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SERVICE PROVISION FOR DIABETES AND HYPERTENSION AT THE PRIMARY LEVEL IN THE JOHANNESBURG METROPOLITAN AREA

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of

Master of Public Health

Johannesburg, 2007

I, Chad Smith declare that this research report is my own work. It is being submitted for the degree of Master of Public Health in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

_____

_____ day of _____ 2007

For Harry Craft and his Rotarian spirit of Service Above Self

And

Brad Smith for going first

To my family – We did it together

Executive Summary

Non-communicable disease currently accounts for 59% of global deaths and 46% of the global burden of disease. In 2000, 38% of all male deaths and 43% of all female deaths, in South Africa, were due to non-communicable disease. Like all health systems, the South African health system is not adequately equipped to deal with these types of diseases. The burden of chronic disease will grow over time due to factors such as urbanisation and associated behaviours regarding food consumption and physical activity.

The World Health Organisation has developed the Innovative Care for Chronic Conditions (ICCC) framework for resource-constrained settings. The ICCC framework is structured into three levels: macro (positive policy environment), meso (community and health care organisation) and micro (health care interactions) levels.

Using diabetes and hypertension as examples of chronic disease, this research drew upon portions of this framework to examine service provision for chronic diseases in the Gauteng Province. The overall aim of the study was to document the resources available to manage chronic disease in the Gauteng Province by investigating primary health care clinics, community organisations, and provincial and district support. The objectives were to describe the following: health services offered by primary health care clinics in the city of Johannesburg for the management of patients with diabetes and hypertension; the role of district and provincial management in chronic disease care; and the role of community based organisations within the city of Johannesburg in promoting good health, preventing chronic illness, and providing curative and rehabilitative services. The micro level is represented by primary health care (PHC) clinics, the meso level is represented by community-based organisations (CBOs), and the macro level is represented by provincial and regional managers.

This is a qualitative, cross-sectional descriptive study. The study population is PHC clinics, associated CBOs, and managers operating in Metropolitan Johannesburg, which is managed by the provincial government. One Gauteng province sub-district was selected by simple random sampling from a list of sub-districts containing at least five provincial PHC clinics. The selected sub-district was located in Soweto and the four PHC clinics and two community health centres were included in the study. Snowball sampling was used to select the CBOs after contacting the PHC clinics. Chronic disease managers at the regional and provincial level were also selected for the study.

Data was collected entirely through interviews. One key respondent was selected at each site after contacting the site via telephone. The interview was in-depth and guided by a pre-determined list of questions. The issues probed included topics common to all three levels such as: challenges in chronic disease management, goals for chronic disease management, financial and human resource issues and patient information. Interviews were tape recorded, transcribed and analysed thematically. Ethics approval for the study was obtained from the University of the Witwatersrand's Human Research Ethics Committee and authorisation to conduct the research was acquired from the Gauteng Provincial Department of Health.

A total of 13 people were interviewed. At the micro level (PHC clinics), health care workers believed there was an adequate skill mix for chronic disease care but felt unsupported and understaffed. They did not feel motivated by the incentives currently offered. No health information was maintained at the clinic and all patient information was kept on cards. These cards were used to track patients' progress, clinic attendance and compliance. The only information collected, and sent for analysis, was a patient headcount. Clinics primarily focused on curative treatment. Patients were deemed to be 'controlled' or

'uncontrolled' based on their ability to return to the clinic for monthly check-ups and consistently achieve acceptable clinical indicators such as blood pressure and/or blood glucose level. Medical doctors, the only health care workers permitted to initiate insulin therapy, are present only at the community health centres. Patients at PHC clinics must therefore receive referrals and travel to CHC to receive such treatment. PHC sisters did not express an interest in being able to begin insulin therapy, suggesting it is too dangerous and should only be performed by a medical doctor.

Five CBO representatives were interviewed. Only two community-based organisations could be identified as having dealt specifically with chronic disease. Both of which focused on diabetes but were inclusive of hypertension due to the number of patients with both conditions. These organisations operated with no budget, paid staff or dedicated office space. They maintained close relationships with clinic staff and ran support groups at the clinic, many times with the help of sisters at the clinic. The other CBOs included in the study were home-based care in nature and dealt primarily with HIV/AIDS. They began treating these chronic disease patients when they realised the stigma of HIV/AIDS was ultimately affecting their outreach. In contrast to the two chronic disease CBOs, the AIDS related organisations all received government training and funding, which included stipends. It was felt that the government training did not provide enough information regarding non-communicable chronic disease such as hypertension, and instead focused almost exclusively on HIV/AIDS. A monthly meeting was held for all Soweto-based CBOs to discuss issues and receive information from government representatives.

