions to alter the physical, social, economic, and regulatory environments to support the adoption and maintenance of health behaviour are thus becoming increasingly popular (Crosby et al., 2011).

Ecological approaches have been used to understand levels of influence on physical activity (Fleury & Lee, 2006; Sallis et al., 2006; Ball et al., 2007); diabetes self-management (Sallis et al., 2006); healthy eating and exercise (Schulz et al., 2005); and weight management (Greaney et al., 2009). Moreover, major public health goals have been achieved through the adoption of comprehensive programmes, the prime example being the measures taken by many countries to reduce tobacco consumption by restricting advertising and sponsorship, increasing taxation, banning smoking in public places and controlling access of minors.

Conclusion

In the context of the current study, both the socio-ecological model and SDT proved helpful in understanding the phenomenon under study. On the one hand, SDT assisted in the identification of individual factors, such as perceived autonomy or competence to adopt health protective behaviours, and of social factors that elicit different types of motivation in different settings. On the other hand, the socio-ecological model assisted in providing insight into the effects of multi-faceted environmental factors or barriers on individuals' motivation to modify their lifestyles.

It is important to caution that even though the theoretical framework described above guided the investigation and the data analysis, it was not allowed to impose a rigid structure over the data, since the focal point of the study was to discover ideas or themes from the participants themselves.

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CHAPTER 3: METHODOLOGY

INTRODUCTION

This section outlines the methodology used in this study. The first part deals with the study design and setting. This is followed by a description of the study population and sampling, data collection procedures and a discussion on the data analysis process. The last section deals with ethical considerations.

3.1 STUDY DESIGN AND SETTING

3.1.1 Study design

A qualitative study design was chosen because of the research objectives. The overall aim was to explore the participants' experiences of health care services and their capacity for self-management of their condition. A qualitative paradigm was best suited for the study's purpose because it gives emphasis to the meanings, views and experiences of participants and allows for understanding of social phenomena in a natural setting (Al-Busaidi, 2008). Qualitative research is increasingly being used in health research to understand issues related to experiences in health care (Al-Busaidi, 2008). It allows researchers to uncover what is really important to patients and health care providers, and to identify the multi-faceted barriers to change and how to improve patients' experiences of care (Al-Busaidi, 2008).

Content analysis is one of several approaches commonly employed for data analysis and interpretation in qualitative research (Elo & Kyngäs, 2008; Elo et al., 2014). . Data is usually reduced to concepts that describe the phenomena by creating categories, a model or a conceptual map (Elo & Kyngäs, 2008; Elo et al., 2014).

Three main phases are usually involved: preparation, organisation and reporting of results (Elo et al., 2014). The preparation phase consists of data collection, making sense of the data and selecting units of analysis (Elo et al., 2014). The organisation phase includes open coding, creating categories and abstraction (inductive approach) or categorisation matrix development (deductive approach) (Elo et al.,

2014. In the final stage, the reporting phase, results are described by the content of the categories describing the phenomena (Elo et al., 2014).

3.1.2 Study setting

The research was undertaken in three community health centres (CHCs) within the Cape Town metropolis. CHCs form part of the first level of care alongside primary health care (PHC) clinics. They are usually easily accessible and are free of charge (Steyn et al., 2008). There are forty-four CHCs in Cape Town, run by the Western Cape Province Department of Health (Haque et al., 2008). Approximately 80% of the total Cape Town population rely on public sector facilities for health care (Haque et al., 2008).

CHCs provide 24-hour maternity, accident and emergency services, in addition to PHC services (Zwegenthal et al., 2009). They are usually run by registered nurses and general Medical Officers who provide care and referrals where necessary (Steyn et al., 2008). Each Medical Officer usually manages between forty to seventy patients per day (Steyn et al., 2008).

The CHCs chosen for this study were purposively selected under the direction of the Western Cape Department of Health. Issues considered in the selection of clinics included how much other research was being conducted in the facility at the time, the community in which the clinic was situated, as well as accessibility in terms of public transport (for the researcher).

The specific CHCs selected were Retreat CHC, Gugulethu CHC and Lady Michaelis CHC. The Gugulethu CHC is situated in a predominantly low-income community where the majority of residents, as well as the surrounding communities, are black isi-Xhosa-speaking patients. Lady Michaelis CHC is situated in a low-income community where the majority of the residents and surrounding communities are coloured. Retreat CHC is, however, frequented equally by both black African and coloured patients from the surrounding communities.

3.2 STUDY POPULATION AND SAMPLING

3.2.1 Study population

The target population from which the study sample was selected consisted of patients diagnosed with type 2 diabetes and/or hypertension attending PHC CHCs in the Cape Town metropolis. This population is characterised by low socio-economic status, low levels of education and low health literacy (Mash et al., 2012).

3.2.2 Sampling strategy

The aim of sampling in qualitative research is to identify specific groups of people who live in circumstances or hold characteristics relevant to the phenomena being studied (Burnard, 2004). Purposive sampling was used to recruit the participants in this study. This is non-probability sampling, in which study participants are deliberately chosen on the basis of set criteria such as knowledge, experience or capacity to participate in the research (Teddlie & Yu, 2007). For this study, inclusion into the sample was based on the predetermined criteria discussed below:

- Adult (18 years and above);
- Utilise PHC hypertension and/or diabetes services;
- Received a diagnosis of hypertension or diabetes within the last 10 years, but for longer than the past three months;
- Willing to be interviewed within the clinic environment and spare at least an hour of their time.

Participants were excluded on the basis of the following criteria:

- Those who had been living with their condition for more than 10 years;
- Those with serious complications arising from uncontrolled hypertension or diabetes, such as strokes or amputations.

The reasons for exclusion were two-fold. Firstly, the limit of ten years was chosen to try to ensure that not too much time had passed, to the extent that there was little or no recall of the early stages of living with the illness. Secondly, those suffering from

complications are supposed to be attended to at a secondary or tertiary level of care, and would, in all likelihood, have a very different and more complex psychological profile, given the serious nature of their condition.

3.2.2.1 Sampling procedure

I visited the clinics on specific days (so called club days¹⁵) when diabetic and hypertensive patients are seen by the doctor. Patients were recruited while they waited in line for their appointment with the health provider.

I started at Gugulethu CHC where the nursing staff assisted me with the recruitment process. While I waited in the club/ prep rooms, the nursing sister checked the patients' folders to see who met the study's inclusion criteria. Those who met the inclusion criteria were requested to participate in the study, with a guarantee from the sister that they would not lose their place in the queue.

I then went to Lady Michaelis and Retreat CHCs, where the recruitment strategy changed as a result of the unwillingness of some patients to be interviewed, as well as the unwillingness of some nursing staff in the prep rooms to accommodate me. Patton (2002) has identified sixteen different types of purposive sampling techniques, and states that a researcher can use more than one purposive sampling technique in their research.

In my case, I ended up resorting to convenience sampling as a result of time constraints. Though the sampling was still purposive - participants still had to meet the predetermined criteria - only volunteers were interviewed. As a result, self-selection bias was a potential limitation in this study. Self-selection bias is commonly used to describe situations in which the characteristics that cause individuals to select/volunteer themselves introduce bias into the study findings (Heckman, 2013).

¹⁵ Hypertension and diabetes clubs are found in various primary health care centres and consist of the following generic features: 1) A booking system so that patients can get assurance that they will be seen on a particular day 2) Patients are assessed and monitored by a nurse before seeing the doctor 3) Some form of patient education is given to patients by a nurse or a trained health information officer (Slingers & De Villiers, 2009).

3.3. DATA COLLECTION

This study used individual in-depth interviews as a method of data collection. Interviews were deemed appropriate since the focus of this study was to explore how patients react to existing health care materials/interventions at health care facilities. In addition, this format allows for an in-depth and confidential exploration of the factors that underpin the participants' opinions, beliefs, feelings and actions. In-depth interviewing also enables collaboration between the researcher and the participants, which allows for shared reflection and enquiry (Ritchie & Lewis, 2003). Finally, the in-depth format allows for flexibility and structure. Even though the interview is based on an interview guide setting out the key topics and issues to be covered during the interview, the structure is flexible enough to give participants free rein to shape their own narratives (Ritchie & Lewis, 2003).

Prior to commencing the research field work, I enrolled in and completed a qualitative research methods short course at the University of Stellenbosch in order to prepare for the interview process and learn the necessary qualitative research skills.

The course included training in conducting in-depth interviews, transcribing, coding, and report writing. Subsequent to this training, I conducted several practice interviews under the mentorship of my thesis supervisors before the fieldwork commenced. After completion of the course, a pilot study was conducted at the Diabetes Clinic at Groote Schuur Hospital, with the assistance of Professor Levitt, who runs the diabetes clinic at the hospital. The purpose of the pilot was to evaluate the interview schedule and to practice and test my interview skills under the supervision of my thesis supervisor. Six patients were recruited with the help of a nursing sister. The interviews were then transcribed and discussed with my supervisors. Certain improvements were made to the interview schedule after the pilot study so that it was more suited to answer the research question.

Thereafter, the study interviews followed. These were conducted in a private room within the CHC facility. Patients were given a detailed explanation of the nature of

the study before the interviews began. A brief questionnaire was administered prior to each individual interview. This was used to collect basic demographic data such as age, marital status, and level of schooling, employment status and the year of diagnosis. The questionnaire is presented in Appendix C.

An interview schedule was used to guide the interview process (see Appendix D). An interview guide is usually used in research to assist the interviewer to pursue the same basic line of inquiry with each participant and to manage the interviews in a more systematic way (Burnard, 2004). Questions on the interview guide were formulated on the basis of the study objectives and the theoretical constructs of Self-Determination Theory, namely, autonomy, relatedness and competence. The interview guide was used to ensure that topics important to the investigation were covered.

Each individual interview was audio-taped with prior permission from the participant, so that it could be accurately transcribed. As the principal investigator, I conducted all the in-depth interviews, with the assistance of a translator where necessary. I kept an interview diary throughout the entire research process so as to allow for reflection at a later stage. For instance, going over my research diary made me reflect on how I was perceived as an “outsider” by some of the patients and clinic staff, particularly at Gugulethu CHC because I couldn’t speak isi-Xhosa. This resulted in some of the patients refusing to be interviewed, which is a potential limitation for this study.

Data collection continued until saturation was reached. There are two commonly used forms of saturation in qualitative research, namely theoretical and data saturation. Theoretical saturation originated within grounded theory and is used to refer to the point when sampling has to stop because categories that emerged from the data are well developed, and the variability/similarities between them have been explained and validated, and no additional data are needed (Lewis-Beck, Bryman & Liao 2004; Tuckett, 2004).

Data saturation refers to the point in sampling when recruiting new participants to the study becomes redundant because no new themes emerge (Bowen, 2008). Saturation has been deemed to be a useful concept in qualitative research because it relates to the adequacy of sampling, which means that both depth and range of information have been achieved (Tuckett, 2004).

The final decision to stop data collection for the current study was based on indication of data saturation. This occurred when no new information was being obtained for on-going thematic development (Tuckett, 2004). This was facilitated through contemporaneous collection of data and data analysis. New data that emerged from subsequent interviews was repeatedly compared to data from previous interviews until it became evident to the researcher that no new information of significance was emerging from additional interviews. This point was reached after 22 interviews.

3.4. DATA ANALYSIS

Data analysis began soon after the fieldwork commenced and continued contemporaneously with further data collection. The interviews were transcribed verbatim by a transcriber who was paid for that purpose. As already mentioned, the method of content analysis was adopted for this study. Like other qualitative research methods, the aim of content analysis is to attain a condensed and broad description of social phenomena, and often, to build an explanatory conceptual model, which offers a deeper understanding or new insights into the perspective or experience of a group or an individual or an event or series of events. Effective reporting of qualitative data can also often require the use of the data, and the ideas generated by the data, to build arguments for social action or to identify opportunities for social intervention (Pope, Ziebland & Mays, 2006; Elo & Kyngäs, 2008).

The unit of analysis in this study was the transcribed text of the audio-taped interviews with the respondents about their experiences of living with hypertension and/or diabetes. Data analysis proceeded according to the discrete steps for content

analysis as outlined in the articles by Pope, Ziebland & Mays (2006); Elo & Kyngäs (2008); and Hennink, Hutter & Bailey (2010). The different stages of analysis involve describing and interpreting the data at increasing levels of abstraction. This process, whereby condensed text is abstracted into increasingly higher order headings, involves the creation of codes, categories and themes (Pope et al., 2000; Elo & Kyngäs, 2008; Hennink et al., 2010). The discrete steps involved in the analysis are outlined below.

Step 1: Familiarisation with the data

All the interviews were read through several times before analysis began so as to get a sense of the data as a whole and its key features. At this stage, the notes that were written down in my fieldwork journal at the time of the interviews proved useful in reminding me of the context of the interviews and my initial reflections on how the interviews had progressed.

Step 2: Coding

In the first stage of analysis, units of meaning were identified in the text. Charmaz (2006) defines coding as 'naming a segment of data with a label that simultaneously categorises, summarises, and accounts for each piece of data'. A code can be a word, a key phrase or even a sentence derived from theoretical considerations prior to the data analysis or from the text itself (Gläser & Laudel, 2013). During coding, codes can be written in margins of the text while reading or entered into the coding field of transcripts saved in a programme, in this case ATLAS-TI.

Step 3: Categorising

Various codes were then compared for differences and similarities, and were sorted into fewer content-related categories. Creating categories is the core feature of qualitative content analysis and involves the researcher making meaning from what the respondents said, the issues they raised, their opinions and experiences (Elo & Kyngäs, 2008). Successful content analysis requires that the researcher analyses and simplifies the data to forms/categories that reflect the subject of study in a reliable

manner (Kyngas and Vanhanen, 1999 cited in Elo & Kyngäs, 2007:109). Categories can have sub-categories or different dimensions (Graneheim & Lundman, 2004).

Codes and categories can be derived either inductively or deductively (Elo & Kyngäs, 2007). Inductive codes/categories emerge directly from the data (often terms used by the respondents can form the basis for these types of codes or categories). Deductive codes/categories, on the other hand, originate from the topics in the interview guide that were derived from concepts or theory in the research literature (Hennink, Hutter & Bailey, 2010). Table 3.1 is an example of how the coding and categorising process was done. See Appendix K for more examples of codes and categories.

Table 3.1: Example of the coding and categorising process

Excerpt from interviews	Codes	Category
Food is very expensive because I get little money where I work. Sometimes I feel like eating spinach, but it is R6 or R7 for a head of spinach...That is expensive for me because I have to send money home to the Eastern Cape. I have a daughter therebut she also has a baby boy who is one month old so everything is expensive for me. Everything falls on my shoulders	<p>Healthy food perceived to be expensive</p> <p>Supports family in Eastern Cape</p> <p>Struggles to live on low income/ burdened by family responsibilities</p>	<p><i>Barriers to lifestyle modifications (socio-economic)</i></p> <p><i>SDT- affects competence to change</i></p>

At an early stage of the analysis, tentative codes and categories were discussed and agreed with the supervisors, who also read and coded a number of the early interview texts. As data collection proceeded, some codes and categories were revised and reconceptualised, again in consultation with the supervisors.

Step 4: Themes

Finally, categories were organised into themes, which reflected the underlying meaning or the main messages which can be extrapolated from the text. This is

referred to as the latent content of the data (Kondracki et al., 2002 cited in Graneheim and Lundman, 2004:106). Creating themes is a way of linking the underlying meaning of several categories together. It can be something which occurs regularly within or across categories and the interviews. A theme can be considered as a thread of meaning that recurs through the data on a more interpretative level (Graneheim & Lundman, 2004).

Themes are used to explain the findings and to attach meaning and significance to the analysis (what are the main lessons learnt, what is new, what application the findings have?)(Bazeley, 2009). It is often helpful to include quotes and descriptive examples to illustrate your points and to bring the data to life. Themes attain their full significance when they are linked to form a coordinated picture or an explanatory model (Bazeley, 2009).

3.5. CASE STUDY

Before the description of the overall results, a case study was presented to show a holistic picture of one participant's experiences in the specific circumstances of his life. In addition, the case study served as an introduction to the overall study findings.

3.6. ETHICAL CONSIDERATIONS

Ethical clearance was obtained from the University of Cape Town's Human Research Ethics Committee (Appendix F). Permission was also obtained from the Western Cape Provincial Department of Health; this is necessary in order to conduct the research in their facilities (Appendices G and H). Doctors and Sisters in charge of the diabetes and hypertension clubs were consulted telephonically and via emails regarding the dates and nature of the fieldwork.

This study did not pose any risks to the participants. Additionally, in order to ensure that patients did not lose their place in the queue, they were only interviewed after they had been seen by the nurse, who checked their weight, blood pressure and glucose via finger prick. The researcher was lucky enough to always get allocated an

empty room in the CHCs by the facility manager which was in close proximity to the doctor's consultation rooms. This allowed the interviewees to check at intervals how far they were in the queue. For those interviewees who were accompanied by family members, the family member would keep the participant's place in line and come to notify the participant when it was time for them to go in and see the doctor.

The study did not involve any medical procedures or the administration of any medication. Participants were only required to participate in a voluntary, private discussion about their personal experiences of living with type 2 diabetes and/or hypertension. Through their participation, informants were given an opportunity to talk about their experiences or difficulties in changing their lifestyles, which may have assisted them in reflecting on their situation in a constructive way.

The purpose and nature of the project was explained to participants by the researcher during recruitment. Each participant was given an information sheet detailing in plain language the aim and objectives of the study, as well as the study procedures. They were then asked to sign a consent form. Participation was voluntary and participants were informed that they could withdraw at any time. The confidentiality of their identity and their opinions was assured. No names were used in documenting or reporting on the findings.

A token of appreciation was given to each participant for their time after the interviews. Participants were not informed of this token before participating in the study lest they assume that there was payment involved for participation. The ethical integrity of the study depended on voluntary participation, and this was reiterated to participants during the recruitment process.

The token of appreciation was a R50 Shoprite food voucher and a recipe book developed by the Medical Research Council, The Heart Foundation and the Chronic Disease Initiative in Africa. Participants were asked to sign for receipt of the vouchers and recipe books to ensure transparency of and accountability for research funds that were provided by the Chronic Disease Initiative in Africa.

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CHAPTER 4: RESULTS

INTRODUCTION

This chapter, which describes the study findings, consists of three sections. The first section is a description of the participants' socio-demographics. This is then followed by a case study of one individual patient, which exemplifies many of the themes that emerged from the research. The last section is a description of the overall findings of the study.

4.1 THE PARTICIPANTS' SOCIO-DEMOGRAPHICS

As a starting point, it is important to mention that the description of the study sample's socio-demographics is merely a description of the characteristics of the study sample. No quantitative conclusions/statistical inferences were extrapolated from them. For example, they give the reader insight into how varied the sample was.

Of the twenty-two participants; eight were in the 30-45 years age group; five in the 46-59 years age group; four each in the 60-70 years; and five in the above 70 years age groups. Their educational levels varied; six participants reported that they only had primary school education; eleven reported that they had high school education and the remaining five participants reported having received tertiary education. In terms of employment; four participants had formal employment, whereas the rest were either unemployed or doing informal jobs. Table 4.1 is a summary of the participants' demographic characteristics.

Nine people suffered from hypertension, six from diabetes, and seven were hypertensive diabetics. More females than males participated in the study. This was due to the over-representation of females at the clubs where the participants were recruited, as well as the general willingness of more females to be interviewed as opposed to males. As a result, sixteen women were interviewed, compared to only six males.

Table 4.1 Socio–demographic characteristics of participants

VARIABLES	DIABETES	HYPERTENSION	HYPERTENSIVE DIABETICS	TOTAL
AGE (years)				
30-45	2	5	1	8
46-59	1	2	2	5
60-70	2	1	1	4
>70	1	1	3	5
SEX				
Male	1	3	2	6
Female	6	6	4	16
MARITAL STATUS				
Widow	0	1	2	3
Married	2	1	3	6
Single	5	7	1	13
EDUCATION				
None	0	0	0	0
Primary School	2	3	1	6
High School	2	6	3	11
Tertiary Education	2	2	1	5
OCCUPATION				
Pensioner	1	1	2	4
Unemployed	2	0	2	4
Informal Employment	2	7	1	10
Formal Employment	2	1	1	4
COMMUNITY HEALTH CARE CENTRE				
Retreat	1	1	3	5
Gugulethu	4	7	1	12
Lady Michaelis	2	1	2	5

At the time of the interviews, the time periods for the disease diagnoses ranged between three months and ten years. Nine people had been living with their diagnosis for more than three months but for less than a year at the time of the study; six people had been living with their diagnosis for about a year to two years;

four people for about three to six years; and two people for about nine years. Only one person had lived with the diagnosis for ten years.

Co-morbidities were common in the study participants. Seven of the respondents reported that they also suffered from one other chronic condition such as HIV, gout, breast cancer or arthritis. Five of the respondents reported suffering from two or more co-morbidities, in addition to their diabetes or hypertension diagnosis. For instance, one female respondent who suffered from diabetes reported that she also suffered from hypertension, arthritis and thrombosis. Another respondent who was diabetic reported that he also suffered from ischaemic heart disease, high cholesterol and high blood pressure. Participants also reported that they suffered from complications as a result of their chronic condition or the medication that they were taking.