There exist dedicated chronic disease programme managers at both regional (covering two districts) and provincial levels. Both levels support one another as they work with the PHC clinics in managing chronic disease. Managers felt free to communicate

'upwards' from region to province and province to the national level on an as-needed basis. With respect to PHC services, they saw their role largely as conduits. They provided guidelines to the clinics that were created at the national level and then subsequently monitored their guideline implementation by conducting random site visits. Managers felt that health care worker support was to be accomplished at the clinic level, rather than being their personal responsibility.

Chronic disease services, in the study area, held the primarily focus on curative care rather than on health promotion, prevention and early diagnosis through screening. Nearly all patient education was delivered to individuals who had already developed one or more chronic conditions. Community-based organisations motivated those with chronic disease to adhere to treatment protocols, make positive lifestyle choices, and provide patients with a forum to discuss their conditions and learn from one another. They also worked with the government to implement awareness campaigns each month. These campaigns included the community and provided education to those whom had not yet developed a chronic disease.

All three levels of the ICCC are functional and communicate with each other, though to varying degrees. While communication between levels is present, there exists a top-down management style where workers feel unsupported. The government is heavily involved in all three levels of chronic disease management. They train and pay PHC clinic staff and CBO workers. The government produces and disseminates all guidelines and protocols and monitor their implementation. The government accomplishes all these tasks while collecting only monthly patient headcounts from each clinic.

Patients retain all clinical data and managers see no need to collect any data other than a monthly headcount from each clinic. Nurses are unable to initiate insulin therapy and are unhappy with the current incentive program. There are only two CBOs dedicated to

chronic disease, all the rest focus primarily on HIV/AIDS. CBO workers do not feel there is enough training regarding chronic diseases. Each level cite various challenges to successfully managing chronic disease. These include, but are not limited to, low patient compliance, finances, lack of family support, and human resource issues.

The research applied only a portion of the ICCC framework to one group of government clinics - provincial PHC clinics and CHCs. Examining a larger number of clinics and managers and applying a greater portion of the ICCC framework would be valuable further research.

The following recommendations are a partial list of those generated by this research:

- Increase the amount of chronic disease information presented in the mandatory government training of all CBO health care workers.
- Construct a comprehensive list of all CBOs that includes: contact information, where they operate, services provided, current client addresses, etc. This will strengthen their ability to partner with one another and reduce overlap in patient care.
- Educate patients better regarding how insulin works. This will decrease the usage of herbal medicines that mask health problems and lessen patients' fear of insulin.
- PHC nurses could be trained and permitted to administer and/or initiate insulin therapy.
- Enable managers to realise they can affect change in clinic staff, rather than feeling this responsibility belongs solely to the clinic manager.

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Chapter 1: Introduction

In this chapter, the published literature on chronic disease in South Africa is reviewed. This includes a review of chronic diseases in both South Africa and globally. The World Health Organisation's (WHO's) modification of Wagner's Chronic Care Model is described in addition to a current initiative to implement this model, termed the Innovative Care for Chronic Conditions (ICCC). The chapter ends with the study's aims and objectives.

1.1 Background Information

Chronic illness is the leading cause of mortality and morbidity in the world today and can be divided into two categories: non-communicable and communicable. Cardiovascular disease, diabetes, and other non-communicable diseases account for 59% of global deaths and 46% of the global burden of disease (Beaglehole, 2004). Chronic illnesses share a number of key features. Most have "a long latency period, a prolonged course of illness with the unlikelihood of cure, non-contiguous origin, functional impairment or disability, and complex causality" (McQueen, McKenna and Sleet, 2001 p. 295). HIV/AIDS is one such communicable chronic disease that has recently received great attention (Kitihata, Tegger, Wagner and Holmes, 2002).

The 2000 South African National Burden of Disease study states South Africa is experiencing a quadruple burden of disease including communicable, non-communicable disease, injuries, and HIV/AIDS (Bradshaw, Nannan, Laubscher, Groenewald, Joubert, Nojilana et al., 2000). Chronic diseases place a tremendous burden on health care systems globally and are not restricted to the developed world. Over 66% of the world's diabetic population lives in developing countries (WHO, 2003). Compared with developed nations, there are twice as many deaths, due to non-communicable disease, occurring in developing countries (Beaglehole, 2004). Industrialisation and globalisation are two factors driving the

increased prevalence of chronic disease. These social movements are associated with a change in food consumption and decreased levels of physical activity (WHO, 2003).

1.2 Problem Statement

Non-communicable chronic diseases, such as diabetes and hypertension, pose a great threat to the health of Gauteng province. Being obese or overweight are risk factors associated with numerous chronic diseases. Gauteng has one of the highest prevalence rates of obesity within all South African provinces (South Africa Department of Health, 1998a). Those living in urban areas have a greater likelihood of being overweight or obese, with Gauteng being the most urbanized province; there exists a greater amount of obese individuals in a more centralized location (SADoH, 1998a).

WHO recommends a multifaceted approach that includes health promotion and prevention, as well as curative and rehabilitative strategies and methods (WHO, 2003). Using diabetes and hypertension as examples of chronic disease, this research explores the health services made available by the Gauteng provincial primary health care facilities in the Johannesburg Metropolitan area. It also documents the resources available to manage chronic disease by investigating three settings identified by the WHO's Innovative Care for Chronic Conditions framework. These settings are detailed further.

1.3 Justification

This research will apprise the Gauteng Provincial Health Department as to how chronic disease is currently being managed. Documenting services, currently available to chronically ill patients, will assist the department in identifying service provision gaps in order to improve the health of those served. Chronic disease in the Gauteng province is an important issue that deserves attention. Gauteng's high obesity rate places many individuals at an elevated risk for developing chronic disease. Numerous initiatives to improve the

population's health and quality of life have been implemented. The Gauteng health department's first strategic goal is to: "Improve the health status of the population of Gauteng".

In order to accomplish this goal and support the various initiatives, chronic disease must be managed properly. Middle aged and elderly populations are particularly susceptible to chronic diseases. Health promotion and prevention, when applied early, are proven to be cost effective and as a result improve quality of life (McQueen et al, 2001). A comprehensive approach, thus including promotion and prevention, is necessary due to the life-long nature of chronic illness, the burden it places on health systems, and the ability to prevent disease from occurring and/or worsening (Epping-Jordan, Pruitt, Bengoa and Wagner, 2004).

1.4 Literature Review

Both males and females, in developing countries, are at a greater risk of premature death due to non-communicable disease. Thirty-five percent (35%) of Disability Adjusted Life Years (DALYs) lost in sub-Saharan Africa are due to non-communicable disease (Setel, Saker, Unwin, Hemed, Whiting and Kitange, 2004). Although six of the top ten causes of death are still communicable disease (Beaglehole, 2004), this is predicted to change by the year 2020. At which time, a shift from acute illness to chronic illness is expected to occur. This is referred to as an epidemiological transition (Orman, 1971).

By extrapolating preliminary data and reviewing historical trends of developed nations, it is predicted that the developing world's experience of chronic disease will proceed faster and attack a larger portion of the population. This will be mainly due to the increasing percentage of elderly individuals (McQueen et al., 2001). As the population increases in age,

this is accompanied by an increase in the burden of chronic illness (WHL Declaration, 1996).

Non-communicable chronic disease is a serious problem in South Africa. In 2000, 38% of all male deaths and 43% of all female deaths were due to non-communicable disease (Bradshaw et al., 2000). Urbanisation and associated psychological factors are thought to contribute to a shift in many South African's eating habits, which are associated with chronic disease risk factors (Vorster, Venter, Wissing, Marquetts, 2005). In a national Demographic and Health Survey conducted in 1998, 55% of women and 28% of men in South Africa were obese or overweight. Eleven percent (11%) of men and 15% of women in South African suffered from hypertension. Of that group, only 9% of men and 23% of women were equipped with the knowledge they were hypertensive (SADoH, 1998a). A 2001 study examining diabetes in South African factory workers found age-adjusted diabetes prevalence rates of 4.5% (Erasmus, Blanco, Okesina, Matsha, Ggweta et al, 2001). These numbers point to a profound lack of awareness of and screening for chronic disease care.