All participants took medication/prescribed drugs for their condition. Some participants, however, reported combining their medication with other non-pharmaceutical remedies, for example herbal remedies such as aloe vera and 'holy' water (water that has been prayed for) which they received from their church to cure them.

The section that follows is a case study which exemplifies the experiences of the study participants. I met and recruited this particular participant at the hypertension and diabetes club at Gugulethu CHC. For the purpose of presenting this case study, this patient will be called Buhle.

4.2 PERSONAL NARRATIVE

Buhle had a follow-up appointment with the doctor regarding his hypertension on the day he was recruited. Aged 34, he worked as a driver. He had high school education, but had failed his matric. Buhle had two children from a previous marriage, who lived with their mother. At the time, he was living with his two sisters and their children and was the only breadwinner in a household of five people. He had been diagnosed with hypertension only three months prior to the interview. The full interview transcript can be found in appendix M.

In the opening question, the participant was asked to share with the researcher his experience of receiving his diagnosis. He stated:

The day the doctor told me that I have high blood pressure I was very shocked because I didn't know where this thing was coming from... I was shocked because you don't expect that at this age. I am not that old. I thought that high blood pressure and diabetes affect old people. I never really knew that even young people can get this thing.

The patient's emotional reaction at the time of his diagnosis appears to have stemmed from his misperception that hypertension only affected elderly people. His perceived level of risk had been very low. While in the midst of this emotional turmoil, the doctor gave him a lot of information:

She (the doctor) explained a lot of things but at the time I was so stressed because I was thinking that this is the end of my life.

As is evident from the respondent's own words, his experience of shock at the time of diagnosis overwhelmed him, to the extent that it disrupted his ability to absorb all the information given to him. The fact that the doctor gave what he regarded as "too much information" at this time was probably also not helpful. Buhle, however, recalled some of the advice that he received from the doctor, which indicates that although he was overwhelmed at the time, he retained some of the information given:

She (the doctor) said, the salt...I must just put a little bit...and she even told me the way that I must eat...not too much food. And she even said that my weight is too much, so I have to exercise while I am taking this medication. And then they gave me tablets, temporary tablets... just to check if this thing can work...they are trying to bring down the level.

A salient finding that emerged from the interview with Buhle was how little he understood his condition. When probed about what he thought caused hypertension, he said:

I don't know the cause of this thing or how it got into my blood because my father does not even have this thing. My mother is clean, my young brother is clean, and even my children are clean...

Later on in the interview he added:

You know to be a young guy with an old people disease is embarrassing. If some of the young people saw me here, they would say hayebo! What is this man doing here with the old people?

This response suggests that the respondent felt ashamed to have hypertension at his age and was apprehensive about how his peers would view him. His use of the phrase “clean” to describe his family members, who did not suffer from hypertension, also connotes stigmatisation of the condition and feelings of shame. His lack of knowledge regarding the aetiology of his condition seems to lead to incorrect attributions of another health issue to hypertension, resulting in a failure to seek appropriate treatment for it:

Ever since I got this high blood pressure, sometimes when I go to the toilet my urine feels very hot. Sometimes when I am having sex it burns, and I am not sure why because I use a condom. I don't know if it's because of this thing in my body (high blood pressure). I am really not happy with this.

When the respondent was asked whether he had received any information about the cause of hypertension from the health care provider, he responded:

She (the doctor) said diabetes is different from high blood pressure. She said that the high BP is just normal. It is not like diabetes, which is for old people... And then I asked her what causes it. And she told me the same thing, about the salt and stuff. Sometimes the high BP can be high because of the stress, or sometimes depression.

Judging from the quote above, the respondent did not come away from the consultation with a clear understanding of hypertension and remained distrusting of the diagnosis. Without the necessary information on the aetiology of hypertension, he also misunderstood it as being a short-term condition and believed that after a course of treatment over a few months he would be cured:

I believe the doctor was lying to me now when she said it's just a normal thing, because a normal thing reaches a point when it gets out of the body. She just said to me, this is normal, everyone has this thing. But I find that its three months now and I am carrying on and on. And I believe today she is going to say take another date again and life goes on. In my mind I thought that maybe this thing, when my high BP gets back to normal, I can stop my tablets, or I'll take time, like two or three months before I have to come back, since they already gave me tablets. Now I find that I get dizzy, and I am thinking if I tell her about this, she is going to say take thing now - Uhhhuuu another packet! So which means there is no change, which means it is going to remain like this...that is the way I see it.

The excerpt above seems to indicate that Buhle felt apprehensive about talking to the doctor because he expected to be prescribed further medication, which he is reluctant to take. This appears to be related to his misunderstanding that the medication should have cured him after a few months. It is clear that he is psychologically and emotionally ill prepared to deal with the chronic nature of his condition. This is likely to negatively affect his adherence to treatment.

A further reason for his reluctance to take medication on a long-term basis was because of its perceived side effects:

The medication makes me pee. And each and every day I am going to the toilet to pee. To pee, pee, and pee every day... Sometimes I feel embarrassed when I am in front of people and I have to go to the toilet.

The respondent also indicated that he was not coping well with his condition as a result of the physical discomfort that he attributed to his hypertension treatment. He stated:

After I take this medication, I feel a lot of changes in my body. I feel dizzy sometimes, I feel tired. You can't just stand up after eating this medicating like a normal person. Before I was someone who would do exercise in the morning. But since I started taking this medication, it makes me very, very tired, weak...sometimes you feel a headache, sometimes back pains, all of that stuff...even today I was telling myself to ask the doctor if they can make a plan and change my medication because I am not happy really...it's changing my life. I am doing different things now.

The respondent was, in fact, so frustrated with his medication that he considered stopping taking it altogether and turning to other remedies. He admitted the following during the interview:

So far, I am just following the instructions. But they told me (family and friends) that I must take aloe vera, but I am just focusing on my medication until four months. Then after that, I can drink aloe vera if it is necessary, unless the doctor can help me with this problem- the dizziness and weakness from the medication.

The respondent even admitted to defaulting on his medication as a result of what he perceived to be the debilitating side effects of his medication:

My problem is just the medication. When I don't take these tablets, I feel nothing, no dizziness. But when I drink the tablet, I have to take time to focus. I thought that this was the wrong medication. I wish that he or she (the doctor) can change that tablet that I am using...I wish they can change my medication.

Despite Buhle's negative experience with his medication, when questioned by the researcher, he reported not having raised the issue with the doctor. When probed about his reasons for not speaking to the doctor, he did not give a clear answer. However, during the course of the interview, he expressed some apprehension about raising issues with the doctor. This was because he expected to get scolded for not having been cured as he believed he should have been and because he feared being referred to a hospital for not having improved. He understood admission to hospital would signify deterioration in this condition, which he felt unprepared for:

She (the doctor) sometimes asks why my BP is too high. And then I have to explain this and that... and sometimes I think she is going to say I am going to refer you to the hospital, what you call it Jooste hospital. I have never been to hospital before. I don't want to go to Jooste hospital because I feel like if I go to hospital then things have gotten worse...It starts there...next thing I will be told I am worse and I have to sleep in hospital.

Even though Buhle was trying to pluck up the courage ("*Even today I was telling myself to ask the doctor if they can make a plan and change my medication*"), this suggests that it is unlikely that he will engage the doctor to resolve his unhappiness about the medication and uncertainty about his condition. Again, this has implications for his compliance with treatment.

Buhle's narrative also revealed that he struggled with the changes to his self-identity that were brought about by the diagnosis of hypertension:

I am different now; I have to cook two pots now. Sometimes you waste a lot of food. So to eat different food, it's like you are a kid. It's not nice. You know the kids; they just eat their own food. I am an old man now: I have to eat different food from my family. When they eat meat, I have to take the fat away and it must not be that salty.

It is evident from the above quotation that chronic illnesses like diabetes and hypertension, and their treatment, can introduce major disruptions to self-identities and daily activities and routines. Buhle feels a sense of shame and isolation having

to eat different food from his family. There appears to be tension between his perceived identity as an adult man and his identity as a hypertensive patient. His role as a man and as the sole breadwinner in his family seems to be threatened by his role as the patient, which includes eating different foods from the rest of his family “like he is a kid.” Yet, at the same time, he defines himself at the age of 34 as being “an old man” because he has an illness associated with the elderly.

The respondent also expressed a lack of competence in relation to managing hypertension through diet and again mentioned that he did not get the assistance he would have liked from the doctor:

I don't know what I must eat at home...the doctor did not tell me about the food. She said that I must leave the salt in the food because the danger is the salt. But she didn't explain what kind of food I must eat.

The respondent also spoke about the scornful response he got from his peers to his attempts to comply with the recommended dietary changes:

My friends like salt. When they taste my food, then they say yho! Are you crazy, why are you eating like this? You know the friends always go like wawawa (talk too much) but I am happy to eat alone now, they don't help me anymore. They won't eat a vegetable, but the meat; if I take off the skin they help me by eating that skin. They say I am stupid for removing the skin...

This suggests that the social norms of a community can also facilitate or impede behaviour change. His friends make him feel like a social outcast, and put him at a high risk for non-compliance with dietary recommendations, in order to feel accepted. This is a further example of how the diagnosis of hypertension caused a disruption to his social relationships, resulting in feelings of isolation.

In contrast, the respondent received emotional and practical support from his parents:

My parents support me big time. They don't say I am different. They support me most of the time. Sometimes they bring me something, like a vegetable or a fruit, they

share everything with me. I accept it because it is from my family. They mostly like to give me vegetables.

Several structural factors also emerged from the respondent's narrative that made his efforts to adhere to medical treatment difficult. Firstly, the respondent talked about his fear of losing his job as a result of having to take time off work to attend the clinic every month. He lamented:

I informed my boss yesterday that I have to come to the hospital, but he always asks, "why are you are always going to the doctor, what's happening". He is curious. He wants to know exactly what is happening. But I told him, I have this thing in the blood. He says yeah we understand, but to have you absent from work each and every month...you are not here. Yes they may smile in front of me, but behind my back they say, "it's too much". One day I don't know what is going to happen. My life is at a big risk now, even my work.

The respondent explained how long the process takes:

I take more than 2 hours at the pharmacy. That is why if I come to the hospital I have to take the whole day off from work, because I know I have to see the doctor, and then stand in the line for the pharmacy...see what time it is now, I can't go back to work now. It's not like the private doctors outside, where they do their things quickly and you can go back to work. This is a day hospital. You have to accept the way that they work because everyone comes here.

In situations where employers do not accommodate patients' health needs, the patient may end up being put in a position where they decide to prioritise work. This may result in infrequent or poor clinic attendance for follow-ups, especially in situations like that of the respondent, where he is the sole bread winner in his family and has five dependants.

Another issue that the respondent raised that impacted on his ability to effectively manage his hypertension was the cost of food:

Before, I used only R700 for groceries for the whole month. But now we finish before the end of the month, like on the 25th because we cook two pots...my food cannot have salt so I cook my own separate pot. The food now finishes early and I have to buy some food again. We are 5 and I am the only one who is working, so I have to deal with that crisis. But I don't know what is going to happen because if the price of food keeps going up...and the strike also... The price are now going up and up because of the less stock which means the food is going to go up and up.

In the quotation above, the respondent refers to how the price of food was affected by the service delivery strikes which were ongoing at the time of the interview. His ability to sustain his family and the perceived conflicting requirements for a healthier diet are a major source of anxiety for him. The rising cost of food and the extra cost of preparing separate food are seen as potential barriers to maintaining his low-salt diet over the long term.

When he was asked at the end of the interview about what motivated him in his efforts to comply with medical recommendations, he stated:

I don't want to die, that is the first thing, and I don't want to get a stroke as the doctor says, so I would like to follow instructions as the doctor said to me. That is why I decided ok, the doctor told me this and this, which is why I have to follow it because they know what I don't know. They saw it in my body...so I just focus and I carry on...because I saw my brother what he looked like, and I don't want to look like him. Because of high BP, he had a stroke. He is now up and down; in and out of hospital ...I don't want to be like that.

It is clear from the quote above that the respondent was motivated to some extent by the clinician's interventions. He recognises the importance of complying with medical recommendations and personally identifies with the need to change his behaviour. He is also convinced of the potential dire consequences that can arise from non-compliance, as a result of his brother's experience with hypertension.

If Buhle's narrative is interpreted within the SDT theory and socio-ecological framework, it becomes evident that health behaviour is influenced, not only by complex individual factors such as health literacy, motivation, perceived competence and autonomy; but by broader economic, social and institutional considerations as well. For instance, Buhle's competence to change behaviour and his willingness to adhere to ongoing treatment were significantly affected by his lack of understanding of hypertension and/or diabetes as chronic conditions and more specifically, his lack of sufficient in-depth knowledge of how lifestyle plays a role in the aetiology and control of NCDs.

This lack of understanding can be linked to the fact that a sense of relatedness was not established between Buhle and his doctor. His interview suggests that the health care providers he had contact with did not engage him in such a way as to make him feel comfortable to ask questions that could clarify his understanding of the diagnosis and allay his anxieties.

As a result, he remains distrusting of the doctor's diagnosis and prescriptions and is at risk of defaulting on treatment, despite showing some motivation to "follow the doctor's instructions." Buhle's story also provides an insight into how different factors in the patient's environment (social, economic and political) can impact on the individual in such a way as to facilitate or impede behaviour change.

4.3 OVERALL STUDY FINDINGS

The qualitative analysis resulted in five core themes (see Table 4.2 for the summary of results). These themes are discussed below in relation to their likely impact on participants' motivation and ability to modify their lifestyles in order to control their condition. Verbatim quotes from the interviews have been used throughout this section for several reasons: to give the participants a direct voice, to convey a sense of the speaker's emotional intensity and to reflect support in the data for the points made by the researcher.

Table 4.2: Summary of main findings: themes, categories, codes and quotes

THEME	MAIN CATEGORY	DESCRIPTION OF CATEGORY	SUB-CATEGORIES: I.E.: DIFFERENT DIMENSIONS OF CONTENT IN A CATEGORY
1. “I just don’t understand”: Low levels of health literacy and the impact on competence and motivation to change	Responses to diagnosis of diabetes or hypertension	Any thoughts, feelings or behaviours that occurred as a result of receiving a diagnosis	<ul style="list-style-type: none"> -Misunderstanding of the illness -Misplaced emotional reactions -Lack of health education and information at health care facilities <p style="text-align: center;">vs.</p> <ul style="list-style-type: none"> -Understanding of illness leading to active engagement with diagnosis -
2. “They don’t explain anything”: Lack of a sense of ‘relatedness’ with health care providers	Interactions with healthcare providers	Any positive or negative account of patient-doctor interaction	<ul style="list-style-type: none"> - Lack of time for explanations in consultations - No effective communication about lifestyle modification - Lack of social support <p style="text-align: center;">vs.</p> <ul style="list-style-type: none"> - Positive interaction - Advice and counselling received

... continued

... continued

THEME	MAIN CATEGORY	DESCRIPTION OF CATEGORY	SUB-CATEGORIES: I.E.: DIFFERENT DIMENSIONS OF CONTENT IN A CATEGORY
3. “Lots of things change in your life”: The life-changing experience of living with a chronic condition	Personal experiences of living with the condition	What it is like living with diabetes or hypertension; how diagnosis changes everyday life of the patient	-Emotional changes -Living with chronic symptoms and discomfort
4. “It’s hard to live with this thing”: Multiple barriers make lifestyle change and adherence to treatment the more difficult choice	Perceived barriers to adherence to treatment and lifestyle prescriptions	Any barriers (to treatment adherence or to changing health behaviours)	-Structural, intrapersonal or interpersonal barriers to adherence to medical and lifestyle recommendations vs. -Facilitating factors
5. “I don’t want to have a stroke”: A continuum of motivation and the potential for behaviour change	Sources and quality of motivation to change lifestyle	Anything that motivates people to modify their lifestyles (identifying different types of motivation, using concepts from SDT)	-Sources of motivation -The quality of motivation

4.3.1 THEME 1: “I JUST DON’T UNDERSTAND”: LOW LEVELS OF HEALTH LITERACY AND THE IMPACT ON COMPETENCE AND MOTIVATION TO CHANGE

4.3.1.1 Misunderstanding the causes of the illness

Overall, the lack of understanding about the cause and nature of their condition was a striking finding in participants’ narratives. When participants were asked to share their own understanding of why they ended up with their condition, various misconceptions emerged.

A number of participants held specific misconceptions about the causes of diabetes and/or hypertension. This is evidenced from the following excerpts taken from interviews with some hypertensive patients:

One participant indicated that she believed that her hypertension might be caused by her medication. She stated:

To be honest, I really believe it is this medication that is making me sick. I understand the heart attack because we have heart problems in my family. I mean after I had the heart attack, where did the high blood pressure come from? Where did the cholesterol come from? I was a very healthy person. I really believe it’s the medication that is making me sick (Interviewee 13: female, 66 years old).

Another believed that she had hypertension because she was HIV positive. She knew that HIV caused a lot of co-morbidities and assumed hypertension was one of them. Stress from work, finances, family matters, and loss was another common attribution - either as a cause or exacerbating factor for hypertension. For example:

My home life is extremely pressurised. I’ve got a husband that has got emphysema, stage five, so I think that has a lot to do with it. I’m under a lot of pressure; I’ve got kids, so I think that probably has a lot to do with it (Interviewee 2: female, 46 years old).

Another stated:

I have high blood pressure because my son was shot in 2006. Maybe I couldn’t take it.

I don't know why I didn't cry ... and I never went for counselling. So, then afterwards it worked on me. So that's why I have high blood pressure (Interviewee 4: female, 54 years old).

With regard to diabetes, a misconception that emerged regarding the cause was that diabetes may be linked to “impurities in the blood”:

There is a lady who always told me that this (diabetes) is caused by dirty blood. She told me that I must clean my blood with Vitamin B (tablets) or get the Vitamin B injection from the chemist and then my blood will be okay (Interviewee 18: female, 62 years old).

In contrast, there were participants who appeared to understand the link between their chronic conditions and their lifestyles. For example, a participant suffering from hypertension stated the following:

I think its lifestyle. It depends how you live... not eating properly and not exercising enough (Interviewee 11: male, 77 years old).

Similarly a male participant suffering from diabetes said:

I think its lifestyle. I am a smoker and the doctor spoke to me about quitting but it's hard to quit because I stress a lot. I am married and a father of three you see... (Interviewee 5: male, 30 years old).

There were also those participants who admitted to having no knowledge about the cause and nature of their condition. For example, two participants who suffered from diabetes shared the following:

I am not sure what it is, but at least what I am doing is just to always get my medication (Interviewee 10: female, 58 years old).

Similarly:

I really don't know. When I came to the clinic, tests were done and the doctor just recorded a lot of things down...maybe from what he was seeing in the folder. They didn't really explain anything to me (Interviewee 3: female, 65 years old).

4.3.1.2 Misplaced emotional reactions to the diagnosis

It is to be expected that people experience strong emotions when first diagnosed with a chronic illness. Feelings can range from being scared, shocked and panicky, to being angry or resigned (Nam et al., 2011). For the current study, there were some variations in the response to the question about reactions at diagnosis. Reports of high levels of fear and stress at diagnosis, however, emerged as a salient feature in the data. These fearful emotional reactions to the diagnosis were often related to patients' misperceptions about their illness, which appeared not to be identified and dispelled by health care providers. For instance, one participant who suffered from diabetes stated:

I was diagnosed last April. When the doctor told me that was diabetic, I was scared. I thought that I was going to die and I have to cut my legs off. So I was scared of diabetes (Interviewee 21: female, 31 years old).

Similarly:

When the doctor told me that I was diabetic, I cried...and I was quick to think that it meant that I was going to die soon (Interviewee 14: female, 56 years old).

These participants believed that diabetes was a "death sentence", and in the case of one of the participants, she believed that having diabetes automatically resulted in amputations. She did not seem to be aware of the fact that the mortality and morbidity associated with diabetes can be delayed or prevented. Other respondents who reported fear and shock at diagnosis also displayed certain misconceptions. For instance, some held the view that only the elderly were affected by diabetes and hypertension:

I didn't expect to find out that I was diabetic. I used to think that diabetes only affects old people. I didn't know that when you are still young you can get diabetes (Interviewee 18: female, 62 years old).

Other participants indicated that their response to the diagnosis was denial, and as a result, they expressed a struggle to integrate the diagnosis with their self-identity. One of the participants who was diagnosed with diabetes stated:

I used to be a nurse in a home and I saw what diabetes did to people, and I was also afraid of insulin. So I did not want to accept this at first. I knew what the symptoms of diabetes were but I ignored them and did not want to come to the hospital. But then I bumped my toe and I got a wound. The wound did not heal you see, so after two weeks I finally came here because I knew that the wound wasn't healing because of the diabetes (Interviewee 9: female, 34 years old).

Similarly:

I really struggled to accept this diabetes diagnosis because no one in my family has diabetes (Interviewee 13: female, 66 years old).

As the following quote reveals, such a response can result in the patient defaulting with treatment:

The chemist tested my sugar and it was 39.4. He gave me the diet (sheet) and said I should come to the clinic. So I came to the clinic and then after that I ignored to come to the club and to take the tablets because I told myself, no man, it's too much for me...I only came back because I became ill because my sugar was very high...

It's difficult to have diabetes because sometimes you meet a person who doesn't understand the diabetes...and they can ask something hurtful... (Interviewee 9: female, 34 years old).

In contrast, other respondents accepted their diagnosis in a fatalistic way because they believed strongly in genetic or family predisposition. One of the respondents explained:

When the doctor told me that I've got high blood pressure, I was ready for it. My grandmother used to have high blood pressure when she was alive. She used to complain about headaches and dizziness. I had the same symptoms as well, before I was diagnosed. So on the day that I was diagnosed, I was waiting for it (Interviewee 17: female, 35 years old).

Another respondent with diabetes stated:

When I sit and think sometimes I think maybe it's because of my mom (Interviewee 8: female, 55 years old).

Other participants displayed a passive acceptance because the news came from an authoritative figure. For example:

When I was diagnosed (with diabetes) I was fine. I had to accept it because I was told by the doctor (interviewee 3: female, 65 years old).

Similarly:

He (the doctor) told me that it's not a bad disease (hypertension). He said that I mustn't feel bad and that it is just a normal thing. So I was fine (Interviewee 15: male, 52 years old).

4.3.1.3 Lack of health education and information at health care facilities

In an attempt to explore why the study sample lacked knowledge regarding their illness, participants were asked to describe the health education materials they had received from the clinic and/or any health education activities that they had participated in at respective health facilities. At Gugulethu CHC, five participants reported having received health education on lifestyle modification through one-on-one consultation with the doctor; six participants reported having received group education. In terms of written education material, the data showed that only one participant out of twelve from this facility received a pamphlet, and only two respondents received diet sheets on their visits to the CHC. Only two people reported having seen posters at the facility about lifestyle modification and self-management.

In terms of responses regarding the health education services available at Retreat CHC, all five participants who were interviewed from this facility reported never having received any group education. This was despite the nurses having reported to the researcher during introductions to the facility that this service was available at this facility for all patients who attended the diabetes and hypertension clubs. Two of the five participants, however, reported having received information about lifestyle modification during one-to-one consultations with the doctor.

When it came to written education material, three of the participants reported having received either a diet sheet or a pamphlet containing information on diabetes and/or hypertension management. This was provided by the nurses at the diabetes/hypertension clubs and only occurred once. Only one participant stated that they had seen and read posters on the walls at the facility that related to self-management of NCDs.

Similarly, of the five participants who were interviewed at Lady Michaelis CHC, two reported that they had received either a diet sheet or a pamphlet. Two participants reported that they had received advice on self-management and lifestyle modification during group education sessions. Two respondents reported having received advice on lifestyle modification from their doctors at diagnosis, as well as information on dietary modification and exercise. No respondents reported seeing any relevant posters. Figure 4.1 below provides a summary of the overall response of the study sample regarding the type of health material/education that they received from the clinics.

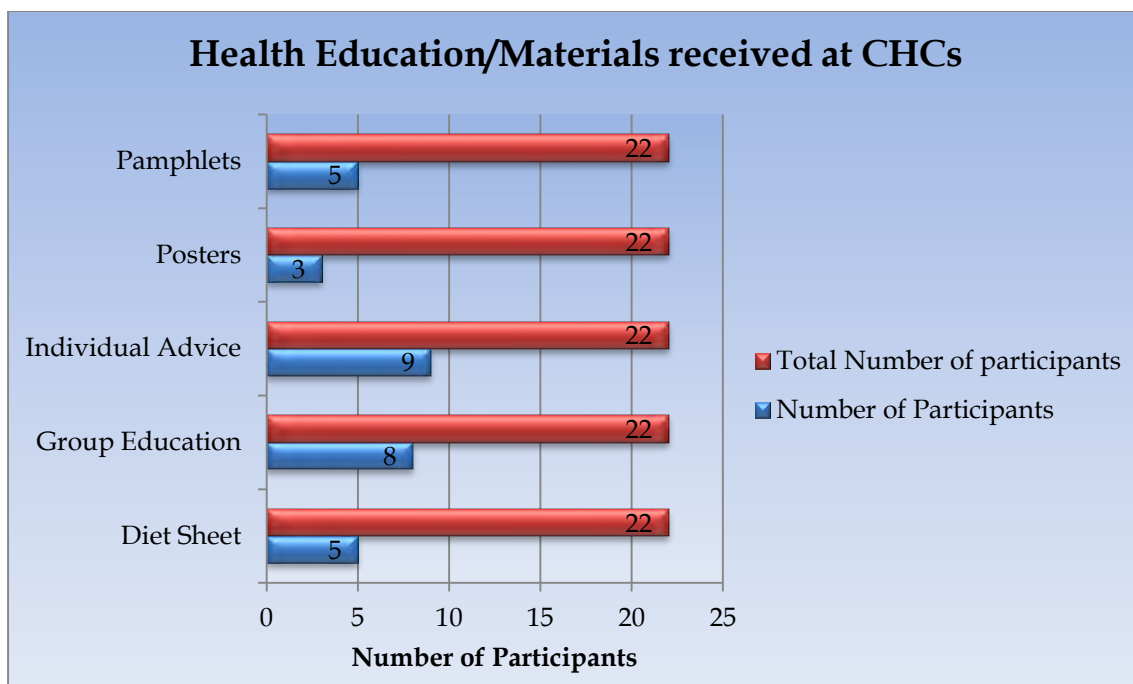


Figure 4.1 Summary of the number of participants who reported exposure to Health Education/Material at CHCs

The researcher's own observation at the facilities was that there were plenty of posters on the walls, written in both English and either Xhosa or Afrikaans, depending on the community that the CHC served, which contradicts the reports of the respondents. This may be because patients were not observant, did not find the posters appealing or failed to recall seeing them. The posters contained messages mainly regarding symptoms of diabetes, foot-care and dietary advice. The researcher, however, did not observe any posters containing messages specifically concerning hypertension. In addition, the researcher did not see any pamphlets on diabetes and/or hypertension management in the club rooms in any of the three facilities that were visited, which verifies the respondents' reports of a lack of available material. Other sources of information included the print media, television, radio and social networks.

Though the results show that the majority of patients have poor knowledge about the causes and nature of diabetes and hypertension, there were participants who seemed to have a better understanding of these conditions and their link to lifestyle risk behaviours. They reported having acted on the information and initiated

behaviour change. These participants reported that they had received their information from the following sources: the internet, media, and consultations with the doctor.

Whilst respondents generally had poor knowledge about many aspects of their illness, they seemed to have relatively more knowledge about the recommended diet for diabetes and hypertension control. They obtained their information on diet from a variety of sources, including friends, family, TV, the internet and health care facilities. Table 4.3 contains some examples of correct dietary knowledge which emerged from the interviews. This knowledge pertained to three areas: food preparation, food choices and dietary prescriptions.

Table 4.3: Respondents' correct dietary knowledge

DIETARY KNOWLEDGE
1. Preparation of healthier food
"She (doctor) told me that the most dangerous thing in our body is the salt. She said that you must just cut down from eating too much salt" -P22
"The doctor told me that I must remove skin off the chicken"- P18
"When I prepare chicken, I remove the skin and just eat the white meat" - P10
2. Healthy food choices
"You've got to eat fruit and vegetables, not so much meat; very little meat. More or less you become a vegetarian"-P11
"I eat what I manage to buy, but it is mostly fruits"-P13
"I eat a lot of fruits and vegetables now. And I don't eat anything fatty anymore"-P20
3. Portion control
"I used to eat a lot of fatty foods, but I try to limit myself now"-P7
"I have cut down everything I used to eat like sausages, cold meats and sweets and all that. Since diabetes I have changed my diet"-P11
"You can eat everything but you must eat less"-P2
"You can eat but you must limit yourself. You must not overdo things"-P4

In contrast, there were also incorrect views about eating healthy that emerged from the data. The two main views being that food must be boiled for it to be healthy, and that to be healthy meant eating "special" types of food:

The change is drastic. And you have to only boil your food.

Another example:

Healthy foods are all expensive. Broccoli and all those things are expensive. Now when I am taking tea in the morning I can't use normal sugar. I have to use candereel sugar, and it is very expensive.

Incorrect views such as those expressed above acted as barriers to effective self-management for these patients, as they deterred them from making the necessary dietary changes.

4.3.2 THEME 2: "THEY DON'T EXPLAIN ANYTHING": LACK OF A SENSE OF 'RELATEDNESS' WITH HEALTH CARE PROVIDERS

An analysis of the data showed that the patients' ill-preparedness to adhere to medical recommendations could be partly associated with a lack of "relatedness" with healthcare professionals. Relatedness – a concept from SDT defined as the feeling of being understood, cared for and valued by significant others (Ryan & Deci, 2000) - influences a patient's process of coming to terms with their condition and impacts on their level and quality of motivation to control their condition through lifestyle modification and adherence to medication (Deci & Ryan, 2012). The general aspects of relatedness that appeared to be missing in the relationship between health professionals and patients included emotional support, positive interactions, discussion of lifestyle changes to control conditions and time for explanations in consultations. A few examples from the data that elucidate this are as follows:

4.3.2.1 Lack of time for explanations in consultations

Participants expressed a need to be talked to and given more detailed explanations about their illness. This sense of alienation indicates that relatedness support from doctors is important to patients. This is illustrated by the following quote:

I know the doctors are busy and there's the next patient waiting and they're under pressure; however, I just feel that maybe there could be more detailed, sort of give us more information, talk about what this whole thing entails (Interviewee 2: female, 46 years old).

4.3.2.2 No effective communication about lifestyle modification

Participants' narratives also revealed a tendency by health professionals to rely on the biomedical model in the management of patients with chronic diseases of lifestyle: in other words, the main emphasis appears to be on medication, with little or no emphasis on secondary prevention through lifestyle modification. This frustrated participant who suffered from diabetes stated:

They (the doctors) didn't tell me anything. They just did a blood test and gave me medication that is all (Interviewee 9: female, 34 years old).

4.3.2.3 Lack of social support

Social support is a transactional communicative process, including verbal and non-verbal communication that aims to improve feelings of coping, competence, belonging and self-esteem. There is actual support – the support that the person receives in terms of what is said, what is given and what is done for the individual – and then there is perceived support, which refers to the individual's belief that social support is available, whether it is considered positively or negatively and meets the individual's needs (Mattson & Hall, 2011).

Some participants reported a lack of social support in their interactions with health care providers, particularly the nurses. This complaint was common across all the three facilities. One of the participants stated:

When it comes to the nurses it is really bad. When you go inside to see the doctor, he will talk to you fine and he will examine you and all that. But when it comes to the nurses, hm-mm, they are rude. It's not a good experience (Interviewee 17: female, 50 years old).

Similarly:

There are days when they (nurses) are nice and there are days when they are so rude.

Then I say to myself, she most probably got problems at home or she's tired. I mean in this situation, we can't expect more... (Interviewee 19: female, 72 years old).

Another participant recalled being scolded by the doctor for not keeping his glucose levels under control. He interpreted this as the doctor having little empathy for his struggles, but felt unable to engage with the doctor to explain his experience and to ask questions about how to improve the management of his health:

The doctors always complain because every time they check my sugar it is very high. I don't know why but it is always high. I just don't understand because I have cut out all the sugar, no cakes, sweets or anything of the sort (Interviewee 6: male, 75 years old).

In contrast, there were also reports of positive interactions with health care providers. For instance, one participant with diabetes reported having received useful information on diet and another on foot-care:

I remember he (the doctor) told me about my diet. What to eat, what not to eat. It was like, some sort of a counselling. So, after that I went home, and I was given a paper about what to eat- the right diet for a high blood pressure person and all that (Interviewee 17: female, 34 years old).

Another stated:

The sister at the club sometimes tell us things that we didn't know, like, what to wear on your feet, and that shoes shouldn't be too tight. And when you use cream, you mustn't put it in between your hands and between your toes. So, they're teaching things that we didn't know (Interviewee 18, female, 62 years old).

4.3.3 THEME 3: “LOTS OF THINGS CHANGE IN YOUR LIFE”: THE LIFE-CHANGING EXPERIENCE OF LIVING WITH A CHRONIC CONDITION

Another salient theme that emerged from the data is how chronic illness can impact on the quality of life. These findings were based on an open question to patients about their experience of living with diabetes and/or hypertension. The responses revealed the following:

4.3.3.1 Emotional changes

Concerns about feelings of emotional volatility since the diagnosis emerged in some of the interviews. Participants who were affected expressed their unhappiness with this new-found emotional instability and resisted the change in self-identity this brought about. They related their irritability to their condition. They reported that this emotional state affected their personal relationships. For example, one mother who suffered from diabetes stated:

When I don't have money and my child wants 50c to buy chips, ooh, I start to stress and shout at everyone who comes next to me. I didn't do that before the diabetes thing, but now I do that when I'm stressed (Interviewee 21: female, 31 years old).

Similarly:

When you have diabetes, lots of things change in your life. It's not you, like you usually, you are, you know. I was nice before, but since I became diabetic I did change... I'm always angry, you know. I don't want somebody to take my things without telling me, I get very angry (Interviewee 18: female, 62 years old).

Another woman described how she had become depressed since her diagnosis:

Since I have become diabetic, I don't feel like myself anymore. Sometimes I am miserable. (Interviewee 14: female, 56 years old).

4.3.3.2 Living with chronic symptoms and discomfort

Symptoms of ill health, especially headaches, dizziness, weakness and chronic pain were reported and were linked to either diabetes and/or hypertension. One participant suffering from hypertension said:

I can't get up and stand straight up. The doctor said I must take about five minutes when I get up in the morning, then start coming up, then start walking, then all the pains will go away but it doesn't go away, I've still got a pain in my head, and get dizzy in the morning man(Interviewee 20: female, 65 years old).

Similarly, another hypertensive participant stated:

For the past two months I have been experiencing pain on this leg every morning when I wake up (Interviewee 13: female, 66 years old).

Sexual dysfunction emerged as a problem for two of the participants who suffered from diabetes. For instance, this female participant stated:

Since I have become diabetic, I don't want my husband to be next to me. I am not interested anymore (Interviewee 14: female, 56 years old).

Similarly:

I feel tired all the time. It's not me anymore. I hate that I have to make excuses because there is a problem down there now... you know, sexual things, I'm not active like I used to (Interviewee 9: female 34 years old).

Interestingly, no one else from the sample who was diabetic mentioned experiencing sexual dysfunction, except for these two women. This was surprising, especially with regard to the men because hypertension and diabetes are known risk factors for erectile dysfunction in men (Giuliano et al., 2004).

The question remains unanswered as to whether the men and the other female participants did not discuss the issue of sexual dysfunction because they did not experience it, or that they merely felt uncomfortable discussing the issue.

4.3.4 THEME 4: "IT'S HARD TO LIVE WITH THIS THING": MULTIPLE BARRIERS MAKE LIFESTYLE CHANGE AND ADHERENCE TO TREATMENT THE MORE DIFFICULT CHOICE

An overwhelming number of participants (nineteen out of twenty-two) revealed that they struggled with adherence to lifestyle changes such as exercise and dietary recommendations. The study identified numerous barriers which fell into three main categories: i) intra-personal factors ii) inter-personal factors and iii) structural factors

4.3.4.1. Intrapersonal factors

Although many patients demonstrated good general knowledge about food preparation, food selection and eating patterns, they also reported that they struggled with adhering to dietary recommendations.

Some participants revealed that they struggled with changing their habitual diets:

It's not easy at all to change my food because I am used to eating the fat stuff but I try to limit myself a little bit. For example, now I try not to eat meat every day. I try to eat it after four or five days, because before I used to eat each and every day (Interviewee 10: female, 58 years old).

Similarly:

I used to love eating pap. I am used to eating pap and red meat almost every day, but now I am trying to change my diet slowly because I don't want to eat what the doctor told me I mustn't eat. But it is difficult (Interviewee 18, female 62 years old).

Another participant revealed that he experienced some anxiety at the prospect of modifying his dietary habits, fearing that it would have a negative effect on his physical strength:

It's very difficult...you see I am afraid. Imagine moving from eating lots of food to very little. I am afraid my system will crash or something (Interviewee 6: male, 75 years old).

Difficulty in controlling impulses to eat certain foods and general taste preferences were also factors that were identified as barriers to dietary changes. One participant who suffered from diabetes stated:

I love chocolate...sometimes I can eat a whole slab of chocolate. I can sit and watch TV and just eat the whole chocolate (Interviewee 2: female, 46 years old).

Another stated:

But really the food that I eat now (sighs) I am really not happy with it. The taste is a problem because I just have to boil my food (Interviewee 22: male, 34 years old).

A further barrier to adherence to treatment for some participants was their experience of side effects from the medication. These were a source a great concern for them, but they struggled to resolve them, as they did not feel able to raise their concerns during consultations with the health care provider. For example, a participant who suffered from diabetes said the following:

They put me on the metformin, neh. This is usually given to people who are overweight. But I am not overweight as you can see. So now the medication made my mouth numb and it made me constipated. (Interviewee 7: female, 48 years old).

Another participant who suffered from hypertension said the following with regard to his medication:

After I take this medication, I feel a lot of changes in my body. I feel dizzy sometimes, I feel tired. You can't just stand up after eating this medicating like a normal person. Before I was someone who would do exercise in the morning. But since I start taking this medication, it makes me very, very tired, weak...sometimes you feel a headache, sometimes back pains, all of that stuff...even today I was telling myself to ask the doctor if they can make a plan and change my medication because I am not happy

really...it's changing my life. I am doing different things now. Something like a... I am not a normal person (Interviewee 22: male, 34 years old).

This relates back to the earlier description of a lack of relatedness with health care providers, or could also be because of the lack of time in the consultation.

Respondents also reported difficulty with the uptake of more physical activity. Overall, walking was the most common form of reported physical activity. It was reported by half of the study sample as part of their self-management regimen. For most of those interviewed, the walking was not actually done specifically for health purposes, but was part of their everyday life. However, it was recognised as being important:

I do exercise because I walk to the station every day. I think it's 20 to 25 minutes to get to the station from my place. So, I do walk (Interviewee 7: female, 48 years old).

Another participant stated:

I take a walk every morning I take a walk to take my child to school and come back (Interviewee 21: female, 31 years old).

Two participants reported engaging in physical activity that is structured and planned for health purposes:

I am part of an exercise group. I started last year and now I go every Thursday. We meet at about 5 pm. I am really happy about joining. We are about 15 and everyone has a chronic illness, so we share ideas (Interviewee 13: female, 66 years old).

Another stated:

I started going to gym...exercise is very important to me now (Interviewee 2: female, 46 years old).

In contrast, eight participants reported not engaging in physical activity at all, largely because of co-morbidities:

When I walk I get a pain in my chest. I don't know why, so I don't really exercise (Interviewee 6: male, 75 years old).

Another stated:

Since I've got this high blood pressure, I'm not energetic, the way I used to be. Like, I'm not fresh man; that fresh. You know, sometimes, it makes me feel like I don't want to do anything, I feel numb; I just want to sit down. So, like, thinking of, let me do push ups or let me jog around the house, no, like it's hard... That is why I don't exercise (Interviewee 17: female, 35 years old).

4.3.4.2. Interpersonal factors

In addition to intrapersonal factors, participants also identified certain interpersonal factors as barriers to adherence to dietary recommendations. For example:

I eat what the wife puts on the table. I don't want to interfere with that. I don't want to get into trouble (Interviewee 6: male, 75 years old).

The statement above is a good example of how relatedness/social support impacted on the patient's food choices. The primary cook, who was the respondent's wife in this case, determined what the family ate and how it was prepared. As a result, he felt that he lacked the autonomy to make his own decisions on food, and expressed a concern that any opposition to his wife's food choices may be seen as a disruption to family roles and thus cause tension.

The issue of the lack of family support in adopting dietary changes came up in other participants' narratives as well, which shows that it is a significant factor to consider when addressing adherence:

If at your house you are the only one who's got diabetes, sometimes, the other people want fish oil and all that stuff; that is another thing that makes it difficult. I mean my mother is not diabetic and my sister isn't, I'm the only one. So, when we cook, they

don't want to cook one pot, they want to cook two pots (Interviewee 10: female, 58 years old).

Another explained:

I live with my husband and five kids. I am diabetic so I have my own private pot. I try to eat what I was told I must eat but sometimes it is difficult. Sometimes I see them eat and I want to eat their food because my food is not nice (Interviewee 14: female, 56 years old).

The quotations above indicate that there is a common perception that healthy eating and healthy cooking is only meant for the “patient” and not the rest of the family. This lack of relatedness support from the family makes dietary modifications difficult, since the patient is still exposed to a family environment where old dietary habits prevail.