In conjunction with the increasing number of people with chronic illness, many patients do not receive proper care (Epping-Jordan, et al., 2004). Compared to developed nations, very little health data is available regarding chronic disease care in developing countries (Beaglehole, 2004). What little information is known about chronic disease management in these countries suggests poor service quality and outcomes. In the Caribbean, 50% of diabetic patients had poor glucose control and yet only 5% received advice during consultations (Gulliford, Alert, Mahabir, Ariyanayagam-Baksh, Fraser, Picou, 1996). A 1997 study of 300 patients in the Western Cape Province in South Africa showed that only 49.4% of diabetics had acceptable blood glucose levels and only 38.5% of hypertensive patients had controlled blood pressure. Noteworthy is that various complications due to these

conditions (retinopathy, cataracts, peripheral neuropathy, amputations, etc.) were almost never included in patients' records (Levitt, Bradshaw, Zwarenstein, Bawa and Maphumolo, 1997). Another study of 200 hypertensive patients in the Cape Peninsula showed that 41.6% had blood pressures over 160/95 mm/Hg (Steyn, Levitt, Fourie, Rossouw, Martell and Stander, 1999). All studies provide evidence to the fact that proper health care is critical.

Low patient compliance to medication is one reason for such poor clinical outcomes. A 2005 study examining the utilisation of chronic disease medication identified gender (female), socio-economic status (wealthy), age (older) and presence of medical insurance as significant to patient compliance. This suggests inequitable usage of medication necessary to manage diseases such as hypertension and diabetes, both of which were included in the study (Steyn, Bradshaw, Norman, Bradley, Laubscher, 2005).

According to a 1995 Centre for Health Policy study of six health facilities in both rural and urban areas, few diabetic patients were appropriately managed. Identified problems included patient compliance, selection of medication and dose, and staff's lack of knowledge regarding diabetes treatment and patient education. This occurred despite the fact that some surveyed facilities had very good glucose testing rates (Beattie, Rispel, Broomberg, Price and Cabral, 1995). Another study of 288 diabetic patients concluded that although most patients received dietary advice, it was often inappropriate and incorrect. The majority of patients exhibited poor nutritional intake (high fat and low fibre), high rates of obesity, and elevated blood pressure and blood glucose levels (Nthangeni, Steyn, Alberts, Steyn, Levitt et al, 2002).

Various studies have identified barriers to chronic disease management. Chronic disease in Gauteng is often managed at the hospital level, even though it can be accomplished more cost effectively and efficiently at the clinic level (Kalk, Veriawa, Osler,

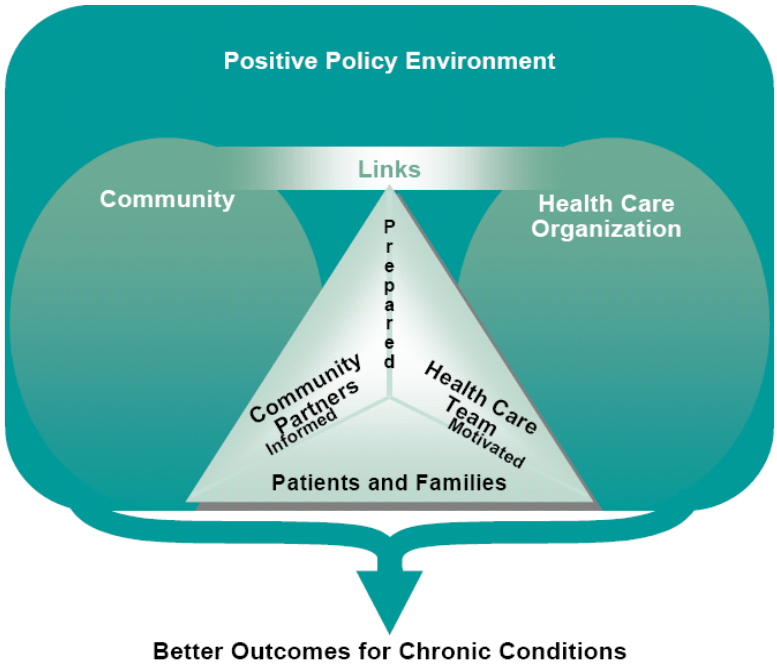
1999). A 2005 study of community health centres in Cape Town had examined the reasons as to why insulin is rarely prescribed for diabetics not responding to the maximum oral therapy dose. It identified systemic barriers, as well as patient and physician barriers, to insulin prescription. Physician barriers included lack of knowledge and lack of experience with guidelines, communication problems with patients and fear of hypoglycaemia. Patient barriers included fear of injections, non-compliance, use of traditional herbs, and mistaken beliefs about insulin. The systemic barriers included lack of time, financial constraints, and lack of continuity of care (Hague, Emerson, Dennison, Navsa and Levitt, 2005). The previous study highlighted the issue of guideline utilisation and acceptance. One study found numerous barriers to utilisation of South Africa's guidelines for hypertension and diabetes. These included the consultative process that generated the guidelines, patient beliefs and conflict with local practises (Daniels, Biesma, Otten Levitt, Steyn et al, 2000).