This “two pots” situation in homes seems to be perpetuated by the assumption that cooking healthily means that you have to boil your food all the time. For example:

The change is very drastic. You must just boil your food (Interviewee 9: female, 34 years old).

The fear of stigmatisation also emerged from the narratives as a potential barrier to self-management. Social norms can influence people’s beliefs and attitudes about general health and dietary habits and preferences, which in turn impacts on how they perceive and manage their illness (Nam et al., 2011).

For instance, one participant divulged that he experienced shame as a result of being hypertensive at his age:

You know to be a young guy among old people is very embarrassing. Do you understand what I am saying? Laughs. When you are very young and you get an old people disease, if some of the young people saw me, they would say, what is this man doing here with the old age people (Interviewee 22: male, 34 years old).

It is clear from the above quote that this misperception of who is at risk and the stigmatisation of hypertension in young people is also shared by his community members. This is problematic since it could potentially cause denial in young people at diagnosis, which can result in poor attitudes towards treatment and lifestyle modification.

Another issue related to fear of stigmatisation which emerged from the interviews specifically among black women was in relation to weight loss:

It's only this loss of weight that worries me; because I have lost weight since this diabetes. You know people, they will start talking. They will ask why has she lost weight, what's going on with her. You see those things...they will think something else is wrong (Interviewee 21: female, 31 years old).

Another respondent with diabetes stated:

Before I was a size 44 and now I am a size 40. I was worried about it at first because people talk. I was worried that they would start asking why you are so thin. What's happening? Maybe you've got the disease. But told myself, I mustn't worry about people because it's the right thing (Interviewee 14: female, 56 years old).

The reference to “the disease” in the extract above implies that weight loss is associated with HIV/AIDS in the respondent’s community. It has been shown that in black African communities an increase in body weight is associated with beauty, prosperity and health, and thinness or weight loss is associated with ill health, especially HIV/AIDS (Puoane, Bradley & Hughes, 2005).

For these respondents this cultural factor was a barrier to diabetes and hypertension self-management, since weight loss is usually recommended for individuals who are overweight or obese and living with these conditions. In contrast, the coloured women in this particular study did not bring up any concerns about weight loss, and in fact some of them mentioned a desire to lose weight. For instance, one respondent said:

Early this year I started to change my food and to cut down because I have to lose weight. The doctor told also me that I shouldn't be overweight (Interviewee 10: female, 58 years old).

Similarly, another respondent stated:

I started weigh-less this week so I can lose weight. I am fat and the doctor told me that the first thing that has to go is the weight (Interviewee 19: female, 72 years old).

The contrasting narratives about weight loss between black and coloured women indicate how culture can impact on self-management decisions such as weight loss. In this particular instance, it seems that a decision to lose weight among these black women would be affected by whether they feel that they can cope with the stigmatisation associated with weight loss or not.

4.3.4.3. Structural factors

The high cost of “healthy food” was identified as a barrier to dietary changes, which indicates that it may be a significant barrier to self-management for patients with diabetes and/or hypertension of lower socio-economic status. Ten participants complained that food was very expensive:

Healthy food is very expensive. I'm getting little money where I work. Sometimes I feel like eating spinach, but spinach there by us, is R6 or R7...and for me that is too much to spend on just one bundle of spinach (Interviewee 10: female, 58 years old).

Additionally:

Healthy food is so expensive. I can't buy it because I have to eat the food with my family...For example, the rice you have to eat when you are diabetic is not cheap (Interviewee 18: female, 62 years old).

Two participants reported that their inability to afford healthy foods was exacerbated by the fact that they were unemployed:

Food is expensive. But I am not working so that makes it worse for me, because I don't have this money to buy this diet that's right for me. So it's very, very difficult

(Interviewee 21: female, 31 years old).

There was also some variation regarding perceptions of the cost of healthy food, with four of the participants being of the opinion that eating healthy was in fact not expensive:

What is expensive? I mean, carrots, cabbage and, potatoes are not so expensive that you can complain: that's an everyday thing that we eat. So if people can stick to that, and maybe just change their veggies for variety. You see most people think that to eat healthy means that you must eat lettuce and all those expensive things like mushrooms and all those green salad leaves (Interviewee 4: female, 54 years old).

Similarly:

It's not expensive to eat vegetables. It's not expensive at all (Interviewee 11, male, 77 years old).

This shows that perception of affordability is something that varies from person to person, depending on their circumstances and their beliefs about what it means to eat healthily. As indicated in the extract above, some patients find it difficult to change their diets because they assume that eating healthily entails eating certain foods, which are inaccessible to them due to availability or cost.

In contrast, there were also some success stories with regard to dietary modification that emerged from the narratives:

I eat a lot of veg now and sometimes I like to buy fish. I always fried the fish but now lately, I don't like to fry it anymore. I don't eat too much salt in my food. And I don't drink coffee anymore. I used to drink it in the morning but I feel that the coffee's not good for me. I'd rather take a cup of rooibos tea in the morning. I want to look after myself; if you don't look after yourself, no-one is going to look after you (Interviewee 20: female, 77 years old).

This variation indicates that there were some patients who were well informed about

how to change their diets in such a way that they did not incur additional costs. They did not therefore regard cost as a significant barrier to modifying their diet.

Other structural factors that participants complained about which made it more difficult for them to adhere to treatment were related to the PHC facilities. For example, the long waiting times emerged as a problem for the participants. One participant who attended Gugulethu CHC stated:

The big problem here is you have to wait all day. Sometimes you don't have food on you and you are diabetic and that is not good. Here you can wait from morning until 4pm or 4:30 pm (Interviewee 13: female, 60 years old).

Similarly, another participant who attended Lady Michaelis CHC stated:

You can have an appointment for ten o'clock but you will only get seen at two. Then you leave at four after you get your medication. But one understands that you are at a government hospital so you have to put your whole day aside for it (Interviewee 2: female, 46 years old).

The above statement reflects that patients often feel that they have no choice but to suffer through the inconvenience of the long waiting times because the public sector clinics are their only option. Participants disclosed that most of the waiting time is spent when waiting to collect medication. One of the male participants who attended Retreat CHC disclosed the following:

The problem is the pharmacy; we take a long time there (Interviewee 1: male, 40 years old).

One participant expressed that he felt that the waiting problem at Retreat CHC was really a reflection of a bigger problem, which was poor administration. He stated:

The problem here is really administrative. For example, it takes too long to get the folders. You have to wait for an hour just to get a folder. Because of that the queues

are long. And the pharmacy is also disorganised. You have to wait for three or four hours for medication and sometimes there is a mix up and you have to come back again tomorrow and wait. This place really needs to fix their administrative problems (Interviewee 6: male, 75 years old).

Such issues of a lack of staff and poor administration are widely recognised as pertinent in the public health system, especially in district hospitals and clinics (Kautzky & Tollman, 2008). However, none of the participants reported defaulting on clinic attendance as a result of these factors.

4.3.5 THEME 5: “I DON’T WANT TO HAVE A STROKE”: A CONTINUUM OF MOTIVATION AND THE POTENTIAL FOR BEHAVIOUR CHANGE

Self-Determination Theory was used to underpin the analysis of both the source and quality of the study participants’ motivation.

4.3.5.1 The sources of motivation

Fear emerged as a significant motivator for some of the participants; this was evident in a number of ways. One way was through having witnessed other people’s experiences with diabetes or hypertension complications. For example:

For me, it’s from seeing other people’s experience. I used to be a nurse and I have seen what diabetes can do to someone. So that has motivated me to take care of myself since I don’t want to end up like that (Interviewee 9: female, 34 years old).

In addition:

I don’t want to have a stroke because they said if you’ve got blood pressure it can give you a stroke so I don’t want to have that... my mother had a stroke, I saw how it was for her and so I don’t want to be on her shoes (Interviewee 4: female, 54 years old).

Another way in which fear was expressed as a motivator was through participants’ own perceived vulnerability to dying from their condition:

I want to look after myself. I don't want to die because I'm still young (Interviewee 14: female, 56 years old).

For another respondent, the implied consequence of her death for her children was a strongly motivating factor:

I don't want to have a stroke; I've got kids; to have a stroke, ooh, I can't put up with that (Interviewee 17: female, 35 years old).

The above quotations indicate that fear can be instrumental in the initiation and perhaps the maintenance of health protective behaviours, such as the uptake of physical activity and dietary modifications.

In contrast, other respondents were motivated by a positive desire to improve their overall health, which indicates that patients are aware of the role of lifestyle modification in achieving general positive health outcomes. For example:

I want to get well. I want to be on top of things. I don't want my health to deteriorate, so for me, as a person, I'm going to try and improve in whichever way it is, whether it's only going to gym once a week or once a month, I'm going to strive to go that route. Um, I'm going to strive to lead the correct lifestyle (Interviewee 2: female, 46 years old).

This patient was also motivated by the need to feel in control of her own life and be active in determining her future health, rather than feeling controlled by ill health or feeling like a victim to the condition.

Supportive social networks were also mentioned as important sources of motivation. For instance, one participant with diabetes stated:

I am part of an exercise group. I started last year and now I go every Thursday. We meet at about 5 pm. I am really happy about joining. We are about 15 and everyone has a chronic illness, so we share ideas (Interviewee 13: female, 66 years old).

4.3.5.2 The quality of motivation

The next step in the enquiry on motivation was to try and understand the quality or type of motivation that respondents had, since SDT argues that lasting results cannot be achieved if they are not underpinned by the “right” kind of motivation (Teixeira et al., 2012). SDT was therefore used in the analysis of the respondents’ motives, in an effort to determine which are likely to sustain long-term lifestyle changes and which are likely to fail.

The study sample was found to be extrinsically motivated. This means that the respondents’ health-related behaviours were initiated for their instrumental value in achieving a consequence separate from the behaviour itself. Since many people were extrinsically motivated, their regulation styles were then analysed using the SDT motivational continuum, which was discussed in detail in Chapter 2.

The least internalised form of regulation is *external* while the most internalised form of regulation is *integrated* (Ryan, 2012). In this study, it was found that four respondents’ motives were *externally* regulated. For example:

I just do what they say on the diet sheet (Interviewee 8: Female, 58 years old).

Fourteen respondents had *introjected* regulation, which is reflected by engaging in behaviours out of a sense of guilt or internal pressure (Patrick & Williams, 2012). Behaviours are autonomous but to a lesser degree because they are not experienced as fully part of the self (Ryan & Deci, 2000). For example:

I am so disciplined because I have my children on my neck (Interviewee 19: Female, 72 years old).

Further, two people had *identified* regulation which is reflected by identifying with the importance or value of behaviour (Ryan & Deci, 2000). For example:

I want to get well. I want to be on top of things. I don't want my health to deteriorate, so for me, as a person, I'm going to try and improve in whichever way it is, whether it's only going to gym once a week or once a month, I'm going to strive to, to go that route. Um, I'm going to strive to, to lead the correct lifestyle (Interviewee 2: female 46 years old).

Lastly *integrated* regulation is reflected by engaging in behaviours because of the internalisation of the reasons for action and full assimilation of the value and utility of the task. (Ryan & Deci, 2000). Overall, two people displayed this form of regulation: An example of motivation that is *integrated* would be the following:

It becomes an everyday thing. At the beginning it's a bit of a nuisance, I suppose, with all these tablets and everything, but after a while, you get used to it. You don't even notice it. When you go into the supermarket, you know you must buy, low fat cheese; you must buy low fat margarine; you must buy, fish instead of meat... (Interviewee 11, male, 77 years old).

This respondent has *integrated* regulation because they have internalised the value of lifestyle modification for health reasons as a personal goal. *Integrated* regulation is the most ideal type of regulation due to the fact that it is similar to intrinsic motivation since behaviour is fully autonomous.

However, behaviour is still extrinsically motivated since it is carried out for its instrumental value, as opposed to being carried out for its inherent enjoyment (Ryan & Deci, 2000). For example, the main reason why the respondent above wants to go to the gym is to control her high blood pressure (she ought to); as opposed to the fact that it is something that she chooses to do because she finds it inherently enjoyable. An intrinsically motivated individual would be someone who chooses to exercise because they find exercising inherently enjoyable and in line with their own values or goals.

CONCLUSION

The study findings highlight that overall; most participants in the study struggled with the self-management of their condition due to various inter-personal, intra-personal and structural factors. The findings also provide insight into some of the facilitating factors to effective self-management, such as positive patient-provider interactions, social support, motivation, and confidence in one's own ability to change (self-efficacy).

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CHAPTER 5: DISCUSSION

INTRODUCTION

This chapter discusses the study findings in the context of Self-Determination Theory (SDT) and the socio-ecological framework proposed for this study, as well as the significance of the findings. The discussion consists of five parts: the first part relates specifically to the elements of the theoretical frameworks; the second part deals with the general implications of the study findings. This is followed by the methodological considerations, the study's strengths and limitations and finally, the recommendations and conclusion.

5.1 THE STUDY FINDINGS IN RELATION TO THE THEORETICAL FRAMEWORKS

Relatedness, along with autonomy and competence, are the three psychological needs that require addressing for the internalisation of protective and preventive health behaviours, so that they can be initiated and maintained over the long term (Deci & Ryan, 2000).

5.1.1. Relatedness

Relatedness is a concept taken from Self-Determination Theory (Ryan & Deci, 2000) and is defined as the need to feel close to and to be understood by others. One of the barriers experienced by patients which emerged from the study was the lack of support or "relatedness" from both family members and health care providers. The study participants reported that they struggled to adhere to medical recommendations, such as dietary modification, because of poor family support on the one hand, and poor patient-health provider interactions on the other. In the health care setting, a patient's response can be significantly influenced by the health professional's relational style and the social climate he or she establishes in the consultation (Rollnick, Miller & Butler, 2008). Support for this view was found in the current study as those patients who were found to be better motivated to modify their lifestyles reported experiencing positive interactions with their health care providers. Conversely, those who had negative experiences with health care providers were found to be less motivated to modify their lifestyles.

According to the theory, a lack of relatedness can alienate patients, prevent them from asking questions and inhibit collaboration between patients and health care professionals for better self-care efforts (Aikens, Bingham & Piette, 2005). Support for this proposition was found in the current study, where some participants reported that they did not feel comfortable in their interaction with health care providers, particularly nurses. Complaints about negative attitudes on the part of nurses were common across all three research clinics. The participants' main concern was that the nurses were very rude to them. Though doctors were praised by most participants for having positive attitudes towards them, some complained that certain doctors did not bother to engage with patients about their condition. If a patient detected this lack of interest, they would hesitate to initiate any interaction themselves, either through a lack of confidence in engaging with an authority figure or because they were considerate of the fact that doctors had very little time for the consultation.

Further, some patients reported an intention to visit traditional healers as a result of their dissatisfaction with the service they received at PHCs, as well as their traditional association with traditional healers. This practice is very common in African societies; studies suggest that problems of relatedness are among the reasons why some patients prefer to consult with traditional healers. For example, Lokita et al. (2013) conducted a qualitative study to explore why hypertensive patients attending Natalspruit Hospital in Gauteng Province concurrently used both traditional remedies and western medicine. The findings revealed that traditional healers were perceived to be readily available, more knowledgeable, and to have more confidence in their medicine, in contrast to nurses and doctors, who were perceived to be either harsh or to completely ignore patients' wishes regarding their treatment.

With regard to family support, studies have shown that support from family and friends promotes adherence by encouraging self-efficacy and optimism, which can buffer the stress of being ill (DiMatteo, 2004; Rosland et al., 2008; Rintala et al., 2013). Accordingly, those participants in the current study who reported making

significant lifestyle changes credited social support for their successes. For example, some participants reported receiving healthy foods such as vegetables from relatives, which helped them to increase their vegetable consumption. This finding supports the point that SDT makes about the importance of relatedness support in the initiation and maintenance of lifestyle changes.

Conversely, family conflict, perceptions of not having supportive family members and lack of shared responsibility for illness management have been associated with poor patient adherence (Nicklett & Liang, 2010; Miller & DiMatteo, 2013; Rintala et al., 2013). In the current study, patients who lived in households where their meals were cooked separately from the rest of the family (the “two pots” situation) reported feeling isolated and struggling with adherence to dietary recommendations. Other studies have also found that family members do not always want to eat the same healthier foods the patient eats and that this can be stressful to the patient and negatively impact on adherence efforts (Gallant, Spitze & Prohaska, 2007; Miller & DiMatteo, 2013).

Another important finding from the study was the participants’ strong need for more time in the consultation, so that healthcare providers could explain their condition to them, as well as give them more guidance on lifestyle change. A lack of counselling can send a message to patients that self-management through lifestyle change is not important (Dennison et al., 2007). Adherence to medication is also unlikely if the illness is not properly explained to patients as they are unlikely to integrate the diagnosis into their identity and learn to accept and manage it with a positive attitude (Dennison et al., 2007).

5.1.2. Autonomy

The concept of autonomy within SDT is used to refer to the sense of choice and experience of willingness in doing something as a result of the integration of values into the self (Deci & Ryan, 2002).

The second barrier to self-management that emerged from the findings of the current study was that some participants experienced very little or no autonomy in relation to lifestyle modification. It was evident from the findings that some participants engaged in health-protective behaviours, such as eating more healthily and taking their medication, merely to avoid being scolded by their doctors or family members, and not because they valued doing so. It was evident that they had not fully integrated the concepts of healthy living into their goals and values.

In terms of SDT, a person will develop and maintain more self-determined motivation when the social environment, whether in the family, community or health service, is “autonomy supportive” (Sliwa, Damasceno & Mayosi, 2013). In the health care context, health care providers can provide autonomy support through the provision of Self Management Support (SMS), which involves providing patient education and engaging in collaborative decision-making (Bodenheimer et al., 2005). The purpose of SMS is to inspire patients to take an active role in their treatment. Collaborative decision-making entails working in partnership with patients to make medical decisions, including whether the patient agrees to take the recommended medication or not and exploring which health-related goals the patient wishes to pursue. The health education component of SMS emphasises an approach where information which is of interest to the patients is provided, thereby allowing for engagement and collaboration (Bodenheimer et al., 2005).

It is, however, clear that in developing countries such as South Africa, primary health care providers may not have the time to provide self-management support since they are usually overwhelmed by high patient loads and limited resources.

5.1.3. Competence for change

One of the recurring themes in the data analysis was the low levels of health literacy among participants and how this negatively affected their competence to manage their condition. Health literacy refers to the extent to which an individual can obtain process and understand the basic information and services needed to make appropriate decisions regarding their health (Keleher & Hagger, 2007). Health

education is the process of assisting individuals or groups to make informed decisions about their health (Glanz, Rimer & Viswanath, 2008). From the participants' accounts in this study, the provision of basic health education on their condition from health care professionals was inconsistent, limited, or in some cases, altogether absent. As a result, patients held misconceptions about the cause of their illness. These misunderstandings about the causes of diabetes and hypertension are likely to play a role in how patients conceptualise their illness. Such conceptualisations are likely to affect the way that self-management is thought about and implemented (Boutin-Foster et al., 2007). For instance, if patients believe that the cause of their condition is medication or foreign impurities in the blood, as some of the participants in this study did, they are likely to be at high risk of non-compliance with medical recommendations, in favour of lay remedies.

Knowledge about the causes of diabetes and hypertension, the rationale for treatment and the recommended strategies for effective self-management are widely accepted as pre-conditions for the effective control of these conditions (Whittemore et al., 2003). For instance, poor knowledge of various aspects of hypertension, such as the meaning of hypertension, and of appropriate target blood pressure has been shown to be associated with poor self-control (Viera et al., 2008). Conversely, some studies have shown that the more knowledgeable patients are, the more likely they are to accept their diagnosis, engage in self-management activities and perceive fewer barriers to self-care (Williams, Freedman & Deci 1998; Nam et al., 2011). Nutbeam (2000) also argues that functional health literacy is one of the critical aspects of patient empowerment and that acquiring knowledge and understanding is the necessary first step in allowing patients to make informed choices and become more active in their own care.

However, there are some patients who may adhere to prescribed medical recommendations and treatment without being aware of the benefits of the specific treatment or recommendations (Nam et al., 2011). This was evident from the current study's findings, where some participants revealed that they strictly adhered to

taking their medication, despite having little or no knowledge of why and how the medication was beneficial. All they did was to merely do as their doctors told them.

In addition to the point above, some patients in the current study recounted how they experienced high levels of anxiety at the diagnosis because they mistakenly believed that such a diagnosis meant impending death. A recent South African study by Mshunqane et al. (2012) reported very similar findings: Patients attending focus group discussions at an out-patient clinic in rural Limpopo also described negative emotional reactions to their diagnosis, believing that fatal complications were unavoidable (Mshunqane, Stewart & Rothberg, 2012). They also displayed a significant lack of knowledge on the role of lifestyle modification in preventing type 2 diabetes complications, and were confused about the chronic nature of the disease, expecting that they could be cured by conventional medicine or traditional remedies. This indicates that it is particularly important for health care providers to ascertain, at the time of diagnosis, what a patient knows or believes about diabetes or hypertension so that they can correct misconceptions that may arise from patients' traditional beliefs that all diseases can be cured by traditional healers if the "correct" steps are followed (Truter, 2007).

A further study, conducted in rural North West Province, also reported a critical knowledge deficit about the causes of type 2 diabetes, and its risk factors (Muchiri, Gericke & Rheeder, 2012). As in the current study, the only area where participants had fairly accurate knowledge was in the area of diet, citing the importance of limited sugar and fat intake, reducing portion size and increasing the consumption of vegetables and high fibre starches. In the current study, participants reported that their knowledge about a healthy diet came mainly from the mass media or their family. Patients in this study, as well as in the study by Mshunqane et al. (2012), raised the need for mass media campaigns to address prevalent misconceptions about, and the stigma associated with, diabetes and hypertension, especially in young people.

5.1.4. Motivation for adherence and lifestyle change

SDT argues that two types of motives exist, namely extrinsic and intrinsic motivation (Fortier et al., 2012). According to the theory, intrinsic motivation, which entails doing something because it is inherently enjoyable, interesting and aligns well with personal values, is the ideal type of motivation for the initiation and maintenance of healthy behaviours (Fortier et al., 2012).

The data in this study illustrated that another barrier was that participants were predominantly extrinsically motivated. During data analysis, the participants' motives were classified according to SDT's motivation continuum (as defined in Chapter 2). The motivational continuum within SDT is built on the argument that extrinsic forms of motivation are not all equal, but instead exist along a continuum (Fortier et al., 2012). Accordingly, participants were found to be extrinsically motivated to varying degrees. For example, most participants were found to have *external* regulation (the least internalised form of regulation) and *introjected* regulation (which is reflected by engaging in behaviours to avoid anxiety or for affirmation). Others were found to have *identification* regulation (personally identifying with the importance or value of the behaviour) and *integrated* regulation (the most internalised form of regulation, as a result of full assimilation of the value and utility of the task) (Ryan & Deci, 2000).

Studies based on the theory have found that the more autonomously motivated an individual is, the more they are likely to show greater persistence in adhering to lifestyle changes (Ryan & Deci, 2000; Shigaki et al., 2010; Ryan, 2012). The current study findings provide support for this proposition, as it was found that patients who were generally *externally* regulated struggled more to adhere to lifestyle changes, whereas those who had *identification* and *integrated* motives struggled less to modify their diets and integrate exercise into their lifestyles. By implication, patients who are intrinsically motivated would not struggle to initiate and maintain healthier lifestyles.

Identifying where patients fall on the motivation continuum, as done in this study, can help health professionals or health promoters understand people's individual psychological needs in order to facilitate the processes of internalisation and integration and thereby foster autonomous motivation. Health professionals can foster autonomous/intrinsic motivation by providing relatedness, competence and autonomy support to patients as discussed above.

5.1.5. Socio-environmental determinants

The basic premise of socio-ecological approaches is that health behaviour and the determinants of health are interrelated (Townsend & Foster, 2011). Factors such as place of residence, level of income, educational opportunities, and type of employment or racial discrimination can have a direct or indirect effect on health status and on people's ability to change or modify their health behaviour (Westmaas et al, 2007). This study's data illustrated that there were factors from the broader socio-environment, which hindered lifestyle modification. There is now a considerable body of research that recognises the importance of social, economic and environmental determinants of diseases and their risk factors (WHO, 2005).

Promoting health is understood to require a more comprehensive approach, which explicitly acknowledges social and environmental influences on lifestyle choices, and directly addresses such factors, alongside efforts to educate and communicate with people (Schulz et al., 2005; Atkinson & Veriava, 2006). These multi-level influences usually impact simultaneously on a single health behaviour, resulting in a need for multifaceted approaches for the promotion of healthy lifestyle behaviours (Fitzgerald & Spaccarotella, 2009). For instance, in the current study, the following factors were perceived as barriers to making healthier food choices: difficulty in controlling impulses/cravings for unhealthy foods, such as sweets (intra-personal); the lack of family support in adopting dietary changes, resulting in being forced to eat different meals from the rest of the family (inter-personal); and a lack of availability and the high cost of healthy foods (structural). It is thus clear that barriers to healthy eating need to be addressed at both an individual and policy

level, as do other health-related behaviours, such as exercise, weight loss and adherence to medical recommendations.

Another significant structural barrier implicit in the findings of the current study was the problem of language discordance between patients and health care providers. Though most participants did not expressly mention this as an issue for them, it was evident from their narratives that there were communication problems with health care providers, which could probably be linked to language. This inference is not far-fetched, considering that South Africa is a multi-lingual society with eleven official languages. Health care professionals often cannot communicate in the patients' first language, making effective education and counselling more difficult (Parker et al., 2012). For these reasons, the involvement of CHWs and health promoters, who speak the local language and understand the immediate cultural context, is an important component in strengthening the health system's response to NCDs (DoH, 2006).

Lastly, the majority of patients reported receiving little or no counselling when they were diagnosed and were not provided with any educational material to take home, besides a diet sheet in some instances. This often led to a misunderstanding of the nature of the condition and the role of medication, as well as a lack of awareness of the potential for effective self-management of the condition through medication and lifestyle change. The inconsistency among participants in the reported dissemination of health information at the various health care facilities could be the result of broader external factors not explored in this study, such as uneven or intermittent distribution of educational resources by the Department of Health.

A multi-centre cross-sectional study, conducted by Parker et al. (2012), at thirty PHC facilities in Cape Town to investigate the availability and efficacy of equipment and of health promotion methods and materials, used by health care professionals in the management of patients with NCDs, provides insight into some of the factors that act as barriers to education and counselling in such PHC facilities. The results of the study showed that barriers to education and counselling include factors such as the absence of health promotion materials within the facility, such as the National

Guidelines for the management of diabetes, due to a lack of awareness by health professionals, as well as patient factors, such as apathy and non-compliance (Parker et al., 2012).

5.2. METHODOLOGICAL CONSIDERATIONS

5.2.1 The role of the researcher

Throughout the research process I kept a research diary, which helped reflect on my own subjectivity and personal biases and idiosyncrasies. I realised that my gender, age, educational background ethnicity impacted on my research.

With regard to my race/ethnicity, the patients and nursing staff expected me to be a Xhosa woman, or at least speak the language, merely because I was black. On most occasions, when I introduced myself in English, I was criticised and even rebuked for not speaking in isi-Xhosa. Interestingly enough, explaining that I did not speak isi-Xhosa, or was not even South African for that matter, did not help my situation. There seemed to be a general aloofness and unwillingness to engage with me amongst some of the isi-Xhosa nursing staff and patients at the CHCs. I was usually met with comments such as “why are you talking like a white person, speak our language” or “what black person cannot speak isi-Xhosa?” and “how do you expect us to talk to you if you cannot speak our language. We don’t like to speak English here”.

These comments came as a shock to me because I never anticipated that my nationality could impact on my research. I took it for granted that having an interpreter would give me easy access to patients and nursing staff at the CHCs, which I later realised was a misconception. I now realise that there is a real possibility that some patients who refused to participate in the study may have done so on the basis that they were not comfortable being interviewed by an “outsider”, and not necessarily because they had nothing to share.

With regard to my educational background, I realised that some participants perceived our interaction as that of “doctor and patient”. I would be asked a lot of

questions at the end of the interviews related to their condition and medication, to the extent that it felt like a consultation. I often had to gently remind the participants of the fact that I had no medical training and to rather seek advice from the nurses or the doctors. Being seen as “more educated” could have also led to other assumptions about who I was or what I expected them to say, which could have impacted on the responses that they gave during the interviews.

Another observation that I made during the research process was that female participants tended to share their experiences more in depth than their male counterparts. I suspect that my age and gender played a role in this “clamming up” of the male participants. From my own cultural experiences, from which I cannot generalise, women or young people (and I am both), do not usually have interactions similar to that of interviews. This restraint from asking too many personal questions is viewed as a sign of respect in many African cultures. Though cultures are transitioning and some of the things that used to be taboo are now accepted, I felt uncomfortable with probing too much, as I was aware of the cultural norms. As a result of these examples, I began to appreciate the fact that my own assumptions and reality, as well as that of the participants’, could influence who was prepared to be interviewed and what emerged in the interviews.

5.2.2 The role of the interpreter

An experienced isi-Xhosa speaking interpreter from one of the local communities, who was paid at an hourly rate, accompanied me to Gugulethu CHC and assisted in situations where participants preferred to speak isi-Xhosa during the interview, or in cases where they were willing to speak English, but at times struggled to express certain things. Before the start of the interviews, I clarified with the interpreter what her role would be in the interview process. Role clarification between the researcher and the interpreter is important, so as to avoid instances where the interpreter takes an active part in the research process, such as asking their own questions or deciding which spoken material from the participant is relevant and which should be left out (Murray & Wynne, 2001). In this study, the interpreter was requested to stay as close as possible to the words of the participants and not to interpret or give meaning to

what the participants told her. The interpreter was also requested to seek advice from the researcher if unanticipated issues arose, rather than to formulate questions of her own.

Interviews at Lady Michaelis and Retreat CHCs were conducted without an interpreter, since all the participants were of coloured descent, and were fluent in English. When I conducted the interviews myself, I realised that it was easier for me to build rapport with these participants because I was able to use small talk to put them at ease. This was unlike the interviews at Gugulethu CHC, where, because there was an interpreter, I felt limited to just asking questions. I also felt more in control of the interview process when I conducted my own interviews in English, unlike in the interviews where I used an interpreter. This was because I had no way of knowing if the interpreter was telling me everything that the participant was saying and how much was exactly what the participant said and meant. According to Murray & Wynne (2001) an interpreter from the same ethnic community may be selective in their translations if they feel a need to protect that participant or community from potential harm. This may have imposed limitations on my ability to fully explore issues with respondents at Gugulethu CHC

5.3. STUDY IMPLICATIONS

In conclusion, major public health goals have been achieved through the adoption of comprehensive programmes. For example, the iChange4 health project¹⁶ was launched as a joint initiative by the Chronic Disease Initiative in Africa (CDIA) and Pharma Dynamics, South Africa's largest supplier of cardiovascular medication, to help South Africans change their unhealthy lifestyles and reduce their risk of developing NCDs. Since the pioneering of the project in 2012, a series of helpful motivational booklets have been produced. These provide information and guidance on health care issues, and also showcase people who have changed their unhealthy habits. In addition, an iChange4 Health manual has been developed for use by doctors and other health professionals; this offers evidence-based guidelines on how

¹⁶ <http://www.ichangeforhealth.co.za/index.php/about-ichange-for-health/>

to establish a non-threatening, supportive environment, in which patients can discuss health behavioural issues (Everett-Murphy, Mash and Malan, 2013).

5.3.1. The potential role of health care providers in promoting self-care

Health care providers have been identified by the Department of Health as playing a particularly important role in encouraging and supporting their patients to make and maintain healthier lifestyle choices, given the potential for prevention and management of NCDs, particularly at the primary health care level (DoH, 2013; Everett-Murphy, Mash and Malan, 2013). There is now ample evidence to show that brief behavioural change by health care providers can be effective in changing NCD risk behaviours and improving self-management among patients with existing chronic conditions (Whitlock et al., 2002; Everett-Murphy, Mash and Malan, 2013).

Health care providers, who succeeded in adopting a more patient-centred approach when discussing lifestyle changes, reported that it elicits favourable responses from patients, improves the efficiency of the consultation, enhances perceived quality of care and is considerably more personally rewarding (Maguire & Pitceathly 2002; Stewart, 2005; Rollnick, Miller & Butler, 2008;). However, from the provider perspective, there are a number of common barriers to the provision of patient-centred NCD care and health promotion. These include the fact that health care providers often lack the time to discuss things with patients, that they lack the requisite communication and counselling skills and that the organisation of health care systems is generally unfavourable to patient-centred care.

Additionally, providers of health care cite a lack educational resources and aids, and frustration with patients' non-adherence as barriers to the provision of lifestyle-change counselling to chronic patients (Whitlock et al., 2002a; Parker et al., 2010; Parker et al., 2012). Mshunqane et al. (2012) also reported that healthcare providers were concerned that the long and frustrating waiting times in public sector clinics negatively affected patients' attitudes towards them.

In-service training and ongoing support has been shown to be effective in overcoming some of these barriers. The inclusion of training modules in the curriculum of trainee doctors, nurses and allied health professionals is also important (Emmons & Rollnick 2001; Whitlock et al., 2002b). Training can teach communication skills, change attitudes about the delivery of lifestyle interventions, as well as the style of interaction in behaviour change consultations (Emmons & Rollnick 2001; Everett-Murphy et al., 2010).

However, clinician training has a limited impact on practice if there is no follow-up support and feedback; and when it is not accompanied by strategies which support making behaviour counselling an integral part of routine care (Kinect Australia for the Lifescripts Consortium 2005; Royal Australian College of General Practitioners & Harris, 2005; Harris, 2008). Strategies which increase the uptake of behaviour change counselling by healthcare providers include: risk assessment tools and prompts, patient educational resources and organisational strategies, such as the developing a strong teamwork approach and developing referral linkages, with allied services and community resources (Kinect Australia for the Lifescripts Consortium 2005; Royal Australian College of General Practitioners & Harris, 2005; Harris, 2008).

Given the acute staff shortages and growing numbers of NCD patients seeking public health sector services, allowing sufficient time for interaction with patients is likely to remain a significant barrier. However, on a positive note, health care providers in South Africa express a strong desire for better opportunities for health promotion and see this as critical in improving the quality of care for patients with NCDs (Mshunqane, Stewart & Rothberg 2012; Parker et al., 2012). Nurses, doctors and health promoters working in the public health services have also responded very positively to training in MI and patient-centred, brief behaviour change counselling approaches (Mash & Allen, 2005). In addition, the Department of Health remains committed to a patient-centred approach to care, which emphasises the importance of engaging the patient in decision-making about their health (DoH, 2013; Everett-Murphy, Mash and Malan, 2013).

Furthermore, the national Department of Health, recognising the failures of the current level of NCD care, is currently considering the implementation of the WHO Innovative Care for Chronic Conditions Framework (Beaglehole, 2008). This model proposes the separation of chronic care from acute care services and the integration of care for all chronic conditions, including NCDs, HIV and TB. This makes a great deal of sense in the South African context, as there are high levels of co-morbidity of these different chronic diseases would allow for a more optimal utilisation of limited resources and there are many lessons to learn from the considerable successes and strengths of local antiretroviral therapy (ART) programmes (Levitt et al., 2011).

The present findings may provide health care professionals and health promoters with a better understanding of patients' explanatory models of illness, of factors that impede or facilitate self-management behaviours, as well as their motivation for behaviour change. This data can be used for planning education programmes and interventions that could encourage autonomous motivation for self-management in diabetic and/or hypertensive patients in other similar settings.

5.4. RECOMMENDATIONS

Actions to improve the control of NCD-related risk factors and the management of chronic conditions should include:

- Utilising CHWs in the planning and implementation of interventions to enhance accessibility, sustainability and cultural sensitivity.
- Conducting participatory research, which investigates what kind of interventions are feasible, acceptable and cost effective in the current context and what organisational changes are required to accommodate and upscale them.
- Conducting further qualitative research in order to investigate the views, experiences and perceived needs of both patients and health care providers.

- Planning and implementing structural interventions to alter the physical, social, economic, and regulatory environments to support the adoption and maintenance of health behaviour.
- Training health care providers in innovative approaches, such as Motivational Interviewing (MI) and/or Self-Management Support (SMS) techniques, to enable them to create a non-threatening, supportive environment for patients, in which to discuss health behavioural issues, particularly at the PHC level.
- Tailoring health education materials to audiences of low literacy by writing them in simple plain language.
- Implementing policies which ensure that healthier food choices are made available and affordable.
- Using mass media, for example radio and TV programmes, to provide health education to people with low literacy, especially those who are unable to read and write.

5.5. STRENGTHS OF THE STUDY

One strength of this study is that patients' experiences of living with diabetes and/or hypertension were examined in detail and in-depth. To date, very little data exists on this topic in sub-Saharan Africa. By using individual in-depth interviews to collect data, participants were given a voice, allowing them to share their experiences of living with an NCD from their perspective.

5.6. LIMITATIONS OF THE STUDY

Several limitations deserve mention. Firstly, the small convenient sample used in this study may not be representative of the population, thus limiting the generalisability of the results. However, findings can be useful in other settings, i.e. health care providers from other PHC facilities can use the findings of this study to plan education programmes and to design lifestyle modification interventions. Secondly, the study relied on self-reported data, which can be a source of biases, such as social desirability and selective recall.

Notwithstanding the limitations described above, steps were taken to enhance the trustworthiness of the study findings. Measures to ensure trustworthiness that were used in this study encompass the following concepts: credibility, transferability, and dependability. Credibility refers to confidence in how well data and processes of analysis address the focus of the research (Graneheim & Lundman, 2004). In qualitative research, credibility can be enhanced through strategies such as triangulation, member-checking, and peer examination (Krefting, 1991).

Triangulation entails using different data sources to increase confidence in data (Guion, Diehl & McDonald, 2011). This strategy minimises distortions from a single data source or from a researcher's bias (Krefting, 1991). Member checking entails continually restating and summarising information during interviews and then questioning the participants to determine accuracy (Harper & Cole, 2012). This is a way to ensure that the informants' viewpoints are accurately translated into the data (Harper & Cole, 2012). Peer examination or peer review involves discussion of the research process and findings with impartial colleagues, who are experienced in qualitative research (Merriam, 2009).

For the current study, member checking and peer examination were used to enhance credibility. During the interviews, I made sure that I restated and summarised what the participant had said to me. This gave the participant an opportunity to agree or disagree with me, thus ensuring that the data reflected their views as opposed to my own. I also conducted ongoing presentations and discussions of categories and themes, developed from the data, with the thesis supervisors, fellow students and colleagues at the Chronic Disease Initiative in Africa unit.¹⁷ This was done to ensure that unanticipated topics and discrepancies that emerged from the data could be discussed and fully investigated.

Dependability refers to the extent to which findings can be transferred to other settings or groups (Graneheim & Lundman, 2004). This can be achieved through the provision of detailed background information on the study participants and the

¹⁷ <http://www.medicine.uct.ac.za/news/chronic-diseases-initiative-africa>

research context and setting (Krefting, 1991). According to Lincoln and Guba (1985, cited in Krefting, 1991:221), the qualitative researcher has a responsibility to provide adequate information about their study to allow for assessment by others, who can then decide how transferable the study's findings are. In terms of the current study, transferability was enhanced through the provision of detailed descriptions of the study participants' characteristics, the study context, as well as of the data collection and data analysis processes.

Another strategy used to enhance dependability is that suggested by Guba (1981, cited in Krefting, 1991:221), which is to carry out a code-recode procedure during data analysis. In such a procedure, the researcher codes a segment of the data and revisits it again after a short time period has elapsed, such as a week or two, and then recodes the same data and compares the results. This procedure was followed in the current study.

5.7. FINAL CONCLUSION

NCDs and their risk factors are becoming more common in South Africa as rates of urbanisation increase. Currently, patients with NCDs attending public sector health care services seldom receive an adequate level of care in terms of medical management, health education or lifestyle counselling. Accordingly, far too few patients are achieving adequate levels of control (Levitt et al., 2011).

The findings of this study are reflective of this situation, with patients clearly expressing a need for more support and guidance from health care providers in managing their chronic conditions. Although behaviour change is difficult and individual choices are influenced by broader social, cultural and environmental factors, there is much evidence to show that health care providers can play a vital role in motivating patients to adhere to treatment and to modify their health behaviours, with a consequent impact on health outcomes (Kinect Australia for the Lifescripts Consortium, 2005). This was illustrated in the current study findings when some patients spoke positively about their experience with health care providers and expressed the motivation to modify their lifestyles. This implies that

providing training to health care providers which would enable them to motivate patients with NCDs to make lifestyle change, particularly at the primary health care level.

Finally, although this study was qualitative and did not empirically test SDT, the model's constructs of competence, autonomy and relatedness were found to be workable and valid concepts in exploring and understanding patients' motivation. There is an established empirical basis for the use of this theory, which demonstrates the theory's utility in predicting expected behavioural outcomes in terms of diet, physical activity and weight loss. The findings of this study add support to the usefulness of the model in shaping behavioural interventions, which target the promotion of healthy lifestyles to diabetic and hypertensive patients.

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APPENDICES

APPENDIX A

PARTICIPANT INFORMATION AND INFORMED CONSENT FORM

TITLE OF RESEARCH PROJECT: A qualitative study on diabetic and hypertensive patients in Cape Town, South Africa: their experiences of primary health care and their struggles with self-management

Researcher who can be contacted:	FHS Human Research Ethics Committee
University of Cape Town Thandi Chuma Chronic Diseases Initiative in Africa (CDIA) Dept of Medicine, UCT Tel: 021 4042129	Faculty of Health Science Human Research Ethics Committee Room E52-24 Groote Schuur Hospital Old Main Building Observatory 7925 Tel: 021 4066626 Facsimile: 021 4066411 e-mail: shuretta.thomas@uct.ac.za

Dear Sir/Madam

We would like to invite you to participate in a research study on chronic diseases. We know from research that many people in South Africa suffer from chronic diseases of lifestyle such as diabetes and hypertension (high blood pressure). These are very serious diseases that cause many problems for those who have them. The positive aspect about these diseases is that they can be prevented and well managed if one knows what to do.