To address the need for proper chronic disease management, Wagner's Chronic Care Model has been adapted to resource-constrained settings by the WHO (Epping-Jordan et al, 2004). Experts from developed and developing nations came together to create this framework, entitled the Innovative Care for Chronic Conditions (Figure 1). This action, taken by the WHO, makes clear the urgency of the proper management of chronic disease as well as the priority all countries must place on the issue.

Macro Level (Policy Environment):

Meso Level (Community and Health Care Organization):

Micro Level (patients and providers):



*WHO, 2004

Figure 1. WHO's innovative care for chronic conditions (ICCC)

The ICCC is composed of three levels: micro, meso and macro. All three levels must be present and well integrated for a health system to properly manage chronic disease. The micro level is a triad consisting of patients, their family, informed community partners, and a motivated health care team. This triad is supported by a meso and macro level. The meso level has two components: the community and the health care organisation. The ICCC framework emphasises the community component in order to reflect the situation in many developing nations where the community significantly contributes to health care. Finally, the larger policy environment is the overarching component (Epping-Jordan et al, 2004).

The ICCC framework calls for the following types of health services: promotion, prevention, curative, and rehabilitation. The framework also strives to create a health care

environment where patients are empowered to manage their own conditions whenever possible. This includes educating them, as well as their family members, about their needs and how to best avoid complications. The framework calls for enlisting the community to support patients and their families for optimum chronic disease management.

Despite bleak numbers, countries are striving to implement the ICCC framework. Mexico and Russia are implementing diabetes quality improvement efforts, with Russia also focusing on hypertension and other chronic diseases (Epping-Jordan et al., 2004). Other examples include Rwanda, Morocco and the Philippines (Epping-Jordan et al., 2004). Evidence further shows that chronic disease can be properly managed in countries with poor resources (Coleman, Gill and Wilkinson, 1998). Employing the ICCC framework, this study examines a portion of the three levels necessary for optimum chronic care management (WHO, 2004).

The Chronic Diseases, Disabilities and Geriatrics cluster, housed in the South African Department of Health, is responsible for the nation's chronic disease management. One of their tasks is to formulate national guidelines for chronic disease prevention, treatment and rehabilitation. They are also responsible for providing leadership to interest groups and stakeholders, as well as advancing the rights of those with chronic disease. They issued national guidelines for various chronic diseases, including diabetes and hypertension. These guidelines include descriptions of the disease, clinical definitions (as seen below), symptoms, common treatments, medication dosages and complications. These guidelines and additional protocols are given to the provincial level, which in turn is responsible for their distribution to all provincial clinics.

1.5 Definition of Terms

1. Chronic Disease/Illness is used in this paper to refer to hypertension and diabetes, predominantly the more common adult onset diabetes.

2. Diabetes - refers to Type II, or adult onset diabetes. As defined by the South African Department of Health: a fasting glucose exceeding 7.1 (plasma) or 6.1 (whole or capillary blood) (SADoH, 1998c).

3. Hypertension - As defined by the South African Department of Health: a blood pressure, measured on two separate occasions, exceeding 140/90 mmHg (SADoH 1998b).

4. Primary Health Care (PHC) clinic - clinic operated by the Gauteng Provincial Department of Health.

1.6 Aim and Objectives

Aim

This research seeks to document the resources available to manage chronic disease in the Gauteng Province by investigating primary health care clinics, community organizations, and provincial and district support.

Objectives

1. To record the full scope of health services offered by primary health care clinics in the City of Johannesburg for the management of patients with diabetes and hypertension, including promotion, prevention, curative, and rehabilitation services.

2. To describe the role of community organizations in the city of Johannesburg in promoting good health, preventing chronic illness, and providing curative and rehabilitative services.