The Chronic Disease Initiative in Africa at the University of Cape Town is conducting research with patients with chronic disease to explore their experiences of living with the condition and how they grapple with lifestyle changes.

Are there any benefits for you if you take part in this study?

- There is no direct benefit for you. But the information that you give will help the researchers to develop the best possible education tools. This will help make sure that South Africans stay healthy as they grow older and have a reduced risk of getting chronic diseases.
- Your participation is voluntary

There are a few other very important things that we would like you to know:

- The information we get from you will be strictly confidential. Only qualified researchers and, if necessary, somebody from the ethics committee may handle the information.

- If you decide to take part in this study, you are still free to withdraw from the study at any time; it does not matter what the reason is. This will not count against you in any way.
- If you decide to take part in this study, you will be required to set aside some time so that you can be interviewed at the clinic. The interview session on your experience of living with a chronic disease will last for an hour. This is to ensure that you have enough time to give an in-depth account of your experiences at home and at the clinic.
- The interview will be conducted in a private room at the clinic, and only the researcher and an interpreter (should you require one) will be present to ensure that the process is as confidential as possible.
- No action will be taken against you, no matter what they say, unless a criminal or abusive act is being planned.
- Recordings and transcripts will be held in a safe place, preferably on a password-protected computer.
- Information will be confidential and personally identifying material will be removed from all quotes used.
- Permission will be sought from you to tape record the interview.

If you have any questions about the study please feel free to speak to the researcher. Her contact details have been provided at the top of this consent form. If you have any concerns about the study, or any questions regarding your rights and welfare as a research subject on the study, please feel free to contact the Faculty of Health Science Human Ethics Research Committee. Their contact details have been provided at the top of this consent form.

If you would like to participate in this research, please fill in the attached form.

Participant consent:

Please sign below if you consent to participate in the study.

I (Your full name and surname) give informed consent to participate in this study on chronic disease and healthy lifestyles. I have read and fully understand the information about the study.

Signature of participant:

DATE:

.....

.....

Witness:.....

.....

APPENDIX B

CONSENT FORM TO BE AUDIO-TAPED

AUDIO-TAPED INTERVIEW

I hereby give written consent to be interviewed by Thandie Chuma. I understand that the purpose of the interview (which will be audio-taped) is to discuss my experience of living with a chronic disease (diabetes/hypertension). I also understand that my personal story may be used to inform the development of a training module for primary health-care providers' in brief behavioural change counselling, as well as to inform the development of patient education/motivation materials on NCD risk behaviours by the Chronic Disease Initiative in Africa (CDIA).

Signature of participant..... **DATE:**

Witness: **DATE:**

APPENDIX C

QUESTIONNAIRE ON DEMOGRAPHIC DETAILS

Please tick boxes and fill out in detail where necessary. Thank you.									
Please tick the box of your age.		21-35		36-50		Older than 50			
Please fill in your contact number.		Mobile:				Home:			
Male		Female							
Which schooling did you complete?		Primary school		Junior-High school		High-school		Higher education	
Are you employed? If yes, please specify:									
Which public clinic do you attend?									
Please describe your diagnosis.									
When were you diagnosed?									

APPENDIX D

INTERVIEW SCHEDULE

1. What led you to come to the clinic (symptoms)?
2. Tell me about your experience of the visit where the doctor told you that you had a chronic disease of lifestyle:
 - What do you remember about that day?
 - Did you expect the diagnosis that you got?
 - How did it make you feel?
 - What did the doctor discuss with you after the diagnosis?
 - What advice did they give you (detailed)?
 - Did you receive any HE materials?
 - Did anyone else besides the doctor give you advice on how to manage this disease?
3. What is your own understanding of this disease? (Hypertension/diabetes, or both, if participant has both).
4. Did anything change for you after receiving the diagnosis? (describe what you changed and how you changed and why you made these changes):
 - Your understanding of the disease;
 - Your relationships;
 - Your activities;
 - Your beliefs/attitude about diet.
5. Was a lifestyle change important to you and why? (a lifestyle change can include a change in diet, increased physical activity, smoking cessation, cutting down on alcohol, etc.).
6. When did you get the motivation to change (if you did make any changes)?
 - What motivated you to change (look at extrinsic/intrinsic motivation)?
 - What difficulties did you experience when trying to change?
7. Since your diagnosis, how has your experience of coming to the clinic for medication or follow-ups been?
 - How do you feel about the way the sister/doctor communicates with you?
 - Have you received any HE material?
8. Do you have any preferences in terms of how to receive health education?
9. What advice would you give to someone who is newly diagnosed?

APPENDIX E

STUDY BUDGET

Items of expenditure		Unit	Unit cost	Total cost
Recruitment and implementation of in-depth interviews (30 people)				
Transport costs				
Petrol 1 600 kms	km	1 600 kms	R 1.41	R2,256
Incentives (30 people)	Food vouchers	30	R50	R1500
Training course in Qualitative methods Short course at the University of Stellenbosch				
	Course fee			R2200
Admin:				
Printing of questionnaires and consent forms				R0
Pencils and stationery				R0
Telephone and SMS costs			R 1,000	R1000
Interpreter (Xhosa)	hours	(7hrsx4days)	R50	R1400
Transcriber	hours (4hrs per recording x15)		R60	R3600
Analysis	covered			R 0
				R 0
Write up	covered			R 0
Sub-total				R11956

APPENDIX F

ETHICS APPROVAL



UNIVERSITY OF CAPE TOWN

Faculty of Health Sciences
Faculty of Health Sciences Research Ethics Committee
Room E52-24 Groote Schuur Hospital Old Main Building
Observatory 7925
Telephone [021] 406 6338 • Facsimile [021] 406 6411
e-mail: sumayah.ariefdien@uct.ac.za

04 July 2012

HREC REF: 321/2012

Dear Ms T Chuma
c/o Dr K Murphy
Chronic Diseases Initiative in Africa
J-47 Rm86
OMB

Dear Ms T Chuma

PROJECT TITLE: CHRONIC DISEASES OF LIFESTYLE: DOES A DIAGNOSIS PROMPT BEHAVIOURAL CHANGE TOWARDS A HEALTHIER WAY OF LIFE?

Thank you for addressing the issues raised by the committee.

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

Approval is granted for one year till the 28 July 2013.

Please submit a progress form, using the standardised Annual Report Form (FHS016), if the study continues beyond the approval period. Please submit a Standard Closure form (FHS010) if the study is completed within the approval period.

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

Please quote the REC. REF in all your correspondence.

Yours sincerely

PROFESSOR M BLOCKMAN
CHAIRPERSON, HSF HUMAN ETHICS

Federal Wide Assurance Number: FWA00001637.
Institutional Review Board (IRB) number: IRB00001938

sAriefdien

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

The Research Ethics Committee granting this approval is in compliance with the ICH Harmonised Tripartite Guidelines E6: Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95) and FDA Code Federal Regulation Part 50, 56 and 312.

sAriefdien

APPENDIX G

DEPARTMENT OF HEALTH PERMISSION



STRATEGY & HEALTH SUPPORT

healthres@pgwc.gov.za
Tel: +27 21 483 9907; fax: +27 21 483 9895
1st Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: RP 94/2012
ENQUIRIES: Ms Charlene Roderick

Obz Square Residence
Room 5060
Corner Main Road and Penzance Street
Observatory
7929

For attention: Thandie Chuma

Re: Chronic diseases of lifestyle: Does a diagnosis prompt behavioural change towards a healthier lifestyle

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 the following people to assist you with any further enquiries in accessing the following sites:

Retreat CHC Mr H Lemmetjies 021-712 5105

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 report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pgwc.gov.za).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely,

DR NT Naleai
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 19/12/2012
CC DR K GRAMMER

DIRECTOR: SOUTHERN / WESTERN

Page 1 of 1

APPENDIX H

DEPARTMENT OF HEALTH PERMISSION

28/09/2012 09:30 0214839895

FINANCE

PAGE 01/01



STRATEGY & HEALTH SUPPORT
healthres@pgwec.gov.za
tel: +27 21 403 9907; fax: +27 21 483 9895
1st Floor, Norton Ross House, 0 Kieboek Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: RP 94/2012
ENQUIRIES: Dr Sikhumbuzo Mabunda

Old Main Building
Groote Schuur Hospital
Observatory
7925

For attention: Thandie Chuma

Re: Chronic diseases of lifestyle: Does a diagnosis prompt behavioural change towards a healthier lifestyle.

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 the following people to assist you with any further enquiries.

Lady Michaelis CHC	Sr Weavers	(021) 797 8171
Gugulethu CHC	Dr K Murie	(021) 460 9100

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 report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pgwec.gov.za).
3. The reference number above should be quoted in all future correspondence.

Yours sincerely

DR N. JUREN
DIRECTOR: HEALTH IMPACT ASSESSMENT
DATE: 27/9/2012

CC	DR G PERPZ	ACTING DIRECTOR: KLIPFONTEIN/MITCHELLS PLAIN
	DR K GRAMMER	DIRECTOR: SOUTHERN/WESTERN

APPENDIX I

TIME PLAN

ACTIVITY	March 2012	April 2012	May 2012	June 2012	July 2012	August 2012	Sept 2012	October 2012	Nov 2012
Draw up protocol and interview schedule									
Submit o UCT Ethics									
Obtain permission from Western Cape Health Services									
Training in data collection & Qualitative methods									
Piloting of interview schedule under supervision									
Data collection in the field									
Transcription									
Data Analysis									

ACTIVITY	Feb 2013	March 2013	April 2013	May 2013	June 2013	July 2013	August 2013	Sept 2013	Oct 2013	Nov \ 2013
Data analysis										
Write up of thesis										
Write up of article										
Presentation of thesis										

APPENDIX J

EXAMPLE OF INTERVIEW TRANSCRIPT VOC 121016-0034

Speaker key

IV Interviewer
IE Interviewee

IV Okay, um, thanks again C for agreeing to do this interview. Um, before I start I'm just going to ask you to just tell me a little bit about yourself, um, ja, and why you came to the clinic today?

IE My name and everything or...?

IV No, no, like, just a little bit.

IE Okay, the reason why...

IV yeah, your name and, and, um, what you do...

IE Okay.

IV Well maybe not your name...

IE Ok. I am 53 years old, born and bred in Cape Town. I've got two kids but they're adults, [unclear] and one grandson who are four years old and I'm working as an office administrator, okay. The children are also employed. The reason why I came here, I was diagnosed in 2006 that I've got high blood pressure because my son was shot in 2006. Then maybe I couldn't take it. So, I don't know the reason why I didn't cry and I didn't go for counseling. So, then afterwards it worked on me. So that's why I have blood... [sighs], high blood pressure.

IV Okay, okay, so, um, I just hope you don't mind that in between I'll just be, you know, doing a little bit notes.

IE No, it's fine.

IV Don't let it distract you.

IE Hm-mm, no.

IV Yes, okay, um, okay so now let's go back to 2006.

IE Mm,

IV Um, so tell me about what you remember about, you know, that day when you ended up being at the hospital, the clinic and the doctor is telling you that you have high blood pressure? So, before you, you went, um, to the clinic, or hospital, what, what led you to go?

IE Oh, okay, okay. I had a bad pain at my back on my right hand so I couldn't lift my hand, I couldn't do anything. So, when I came here, and then the doctor said to me, he gave me some, he treated me that day and then she said I must come the following day and that day my blood pressure was 168.

IV Mmmmmm.

IE So, she said I must come back the next day. So, when I came back the next day, it was also high and then she told me that I must go to the club. So and I ask, I thought maybe it was only for that moment that, because I had pains and I didn't sleep well, I thought maybe it's because my blood pressure is for that day. Apparently no, the nurse told me no, I have to go... come to clubs; it's a chronic and I can feel it sometimes. My... actually, I didn't accept it. I didn't want to believe that it's me who's got high blood pressure because I'm not that person who takes everything up and worries a lot, so I thought, ah-ah; I took those tablets, was given a date that I didn't come. I told myself, [clears throat], sorry, I'm not going to accept it, it's not me, I don't have high blood pressure. Then as times goes I can feel my head, like it's a heavy, heavy feeling; it's not painful but it's heavy. There's something that sometimes I get dizzy, and then I came back and that I was told that no, [clears throat], sorry, after two months I came back and I was told that my blood pressure was high. Then I was told that I had to take a medication because I am suffering from high blood pressure so that is when I started to take it.

IV So, um, you, you, mentioned that, um, you know, you...

IE [Clears throat].

IV found out that, you know, you have high blood pressure and it's, it's chronic, um, so, I mean, can you please just, um, ah, explain that for me. You know, what, what, what does, what does chronic mean?

IE Something that you'll die with. It won't be taken away. You will take that medication until you die. That's what I understand, I don't know if it's right or wrong.

IV So, um, so, you know, the first time, um, you... the doctor said that, ah, you have high blood pressure, do you remember any... did you guys talk about anything else?

IE Hm-mm; he didn't say anything to me; he said go to the club, come back tomorrow and then I came back to see her tomorrow and then said to me, go straight to the club.

IV And then at the club, did you, um, did they tell you anything?

IE Mm-hm, mm-hm. Usually they don't tell you much. You just have high blood pressure.

IV Okay, so, um, when you, you mentioned that, you know, there was a point when you just didn't accept that, ah, you have high blood pressure.

IE Mm-hmm.

IV So, when you, during that time, um, when you were, you know...

IE Diagnosed..

IV In complete... when you were just like, this is not happening to me, um, you know, what other feelings, you know, were you experiencing at that time?

IE I started to feel, like, this heavy pain, and this heavy headache. Sort of, my head... I don't like, I don't have that, the normal headache. Oh, my head it's painful but ha-ah, it was something that, I'm carrying a heavy burden or heavy stone on my head. That's what I've experienced. And sometimes I'll forget; those are the two things that, ah, I've experienced ne. Now, I'm very forgetful. Maybe I must accept it because I also asked people, how is there high blood pressure? How do they feel with high blood pressure and people said the same symptoms that I've got. I said, ag, let me go for it and accept it.

IV So, on your second, you know, the second time now that you came back to the doctor...

IE Mm.

IV Um, you know, what did you guys talk about now, that visit when you know, you were ready to accept?

IE Mm-hm, I wasn't told; they just mos look at the folder.

IV Mm-hm.

IE It's there only for this that is all. [Laughs]. They write.

IV But do you know what they are writing?

IE They're logging the medication; that is all.

IV So...

IE Like they don't lecture you about the right blood pressure and tell you some disadvantages. Sometimes, only now, maybe it's two years back where the, at the club [?], they lecture us now, they're telling us what is going on and ah, what you must eat, what you must not eat and all that. Otherwise they wouldn't tell us.

IV Mm, so do you mind sharing with me, you know, that information that they, they, they give when, um, I'm asking at the club?

IE Mm.

IV Ja, what, you know, what sort of, information do they give you. What exactly do they say you shouldn't eat and you should eat and, you know?

IE Like red meat, you mustn't eat spicy food, you mustn't eat, mm, those who take alcohol mustn't take alcohol, what else....and gas drinks. You can have, you can eat but you must limit yourself. You mustn't overdo the things. Like the meat even but I like meat; especially the red meat, they say it's dangerous. You should choose chicken and veg [?] but not a lot of it. Fatty foods ooh, [inaudible]. You must try and boil the things like your fish; you cook it instead of frying it. See, most of the things must boil and your veggies, you boil them instead of frying them with oil.

IV So, on the topic of food, um, how, how do you eat? Do you notice a difference between, um, the way you... the types of food you ate before you were diagnosed and the food that you eat now?

IE I actually eat the same food but have taken some out like, the oil. I don't use oil.

IV Mm.

IE And with my veggies, I don't use oil; I use water. But the food there is no change...

IV So, um, you know, can you, you know, tell me a little bit more about, that you say there's no change, um...?

IE Like, I used to fry my meat with oil, I used to, like if, my cabbage, I used to fry it with oil. I used to use oil for most of my veggies but since then, now, I don't use oil anymore. I don't cook with oil.

IV And when did you start to make these changes, you know, cutting down the oil?

IE You know, after I was diagnosed, I was told, you know, sometimes when you've got something, you do also your own research and I [unclear] and I like to read then, oh, when I read all this about hypertension and all that and I see all this; I mustn't do this, I mustn't do that. [Unclear]. If I see something saying about hypertension, I will take it and I will read it. That's where I got most of the information.

IV So, um, you know, so just tell me about that experience of, of, you know, diet.

IE [Clears throat].

IV You know, during the past six years, how have you, you know, um, been working, um, how have you been dealing with, you know, the diet change and, and, adapting to, you know, the food that you should eat and the food that you shouldn't eat. How has that experience been for you?

IE Mm-hm, it was not a difficult thing to do, ah-ah, that's just, because I told myself, I've got this chronic disease now, I have to accept it so I must do that ABCD for instance otherwise nothing.

IV Well, some people, you know, that I've spoken to have, you know, emphasised on how difficult it is, you know, to change your diet so what would you say to that?

IE Mm, you have to tell yourself, this is what I'm going to do now and I have to do it. You must use a [unclear], then you know. If I'm not going [unclear] I'm going to do it like that. Then I told myself that I'm going to cook like this, then, [unclear]. I told everybody at home, this is how we are going to eat now. So, everybody accepted it so, it's just to tell yourself.

IV So, everyone just accepted it without... any complaints, nothing?

IE Ja, mm-hm, the first thing must be you, [laughs], inside you. I said, okay, like you are going to change, I'm going to change. Now, you tell yourself that I'm going to change, then it's easy because you already told yourself.

IV So would you say that you... you've changed?

IE Ja, I've changed my diet. I mean, I've changed, even my blood pressure is never high or low or what. The doctors always say its fine, it's good. I don't have like, up and downs and all of that.

IV And, and, um, so, I know you mentioned that you don't use oil anymore. So, what else have you introduced in, you know, in your diet? Is there anything you are eating or anything you are not eating specifically?

IE Mm, I'm eating a lot of veggies.

IV Mm.

IE That's good [inaudible] there's a veg; I make sure that I've got veggies every day.

IV So, when it comes to that, um, you know, once again, a lot of people, you know, say, we would like to eat healthy but healthy food is expensive. So, what do you have to say about that?

IE Ah, not really.

IV Mm.

IE What is expensive?, I mean, carrots, um, cabbage and, ah, potatoes, they're not so expensive that you can, that's an everyday thing that we eat. So if they can stick on that or maybe they change their veggies and all that. You see people they like, maybe they think to eat healthy you must eat lettuce and all those things, mushrooms and all those green salad leaves; [laughs], that is diet.

IV So, what is diet?

IE Mm?

IV What is diet?

IE Ha, you can eat everything but you must eat less; you've got to understand. You can eat, you can eat your, maybe eat your potato salad but you must eat less. You mustn't make you a full bowl of potato salad. You understand, bowl full, ah-ah; you eat, but less.

IV So, you mentioned that, um, you have a family, um, you have children. So, you know, how has your chronic illness impacted, you know, you on, on, on the family level? You know, was there any?

IE You know, I'm not that kind of, person you will just see getting weak and all that. Someone else might not notice that I am like that. I'm not that person always sleeping and do all those things when I've got something that is painful, unless it's really painful then I will lie in bed; otherwise, because I manage, [phone rings], sorry, excuse me. [Xhosa]. Sorry, sorry about that. Where were we?

IV How, if there's been any impact on the family?

IE Ah-ah, no, ah-ah, hm-mm because they also, they instead they made a joke of it, [laughs]. That time, were you really joining the club? That was [unclear] because

I didn't look like somebody you see who's got high blood pressure. I never lie down with my high blood pressure. I never had an emergency that my doctor said that my blood pressure's high and all that, ah-ah.

IV Do you have any family member that has a chronic disease or is this your first experience with...?

IE No, my brother's got blood pressure, high blood pressure and my sister was only diagnosed last month; my eldest sister.

IV Mm.

IE But my eldest brother has been diagnosed, I don't know when but it's, the three of us, its hypertension, high blood pressure. No sugar diabetic, nothing.

IV Um, so, um, so when it comes to, you know, your children and you said that no-one complained, you know, when you changed the way you cooked, no-one really complained.

IE Mm.

IV But do they understand, you know, do they understand what it, you... that you have high blood pressure and what it means?

IE Mm.

IV And what causes high blood pressure?

IE Mm, because sometimes when I've got a fight with my son, my son will say he can't argue with me and he says no mummy, don't worry about me, don't stress yourself otherwise your high blood pressure is going to be high so which means he understands; he knows. He says, don't worry about me man, look after yourself otherwise your blood pressure is going to be high.

IV Mm.

IE You see. But you know mos, you worry us a lot. [Laughs].

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IV Um, so is this, in terms of, you know, what, what motivates you, you know. You said that, you know, you make this change in your life and you've been able to maintain it for the past six years, so what is it that motivates you every day to keep, um, managing and controlling your high blood pressure?

IE [Clears throat], sorry, you know, most of, I don't want to have stroke because they said if you've got blood pressure it can give you a stroke so, that, I don't want to have. What else, mm? Those are the things that make, motivated me to eat

healthy; stroke, heart attack, and what else? Because my mother had a stroke, I saw how it was and so I don't want to be on her shoes. So I told myself, ah-ah, if they say I've got this high blood pressure [unclear] because my mother also had a stroke because of that.

IV So was the stroke related to...?

IE Mm, high blood.

IV High blood. Okay, so, um, any other things that motivate you?

IE Mm, weight loss also, because I was more than this so I had to reduce my weight. That also; weight control.

IV So, um, when it comes to, now it's just, um...

IE [Xhosa], [laughs].

IV talk about your experience at the clinic. Um, so, have you been coming here for a long time now so what would you say, you know, ah, you experienced something with the sisters and the doctors?

IE You see, but now it's better than it was when I started here because before when they used to call you and you followed up, they would just look at your medication and write down and then you go back, go... they say go to the pharmacist. But now, at least they ask you, is there anything that you have, maybe something wrong with you and all that. At least now, on these past two, three years, it's better because before they used to take you folder and drink your medicine and go. They gave you the same the medicine. They wouldn't even ask you, if you say no, doctor I've got this, they say no, come another time for that. They don't even... they didn't even ask you, how are the, how's the treatment, um, taking you or maybe do you have any experience, ah, disadvantages about the tablets that they're giving you. Even not asking all those things but now they do ask you, so.

IV And then just in terms of the information, you know, from the clinic regarding chronic diseases, um, you know, how would you describe that. Do they give any information, um, you know, for example have you ever had a leaflet from this clinic? No?

IE Nah.

IV And then the posters on the walls; do you ever look at the posters?

IE Ja, I look at the posters.

IV At the club?.

IE And I read the posters, mm. So, everywhere I go, even if I go to Jooster Hospital for hypertension, then I take the leaflet. I'm sure that's what helped me a lot.

IV Okay, so, then, um, do you think then that this clinic, it would be helpful to have, ah, leaflets, um, or pamphlets since that's what helped you?

IE Yes.

IV Okay, and then, um, what about, what would you say then about the information that, you know, the sisters that, in the, while you... while you are waiting to get your high blood pressure and to see the doctor, um, I know the health promoter comes and speaks to you, so, what, um, what would you say about, you know, that service that they are trying to give.

IE Mm, I mean, it's a very good thing that they are doing now because also it disturbs us not to think, like, everything and all that. In case you listen to something that's going to benefit from it at the end of the day. At least it helps me.

IV So, you find what that... what, the information useful?

IE Mm, it's useful; I benefit from it.

IV Oh okay, um, but, um, any advice you'd give just in terms of, you know, how, how would you personally like to receive information? You know, do you prefer a one on one when you are with the doctor, or the club where it's a group, or a pamphlet, so what do you think is the best way in a clinic setting like this, um, to give out such information... information on health and diet?

IE Mm, for me one on one is fine, okay, but sometimes people will panic; people that come in after you, they will panic and say, oh, this doctor is making a lot, making long and all that. Like, my doctor there, they said he's making longer, they're panicking but which sometimes that helps a lot because you're able to explain to the doctor what have you got, when it started and all that. I think I like it like that and the leaflet anyway then but not in front of everyone. And this one on one and a leaflet, I think it was [unclear].

IV Okay, so, um, about, what about, um, physical activity. Um a lot of people, you know, that I've spoken to they say, well no, the doctor didn't mention anything to me about exercise.

IE No, he did, he did mention to do exercises; they do mention it. I don't want to lie. And today they spoke about weight loss and some exercises.

IV And do you use that information on exercise?

IE Mm, [laughs].

IV Yes?

IE Yes, mm.

IV Okay, so, um, you know, what, what are the... what exercises have you seen work for you. So if you were to, you know, advise someone the easiest?

IE I mean, the long walk, you know. I'm staying near the taxi rank, you see. So for me to go to catch a taxi is not even five minutes, it's two minutes, all right, but eh, that didn't work for me because, [sighs], I was breathing so hard and all that so I decided no man, it's 30 minutes' walk for me to go to the train station, so I've decided, when I did my exercises I said to myself; ah-ah, I'm not going to take a taxi, I want... I'm going to take a train. But 30 minutes to and 30 minute from and it really... and the stairs also, they really worked for me because now I don't have that heavy breathing any more. Because I used to have heavy breathing like that all the time and I... I feel fit, you understand; I don't feel like when you go to the taxi, two minutes and then you come back and then you take... I was like, my knees were like sore because I've noticed on my first day to the station, you see those stairs, for four days, I wasn't myself. I was tired all those cramp and then after a while, I became like a 22 year-old. [Laughs]. So at least that's why, at least those are the exercises that help me. That long walk, to and from, that 30 minutes.

IV Mm, so, if I was to ask you, you know, for, to give someone else advice who just recently found out that they have, high blood pressure; what advice would you give them?

IE To look very after their diet and do your exercises; At least once, if you are not working maybe once in a while take a walk. Even if you go to the shop and then you come back; that's also an exercise. [Unclear], ja. [Unclear], take everything easy, don't stress yourself, ja, I think.

IV Um, so just, you know, how would you say it is now for you living with, you know, high blood pressure as compared to, you know, in the beginning? How, what would be your answer when someone says, you know, how does it feel, like, for you to be living with this disease?

IE Nah, I'd tell them it's not bad, as I was saying [unclear]; after I accepted the thing then its fine. It's like, what I always say to people, ne, sorry to, I mean, to say that about people who are not part of this, like people who've got HIV. Some people who hide it, instead of, you know, let us talk about it. It's like us, because I've also got my pack of tablets, everybody has got his or her own, we call it umgodlo, meaning the lot of tablets. So it's like, if you deal with sugar... whether you've got

sugar diabetic or high blood pressure or HIV that is the same because we are all eating the treatment so there is no way that you can hide it, you see, so.

IV So, um, now that you're mentioning medication and pills, you know, how that pill is for you. I mean, moving from someone who's never been sick to someone who has to take a...

IE Medication.

IV medication every day; you know, how has that experience been for you?

IE [Laughs], it wasn't easy at first but as I was saying, like, I had a decision with myself, [sighs], that I am going to... I am like this now I have to take it. That was it.

IV So do you, um, take it as you're supposed to or...?

IE As I'm supposed to, every morning, first thing.

IV Mm, okay, um, well, do you have any questions for me, um, because otherwise then I think I've, um, asked you everything that I need.

IE Are you satisfied about everything that I have said. [Laughs].

IV [Laughs], were you saying it to satisfy me?

IE I don't know.

IV No, I just, I literally just wanted to hear...

IE From me.

IV About the experience and to hear from you.

IE Okay.

IV So it's not about my satisfaction.

IE Okay.

IV Yes, yes.

IE No, I don't have questions because you've explained to me everything first, before we started the conversation.

IV Okay, well, thanks again, C, for participating.

APPENDIX K

Excerpt from the data: Meaning unit	Labeling of a meaning unit = Open Coding
<p>I would feel dizzy and experience headaches so I went to the clinic. The nurse took my blood pressure and asked me to must come back the next day. So, when I came back the next day, it was also high and then she told me that I must go to the club. So and I asked her for how long I have to attend the club because I thought maybe it was only for that moment because I had pains and I didn't sleep well, I thought maybe my blood pressure was high just for that day. Apparently not! The nurse told me no, I have to come to the clubs regularly; and that high blood is a chronic disease. Actually, I didn't accept it. I didn't want to believe that it's me who's got high blood pressure because I'm not that person who takes everything personally and worries a lot, so I thought, ah-ah,no; I took the tablets they gave me at the clinic, I was given a date but I didn't come. I told myself, I'm not going to accept it, it's not me, I don't have high blood pressure. Then as time went by I felt something was wrong with my head...it felt like a heavy, heavy feeling; it wasn't painful but it was heavy. There's something that sometimes I get dizzy, and then I came back and that I was told that no, come after two months I came back and I was told that my blood pressure was high. Then I was told that I had to take a medication because I am suffering from high blood pressure so that is when I started to take my medication</p>	<p>Experience of symptoms reason for clinic visit</p> <p>Enrolled in Hypertension club</p> <p>Misunderstanding of chronic nature of hypertension</p> <p>Struggled to accept diagnosis</p> <p>Belief hypertension caused by worry</p> <p>Lack of compliance</p> <p>Diagnosis in conflict with self- identity</p> <p>Continued symptoms cue to re-seek medical care</p> <p>Gradual acceptance of diagnosis and compliance with treatment</p>

APPENDIX L

INTERVIEW TRANSCRIPT FOR CASE STUDY EXAMPLE

Notes:

This was the first of my interviews at Gugulethu CHC. The participant agreed to participate in the study.

He is a middle-aged man of about 30, and he works as a driver. He grew up in the Eastern Cape and later moved to Cape Town in his early 20s. He is half Xhosa and half coloured. He said that his first language was Afrikaans because he grew up in a community where they only spoke Afrikaans. He only learnt Xhosa when he moved to Cape Town. He said that he was quite competent in Xhosa now, but around his family, he spoke Afrikaans.

He is a divorced with two children (an 18 year-old girl and a 10 year-old boy).

Educational background:

Only went up to high school level.

Setting and context of the interview:

The interview was conducted in English and took place in an empty consultation room assignment to me by Dr Murie. By the time the interview happened, there were already multitudes of patients lining the corridors waiting to see the doctors, so we could hear the chatter from outside. This chatter however was not too disruptive at the time. It is only now, listening to the recorder that I hear how much noise it picked up, which made it very difficult at times to hear what the participant was saying.

Interviewer: My name is Thandie. I am a Masters student at UCT and I am doing a Masters in Public Health, and I am very interested in how people in local communities in Cape Town live and cope with living with high blood pressure and diabetes. Once again, thanks for agreeing to participate in this study. So I can just to know a little bit about you, please tell me about the first time you came to the clinic

and you were told that you had high blood pressure. What made you to come to the clinic in the first place?

(Pause as someone walks into the consultation room to get something)

P: I am X and I am staying in Crossroads, and I am happy to help you because really, sometimes I like to share some of these things because I never know where this is coming from. The day the doctor told me I am high blood pressure I was very shocked because I don't know where this thing is coming from. I did ask and they told me that it is normal especially for those who like to meat, red meat...and salt. And I like really spice (Laughs). The first that that I get this thing yho! I was very shocked.

Interviewer: Why did you come to the clinic that time?

P: Because I was joining the Old Mutual insurance policy. I wanted to take if from my work and they checked my high blood pressure and it was very high. They sent me to the nearest clinic just to take my medication or some...yeah. And then I just carried on from that time.

Interviewer: How long ago was that?

P: It's almost over three months now

Interviewer: You said you were shocked. Why?

P: Yes! Because you don't expect that at this age. I am not that old (laughs). I was thinking that the high blood pressure and diabetes affect old people. I never really knew that even young people can get this thing (laughs). But seriously, lately I am just... ok the first day they told me about the food...the way I must eat...They said hey, the salt...I must just put a little bit...and they gave me even the way I must eat. And also they say even my weight also, it's too big, I have to do some exercise while I am eating this medication. And then they gave me tablets, temporary tablets... just to check if this thing can work...they are trying to bring down the level. Then the second time they found out that my high blood pressure was low, not lower than

normal, just low. That is why today... they gave another date ...today. But really the food that I eat now (sighs) I am really not happy ahhhhh.

Interviewer: Why are you not happy with the food?

P: Ahhh the taste is a problem because I just have to boil my food... I don't know I am different now; I have to cook two pots now. Sometimes you waste a lot of food. So to eat different food like you are a kid. You know the kids mos, they just eat this, what do you call... you know mose, and then I am old now. I am an old man now but I have to different food from my family. When they eat meat, I have to take the fat away and it must not be that salty.

interviewer: If don't mind my asking, can you please just give me an idea of your eating typically and what don't you eat anymore?

P: I liked red meat and the chicken and all that stuff. But not that much. But I think this thing must come from the salt man.Yeah... But I am not that gimba [fat]when I eat; I just ate normal like other people. I was ok but lately I am just going down. I did not feel like I am getting sick or I am sick in my body until I get tested by Old Mutual. After I take this medication, I feel a lot of changes in my body. I feel dizzy sometimes, I feel tired. You can't just stand up after eating this medicating like a normal person. Before I was someone who would do exercise in the morning. But since I start taking this medication, it makes me very, very tired, weak...sometimes you feel a headache, sometimes back pains, all of that stuff...even today I was telling myself to ask the doctor if they can make a plan and change my medication because I am not happy really...it's changing my life. I am doing different things now. Something like a... I am not a normal person. Laughs. I feel like that because serious, before ...when I wake up, I would take exercise, but now I am not doing that. I am very weak in my body, serious. Especially the headache, serious. That is the thing that is just killing me...sometimes I can't just wake up and open my eyes. I have to take about 2 mins to 5 mins. After 5 mins ...mind you I am working, I have to wake up and go to work... taking all this time.... Another man told me that today I have to tell the doctor to change my medication, or else I don't know what to do... because

seriously I am not happy with this thing. And since I start eating the tablets, my life changed, the way I feel in my body, everything. Seriously. At work, I am always hungry; I am not coping like before...this medication is changing my life. I am like an old man. When I was working before, I would climb the stairs up and down, but now I am taking the lift, I can't handle the stairs. Laughs. But this is a way of life, I don't know...this thing coming from the doctor ...saying they can't help.

Interviewer: Sorry if I take you back a bit, you said that you came to the clinic and you were told what to eat and what not to eat, and you got your medication. Who told you how you have to eat?

P: It was the doctor

Interviewer: Do you remember exactly what she said?

P: She told me that the most dangerous thing in our body is the salt. She said that you must just come down from eating too much salt. This thing comes from your spicy things...all the things that I like. So I was just thinking, serious, if this thing comes from the salt, but now I changed all the things...I leave the salt alone. But actually today the temperature...what you call it, the high blood pressure is low. Because I was just focusing, especially last month until today I am in the clinic. The things are coming down, but my problem is if I eat these tablets I get dizzy. That is my thing I get now. I keep getting weak and weak and weak. It doesn't matter if the high blood pressure. But now it is changing my life. Why now is it like that? That is why I am thinking of telling the doctor if they can change this thing.

Interviewer: So is there anything else that you talked about besides the salt?

P: Yes, about drinking also. Apparently drinking...but I am not even a smoker... But she didn't go into detail about how this thing gets the people who drink alcohol. I am not an alcoholic; I am not even a smoker. So she told me also that this thing is normal, it's not a disease like diabetes. Diabetes is different from high blood pressure. She said that the high BP is just normal. It is not like the diabetes, which is for old people. But she said it's just a normal thing. And then I asked her what the

cause is. And she told me the same thing, about the salt and stuff. Sometimes the high BP can be high because of the stress, or sometimes depression or sometimes you can get depression from your family. Maybe you don't get something that you need. Most of the time... I know all of us have goals and dreams in our minds, so those goals, have maybe not been achieved quickly in that time that you need so the high BP will go shooooooooo. Laughs. That is why I believe sometimes when she says that it's normal. That is why old people can get it instead of young people.

Pause.

P: Do you want more?

Interviewer: Do you have more?

P: As you know, I am new in this industry, I have very little experience. Maybe as time goes on, I can get more, yeah... but so far I haven't got that information...but I am willing to help if there is something that you need...

Interviewer: So before you had high BP, what did you understand about it? What did you think it was or what caused it?

P: I didn't know, I didn't even want to think that my body can have high BP.Serious I don't know. The cause of this thing...I don't know...she explained a lot of things but at the time I was so stressed because I was thinking that this is the end of my life. Laughs. But I was thinking stupid. Laughs. She tried to open my mind (laughs) and show exactly what this thing is. Now I understand. But now my problem is this thing now... when I am drinking this tablet... now seriously, I am very lazy, I am like an old man.

Interviewer: So you feel that your laziness is because of the medication?

P: I have never been like that before. But since I started drinking this tablet, ahhhh my life changed very slowly...maybe next year I will be walking with a stick. I am very very slow.

Interviewer: So from what I hear from you, you get tired, you get headaches, and you have gotten slower

P: Yeah...

Interviewer: Is there anything else?

P: And sometimes when I go to the toilet, my urine feels very hot, because sometimes when I am having sex I use a condom, so I don't know why it's burning like this sometimes. Serious. I don't know if it's because of this thing in my body. But since I started drinking these tablets, I saw those changes. Even last week Wednesday...I am sorry to talk about this since its personal, but when I was going to the toilet yho! My ass was burning (laughs). You would think that I had eating barbecue or chilli (laughs) but I stopped eating those things. I thought that there was something...laughs... the experience that I have...laughs...really...and I am not happy for this thing (laughs) ...it doesn't matter that they calm us down, that's cool... but uhuh... Even my father also told me that there are many ways to clean the blood, using herbal things, called aloe vera. . I can drink it just to clean up my blood. Sometimes the high BP could be that my blood is dirty. I always tell him how the medication males me feel, like today, and he said, "if you feel like this, then try this thing". But I said no; let me finish up my medication first. I don't want to mix things. I must carry on with this medication and if I see that there is no change , then I can drink the aloe vera

Interviewer: So aside from your father, have you gotten advice from anyone else about how to deal with high BP?

P: Yes, my cousin's sister.yeah. I mean she is not my cousin, but I call her my cousin. She is my brother's girlfriend. She is also... but she is not like me, I feel I am worse (laughs) than her, because she has a long time with this thing...high BP

Interviewer: So what did she say?

P: She always tells me just carry on drinking the tablets; try to follow the instructions as the nurse says. She is always like that. I don't mind... What she says...I take her

point, but I failed. It's different... Different... Maybe it's because I am a man. She is a woman. She is used to taking the tablet and these injection things. And I was not even used to come to the hospital. It was my first time to come to the hospital and I get all these things. I never had these things before. Even when I had a headache before, I just used to drink cold water and I would be fine. Even for my body, I used to exercise; I have all these machines at home. I was exercising every day.

Interviewer: So what machines do you have?

P: Just a running machine and just that machine for weight lifting

Interviewer: So how long have you been exercising?

P: It's been a long time. Laughs.

Interviewer: How long roughly?

P: Almost four years. But I don't want to make my body too big I just want to keep my body muscular. I don't want to get big muscles like Undertake, those people in wrestling.

Interviewer: So why did you start exercising?

P: I wanted to keep my body healthy and to get my body in shape. But now see, since I started.... I am gaining like gaining weight now. And the medication makes me pee. And each and every day going to the toilet to pee, pee, pee, pee every day. Sometimes I feel embarrassed in front of people going to the toilet. Laughs. But now at least I think it's going to be...I don't know...serious...But I would like to listen to other people's experience. I'd like to share with other people so they can say when you feel like this, do this, or do that. Sometimes when I go to the doctor, I don't have time that to ask. Laughs. She always sometimes asks why is your BP too high. And then you have to explain this and that... and sometimes I think she is going to say I am going to refer you to hospital, what you call it Jooste hospital. I have never been to hospital before. I dont want to go to Jooste hospital. Laughs.

Interviewer: Why don't you like going to hospital?

P: I feel like if I go to hospital it means that things have gotten worse.

Interviewer: So according to you when you are at the hospital it means that you are really worse?

P: Yes. Laughs. Cause I don't want to go up and up. Mose it starts from standards. Its 1 and then 2 and it just keeps going up. Next thing I will be told I am worse and I have to sleep in hospital. Where is this thing coming from and how is it going to end, that is what is on my mind. And how did it get in my blood because even my father does not have this thing. I am the only person at home now... And even my big brother because of the stroke, they found this high B. My mother is clean. My father is clean. My young brother is clean. And even children my children.

Interviewer: so how long has your older brother had high BP?

P: Its almost 4 years now, if I count right...it's almost four years....it's almost 4 years....because of the stroke now everything is not working. We have to help him to move, all the stuff...when he wants to go to the toilet, you have to help him.

Interviewer: So when did he have the stroke?

P: As I said its four years now...I am not sure...its four years now...I am not sure about the year...but we try by all means to help him. We go up and down to sangomas [traditional healer] all the stuff. You know black people believe in these herbal things. We try our best to help him.

Interviewer: It's interesting that you said that you have even tried the sangomas. What did the sangomas say about high BP?

P: They always say assume...what you call this ... its evil, most of the time. Laughs. Then you don't understand what evil means. But they say no it's evil. It's not high BP, they say it's evil. So they say this man must get some medication to get healed... And also the pastors when you go to the church, they pray and pray, but they can keep praying until they get tired the way I see it (laughs) because the stroke doesn't get out of that body. It's the same. You know Pastor Chris...he is a pastor in Joburg. You see him on television at 4:30 pm - 7:30pm. My brother was there also

because of this thing. His high BP and stroke. My brother went to Joburg but he never got healed. He came back again like that. And he was right in front of that man and he touched him. He said that when I touch you, you will get healed. But he is the same. Then we took him to another place again. There was no change. And my brother I think he was like me because he never used tablets before, then he got a stroke boom! Then the doctor said that his BP was too high, that is why he got this. He really is sick, it's not just. But now lately that he is taking some medication, he is coping. Now he is walking...he tries to walk. He says give me my tablets...he was not even walking but now at least he is trying... I am sure the nerves are coping now, lately. I am happy to see that. Before I was verybut now at least... I don't want to get a stroke like him. Otherwise I sometimes say to my brother, I am lucky, because they saw me before (laughs). But now my problem now is this headache and laziness that I get. I like to do things on my own. I don't like someone to help me all the time, even my girlfriend... wait it's not your house (laughs).

Interrupted by a sister looking for a doctor....

Interviewer: Sorry about that....Have you yourself tried to go to a sangoma?

P: Not so far, it was just on my mind. Laughs...I am just focusing on this medication now.

Interviewer: In terms of the sisters, have they given you any advice?

P: Yes. Sometimes. Each and every day we must eat our tablets, and every time you feel...you must tell the doctor...each and every change you must tell the doctor... she is always advising us and even today. See that club house; she is always advising us each and every day. Since these two months that I get...at least, she is always...especially that other woman...I don't know her name. But she is always really...feel free to tell the doctor that I feel like so and so... that is why I want to tell the doctor about what I feel now lately. She called me and said you are a new member, come and meet this lady that is why I came to you. I was hiding myself. You know to be a young guy among old people is very embarrassing. Do you understand what I am saying? Laughs. When you are very young and you get an old

people disease. Laughs. And if some of the young people saw me, they would say, hayebo... what is this man doing here with the old age people. Laughs. But I am sick, a disease is a disease. You can get it whether you are sweet 16 or sweet 80.Laughs.

Interviewer: Now let's talk more about the food because you mentioned that cutting down salt has been very difficult for you. Just in terms of the type of food that you have to eat, did anyone advice you on what kinds of food to eat?

P: Yeah... the doctor did not tell me exactly about the food. She said that I must leave the salt in the food because the danger is the salt. But she didn't explain what kind of food I must eat. I am still eating my food as usual; the problem is I just cut the salt only.

Interviewer: So what do you eat usually?

P: Usually I like to eat anything. The rice, the porridge, and sometimes we go to Mzolis [a restaurant in the township], to eat but when I go to Mzoli I don't eat the meat. I just go there with friends. But I don't know what I must eat at home. I eat chicken and all the stuff. But I dont like to eat fish and pork. It's not my favourite. When I eat fish, I get allergies. Not lately, even before I got this thing. I am sure even my mother doesn't eat fish because she gets allergies...The pork because I am a Christian. I don't eat pork because the Bible says we are not supposed to eat pork. But there is nothing wrong with the pork. People eat pork but I don't eat it. My problem is just the fish. Sometimes when I go to the sea I don't swim because of my allergy. I prefer to swim in a pool and not sea water, because I know I will get sick later (laughs).

Interviewer: So who cooks your food at home?

P: It's my sister or me when I have the time. And she knows what I eat. I like to eat vegetables now...yeah and fruit. I take out the skin now from the chicken, I just eat the breast. And I also remove fat from the red meat. And most of the time when I eat bread, I eat brown bread, I don't eat white bread anymore. I like to use the toaster

most of the times...toast...my bread must be like that. And the eggs also, I use little salt, but now I don't put salt anymore in the eggs. I just leave it like that.

Interviewer: You mention that now you eat more vegetables and fruits, you remove skin from the chicken...uhmmm why now? Why these change now?

P: Because other people mos they always...it's not only me. Sometimes I go to my friends and ask those who have this thing. A friend of mine, who is also diabetic, told me straight away to try and leave out the fat when I eat. I try by all means to take the skin away from the chicken. But the doctor never told me about that. It's my friend, because he is sick also. He said that I must take off the skin and I must eat vegetables and fruits because that will give my body more performance and more energy. And when I buy tin stuff must look at the total percentage of sodium. But I don't have that time. When I buy something I just buy it. He told me also that when I buy the tin stuff I must look at the instructions to make sure that there is not too much salt in everything. Even when I go to the shop and I buy Vaseline, there is a healthy Vaseline for people who get allergies because sometimes when you get this disease your skin can also change...minor things. But So far I haven't bought any of these things, I am just writing them down. My aim was not thinking that high BP is a disease that is going to stay for long. I was just thinking that if I do this thing, after four months it will come down then I am cool. But now it's carrying on and on...that's the thing.

Interviewer: So how does that make you feel? This high BP just keeps carrying on and on and you thought that was going to stop?

P: I believe the doctor was lying to me to say(Laughs) it's just a normal thing, but a normal thing because a normal thing sometimes reaches a time to get out of the body. She just said to me this is normal, all the people have this thing, A, B, C, D. But now I find out that its two months now and I am carrying on and on and on. And I believe today she is going to say take another date again and life goes on. Laughs. Because in my mind I was just thinking maybe this thing, when my high BP gets back to normal, I can change my tablets, or I'll will take time, like it will take two

months or three months before I have to come back, since they gave me tablets. But I found that hey, I get this thing in my body, like dizzy something like that...now I am thinking if I tell her about this, she is going to say take thing now. Uhhhuuu another packet hey (laughs) so which means there is no change, which means it is going to remain like this...the way I think.

Interviewer: So how does that make you feel?

P: I don't feel alright that I have to carry on my life with these tablets. I was a normal person. I never used these tablets. I am not happy to eat this thing each and every day but I don't have a choice because of this thing. Now I have to force myself, it doesn't matter how I feel. I have to force myself to drink because I don't know what the cause...is although I don't want to get a stroke. As they say so, if I don't want to drink this thing and my high BP goes up, I can get a stroke because I have already started. Maybe if I didn't start, and I went to a sangoma and was drinking some muti [traditional medicine] ...maybe... Pause. It's not nice to feel this thing, to have high BP. And sometimes you get a problem at work also. Every month you get one day off. So the boss is always watching me. What is happening to this man? I did explain, but they don't understand sometime. Why are you always absent, absent, absent, each and every month...we know you are going somewhere. I feel bad sometimes but I can't help it. They must accept it, because its life.

Interviewer: So you become absent from work to come to the clinic or because you are not feeling well?

P: Because of my date. And that is today. I informed my boss yesterday that I have to come to the hospital, but now he is always asking, why you are always going to the doctor, what's happening. He is curious. He wants to know exactly what is happening. But I told him, I have this thing in the blood. He says yeah we understand, but to have you absent from work each and every month...you are not here. Now this is Cape Town (laughs) under Premier Hellen Zllie...so we black people are on the other side, so we have to focus. Sometimes I can get a problem, seriously. They don't understand. Yes they may smile in front of me, but behind

they talk, "it's too much". Because one day I don't know what is going to happen. My life is at a big risk now, even my work (laughs). And also, there is also another man who passed away last year, he was a preacher, he was a strong man, preached to us a lot of things. He fainted and then he died because of diabetes. So now that is why I am getting worried about me. Maybe after this thing it is going to be diabetes. From high BP to being diabetic. Laughs. That is why I don't feel happy, because I was thinking that this disease was for old people. I didn't know that at my age I can also get this thing. Because the other friends of mine are still walking, they don't care about this thing...but I am here. Maybe I can say luckily I am here because now I know my status. They don't know their status. The first day I came here, I checked my HIV status and I was negative. I feel clean. Laughs. I am clean, everything is alright. Just only this thing, high BP.

Interviewer: So after your diagnosis, and the doctor told you less salt, and your father, and everyone advised you on what to do, tell me, how long did it take for you to start making those changing, like using less salt for example

P: I was stressing before because I had to leave everything. Serious. It took me almost two weeks to understand this thing. Because serious, I was not even aware... and now I had to change my food and all this stuff. It took me a long time. Last date... last month, my BP was also up because I was not noticing that this thing is real...but lately, now I understand, serious. Then after that I worked on my food and my exercise. Then I changed my food....then I started eating veggies, it was not even my favourite, but I am trying to eat...at work sometimes, and an orange. And I don't drink acid things; I'd rather drink water instead of cold drink. I drink pure juice only and water. You know the black people when you go to a braai there is no juice. There is no party with a juice mos (laughs). But now I am happy so far with my food. I am used to eating it. There is nothing wrong with it. Like they say, nothing is going to change. I must eat until the end of time.

Interviewer: But are you enjoying your "new" food?

P: Yes I am enjoying. I wish I can get more. But so far it is frozen veg only and taking out the skin and too much fat from the red meat. But not too much red meat. The problem is the red meat also. And a friend of mine also told me about what do you call this...the aromat. There is a different aromat; they are not all the same. There is a different aromat for people with high BP...But I never see those things. Maybe I have to go to Woolworths and Pick n Pay to find out if it's true. Maybe they have less salt I don't know. The aromat [seasoning spice] and the Rama [butter] also...I mean butter.

Interviewer: So you mentioned that you wish you can get more. Can you please explain that?

P: Yes. Because I am already used to eating like this now, and no one helps me, like before. I eat alone. Because they say, "sies!" [used to show disgust] . And I say this is alright, it's my food. Laughs.

Interviewer: So tell me a little more about that. Who are these other people who say "sies" to your food?

P: It's my friends. Laughs. Because they is no salt. They like salt. But when they taste my food, then they say yho! Are you crazy, why are you eating like this? And I say to them but it is my food. And then they say yho, are you sick then I say yes I am sick. But it is my food. At least I am eating something ...you know the friends always go like wwawawa but I am happy to eat alone now, they don't help me anymore. But to eat a veg...ok they like the vege but they wouldn't eat the vege mose, but the meat, if I take off the skin they help me to eat that skin. Laughs. They say you are stupid, but eating only the muscles is alright for me.

Interviewer: So what about your family members?

P: No they are always supporting me

Interviewer: What did they say when you told them that you had high BP

P: They said no, you got this because you like eating too much. The salt. It was my mom; she told me it was all that salt and all that stuff. It's you who changed your life. Then I understood. I was not blaming the doctor when she told me about this thing because I already heard it from my mum. Cause I told her I have high BP and she said yes, it's the salt, leave this thing. But my problem is just the medication. but if I don't take these tablets I feel nothing, no dizziness. But after I drink the tablet, yho, I have to take time to focus. I thought that this was the wrong medication. I wish that he or she can change that tablet that I am using...I wish he can change my medication. I wish seriously. Because my parents support me big time. They don't say I am different. They support me most of the time. Sometimes they bring me something, like a veg or a fruit, they show me everything. I accept mos because it from my family. They mostly like to give me veggies; I like veggies now, but not back before (laughs).They feel very nice in my body. But the problem now is this laziness and getting dizzy. That is my problem.

Interviewer: So like you are saying you had to make a change with the food and you had to start taking medication. What really encouraged you? You mentioned that the first two weeks were really difficult for you, but now you are doing the right thing, you are eating the right food and you are taking your medication. What was the turning point for you? What encouraged you to say I am going to do this?

P: Because I don't want to die first thing, and I don't want to get a stroke as the doctor says, so I would like to follow instructions as the doctor said to me. That is why I decided ok, the doctor told me this and this, that is why I have to follow it because they know what I don't know. They saw it in my body...so I just focus and I carry on...because I saw my brother what he looked like, and I don't want to look like him. Because they didn't notice that he has high BP before. But lately he is walking like this....yes he is my brother, but he never came to hospital for the high BP, but now he has a stroke. He is up and down, in and out of hospital, the sangomas...I don't want to be like that. That is why I say ok; I'd rather follow this...if things happen at least I am willing to help myself. I am on the road... sometimes maybe things can happen It doesn't matter whether I am taking medication or what.

But so far, I am just following the instructions. But they told me I must take the aloe vera and those things, but I am just focusing on my medication until four months. Then after that, I can eat/ drink aloe vera if it is necessary, unless the doctor can help me with this problem that I feel lately. If he can help me, I won't change anything. I will; follow it until the end of time.

Interviewer: So you are giving the doctor's way three months?

P: Exactly (laughs)

Interviewer: And then...

P: I must take another way. If there is another way. Because some of the people are lying. They just take your money from your pocket to lie, and you just die mose. I will just try mos, when you are sick you go up and down because you need more life, a better life, a future.

Interruption by a patient who thought that there was a doctor in the room.

Interviewer: Sorry about the interruption. So uhmmm you know, the change, I know that you are saying that now you are getting used to it. But do you think that this is a change that you can maintain?

P: I think so. You see, if you see it like this, the sheep and the chicken are not like the old days. It's like fonkong [fake] chicken. They are fake most of the time. You see the chicken is making eggs and it's a male. Now they are just using machines and some chemicals. Laughs. So I think, if the sheep now can reproduce without a female, even our food is not exactly like it used to be in South Africa...like when you go to the Eastern Cape and eat food from your garden, very nice vegetables. This is all fonkong. Now I think I have to carry on until I get better. But I will try my best to be a better person. Like others that I see now who say I have high BP, and you say yho! You, but you don't look like it. There are some other people who have this thing but you won't see that they have this thing, this disease. So I just tell myself....if you eat the eggs now....which you know are just fonkong mos, since they don't come from a chicken...laughs....I think that is what is making us sick. If you go to the bus

terminus, there are a lot of stands there. You can get some steak and eat, and you can taste that the meat is not from the village. You can take a sheep from the Eastern Cape and bring it to Cape Town and taste that the meat is different. It's what is causing us problems. I think we are getting sick from the food because it is not the same now. They are just using a machine to grow chickens and all that stuff now and the eggs. So there are no more chicken, no more females, just males who lay eggs. Laughs. So we don't know exactly what is...One day I went to Samora Machel [a township] or that place what do you call it, but there is a farm there, but there was no grass or anything, but there is a bull there and it is so fat. You don't see fokol [anything] but you can see that it is eating something because it is very very fat. Very fat in a dry place, this means there is something. So when you are eating that cow, you are getting fat also because of the medication that they feed the cow. Then they take that cow to the butcheries and then we buy that meat. Then people are gaining, and they get high BP. That is the way I see it, because these things are fonkong, and they make you gain weight. We take that meat and braai [grill] you see, and when you braai, you don't just braai like that, you also add salt. Then you gain the weight...The way we live...we don't know...only God can help us...I think it comes from those things, not only the salt you see. Gaining weight, I think it comes from these cows and sheep and the chickens because I don't think it is healthy to eat that meat with the salt. You have to cook that meat with water and boil so that those things can go one time and then you can eat, but I was one of those people who liked to eat braai. But lately I find this thing now in my blood, on my body. But anyway, I don't know...but I promise I will just keep on eating this thing...the medication until the end of time, if there is the end of time. Laughs

Interviewer: So if you don't mind my asking, how has the change in your food been like money wise?

P: That is the thing. Serious it's a problem. So when I buy my things now, I have to buy a lot of veg and fruits, that thing have added to my budget now more than before. At home we are 5. Now I have to cook two pots. Mine without the salt and they have to cook their own food separately. It is a waste of food most of the time.

It's a waste. Seriously, because I have to make my own food and they have to make their own food. It's a waste...more than before because we used to eat the same thing, at least it was less...now it's more than before

Interviewer: Why the two pots

P: Because of the salt

Interviewer: So the others don't want to eat....

P: Food without salt. Laughs. I tell them for me the salt is poison for me. They don't want to kill me now because I say it is poison. I am affected now, I don't want to die, so it's better that they cook separately.

Interviewer: So do you find that well...

P: The grocery is getting finished early before the end of the month you see, because of double cooking.

Interviewer: Do you think you will be able to maintain that?

P: Yes so far...so far I think so, because I have to. I am the only guy that is working there, but so far I am just telling myself that I have to. But I don't know lately what is going to happen because of the price of the food, and the strike also...which means the food is going to go up and up...I don't know what is going to happen.

Interviewer: When you say the price of food, do you mean food in general or the so called healthy foods, you know your brown bread, your fruits and vegetables

P: Yes, now because of the strike they don't deliver the bread, and we don't know how long it is going to take. Even when you go to Woolworths and what do you call this place, Shoprite, the stock is less because of the strike.

Interviewer: Is this for everything?

P: Yes!

Interviewer: But before the strike, did you notice any difference in price?

P: Yes. Before I used only R700 for groceries for the whole month. But now we finish before the end of the month, like on the 25th because we cook two pots...my food cannot have salt and so I cook my own separate pot. The food now finishes early and I have to buy some food again. We are 5 and I am the only one who is working, so I have to deal with that crisis. But I don't know what is going to happen because of the price of food keeps going up, and the strike also... The prices are now going up and up because of the less stock which means the food is going to go up and up.

Interviewer: Where do you buy your food?

P: Different shops.

Interviewer: So how do you try and cut down the cost?

P: I buy in bulk. I buy rice and veg...not just the small ones but the very big big ones because we are a lot at home and they eat, seriously. Laughs. Before mos I ate normal food, but now because of different things, these things... other things are added to my food. Before I used to just buy mealie meal, rice, flour, meat and beef stock just to keep the food in the right taste. But now the veg is added very much and other light things.

Interviewer: So now to move away from the food, and your medication which you mentioned that is one of the difficult things about having high BP because of the way it makes you feel. Now let's just talk about your experience of coming to the hospital. How would you describe your relationship with the sisters and the doctors?

P: Laughs. The nurses and doctors are treating us very well now. Before there was a lack of a system, now things are nice. Even the doctors and nurses were careless before, they took people easily, like they don't attend us on time. But at least now, when I came this morning I woke up at 6am. At 6:30am they took our cards and gave us the folders, yes they do that. But before eish, we took time, as my mum says, because she works around here. They took a long time and some people will be shouting and moaning and some of them are told to come back tomorrow because of

the lack of attendance. But since I started last month, I see different things not like before. The people are friendly, they like to attend us, they are not moody...the way they speak to us they are nice, and they make jokes. They answer the questions...they say ask me anything you need to know so that I can tell you. Some of the nurses come to you and say how can I help you, how can I help you... we don't stay long in line like before. The problem now is the pharmacy; we take a long time there. I don't know maybe there is a lack of staff, but otherwise I am happy now except for the pharmacy.

Interviewer: So how long do you take at the pharmacy?

P: I take more than 2 hours at the pharmacy. That is why if I come to the hospital I have to take the whole day off from work, because I know I have to see the doctor, and then stand in the line for the pharmacy...see what time it is now, I can't go back to work now. It's not like the private doctors outside, where they do their things quickly and you can go back to work. This is a day hospital. You have to accept the way that they work because everyone comes here.

Interviewer: So how do you feel about the instructions that they give you and the advice that they give you?

P: I was feeling bad before, but lately I am happy now, because it is my life. Just if I can get more information about the way I should eat, then I will be happy.

Interviewer: Have you asked the doctor for more information?

P: No, as I was telling you today I have to, because I want to know more

Interviewer: Have you got any reading material, any leaflets from the clinic?

P: No

Interviewer: Well have you ever seen any reading material lying around at the clinic on high BP/healthy eating ?

P: No only posters. Yeah there is a poster where they tell us about the food we must eat and the limit that we must eat...

Interviewer: Well do you read the posters?

P: No. Sometimes I just look at the posters and just aggghhh...

Interviewer: So for you, what would be the best way then to get information? If you were to advise the hospital on how they should give out information since you look at the posters sometimes, and sometimes you don't, what do you think would be the best method for you?

P: If the doctor can just tell us straight away. They mustn't go like this. They must say Buti(brother), since you have high BP or diabetes; you must go like this, and this and this. That is all. That is the way that they can tell us. But with posters, they are too far. Someone like me, I don't see clear sometimes, and they are small letters, so I don't bother myself to look at those things, they are too far. And with the things that I told you about this thing...the medication making me tired, so I don't have the energy to be looking at walls. But if a doctor can tell me straight about what I must eat, what is good for me and what is bad for me, I can do it. It doesn't matter whether I have earning a little money or not, but I have to know. I have to

Interviewer: So you mentioned that the sisters sometimes say you can ask them anything. Do you find that helpful?

P: Sometimes you feel shy to ask in front of a lot of people especially the men. We don't like to ask in front of a lot of people. You can't find us saying nurse sorry, what must I eat, what must I do...nooo...we don't like to speak like that. We like to sit down and talk about this.

Interviewer: So you want a private one to one...

P: Yes. So that you can focus when you ask something. Not like in a big group, where people will ask another thing that will get you confused. You end up getting other people's experience...or someone thinks you are asking the same thing, but it is not the same, it is not the way you think...So it is better to sit like this than to just wawawawa...so the doctor must just tell us straight away. I also think that we must

have a translator for the old people because some people don't need to speak clear English.

Pause.

Interviewer: Well do you have anything to add...?

P: No.

Interviewer: So my last question is what advice would you give to someone who is newly diagnosed with high BP?

P: It's so simple. Just accept. High BP is in your blood. Just focus on the medication and listen to what the doctor says. Anything that you don't know just ask.

Interviewer: Do you have any questions for me?

P: Laughs. No.

Interviewer: Okay then, I think we have come to the end of our interview. Thank you for talking to me.