3. To describe the role of district and provincial management in the management of chronic illness.

Chapter 2: Methods

In this chapter, the study's design and population are addressed. The application of the World Health Organisation's Innovative Care for Chronic Conditions framework (macro, meso and micro levels) in the study is also explained. The manner in which the three levels were assessed in the study: analysis of data, possible limitations and ethical considerations are discussed.

2.1 Study Design

This is a qualitative, cross-sectional descriptive study. The WHO's ICCC framework describes three levels (micro, meso and macro) that must be integrated and coordinated in order to provide optimal chronic disease management. This research describes aspects of each level, as they currently exist, in Gauteng province. This study examined portions of each level, as a study of the entire framework would have been beyond the scope of this research. For instance, instead of studying the entire micro level (patients, health care team and community partners), only the health care team was included in the form of nurses at PHC clinics.

The province's micro level is examined with key informant interviews in primary health care clinics. The meso and macro levels are documented with key informant interviews of CBOs that support patients and district/provincial managers, respectively. In practice, however, it is recognised that data obtained from each group of stakeholders speaks to other levels as well. For example, interviews with both PHC providers (micro level) and managers (macro level) will reflect on health care organization issues (meso level). The 'Measurement' section below describes what is measured at each level.

2.2 Study Population

Primary health care clinics based in Metropolitan Johannesburg, managed by the Gauteng Provincial Government, and associated community based organizations and management structures.

2.3 Study Sample

One Gauteng province health sub-district was selected by simple random sampling from a list of sub-districts containing at least five provincial PHC clinics/Community Health Centres. The sub-district selected was located in Soweto. All six provincial clinics (4 primary health clinics and 2 community health centres) were included in the study. Community organizations were selected by snowball sampling after contacting each clinic and inquiring whether any CBOs in their area were treating patients with diabetes and/or hypertension. Not enough CBOs could be identified by the clinics and as a result the first CBOs to be interviewed were also asked about other CBOs in the area working on hypertension and diabetes. The most senior chronic disease managers at the province and region levels were selected for the macro level interviews.

2.4 Measurement

Data was collected entirely through interviews. The Gauteng Provincial Department of Health was contacted to assist in negotiating clinic access. One key respondent was selected at each site after contacting the site by telephone. The interviews were in-depth and guided by a pre-determined question list (Annexure 1-3). All interviews were recorded using a tape recorder. The research was piloted with the initial clinic visit and necessary revisions were made at this time. A table was constructed to show the themes explored by the interviews (Table 1).

The issues covered at each level are described below.

2.4.1 Micro Level

- **Micro:** The researcher telephoned selected clinics to relate the nature of the research, the province's endorsement and to identify the key informant (most knowledgeable individual regarding chronic disease management). One key informant was interviewed at each clinic. Interviews lasted between forty-five and ninety minutes and documented the following: services available to patients diagnosed with or at-risk for diabetes or hypertension, presence of necessary resources (medications, equipment, guidelines, etc.), information flow within and out of the clinic, patient education and self-management techniques, staff training; screening and referral procedures, and perceived challenges to chronic care management.

2.4.2 Meso Level

- **Meso**: Five community-based organisations, supporting chronically ill patients in the proximity of the six clinics, were visited. One key informant was interviewed from each organization to gain understanding of the community's role in chronic disease management (Annexure 2). The interview examined the relationship between the community and health sector, the organisation's structure, challenges in managing chronic disease, types of services provided, outreach activities, and access to resources.

2.4.3 Macro Level

- **Macro:** A regional manager (responsible for supporting chronic disease care at the district level within two districts) and the provincial Chronic Disease Care Programme manager were interviewed to document their perspectives and roles in chronic care management (Annexure 3). The interview schedule contained open-

ended questions and produced qualitative data to describe the management of chronic disease by these key actors. The interview also examined the following issues: chronic care management goals, information flow, how they evaluate clinics, the presence of partnerships, communication with the other two levels, and how they are working to bring about continuity and coordination.

Table 1. Themes explored by interview at each level

Macro – Provincial & Regional Management	**Meso – Community-Based Organisations**	**Micro – Primary Health Care Clinics**

• Goals
• Challenges
• Budget
• Personnel
  ○ Skill Mix
  ○ Worker support
• Patient Data
• Identify population's needs
• Communicate with other levels
• How evaluate clinics' performance
• Patient self-management
• Community responsibility
• CBOs active
	• Goals
	• Challenges
	• Staff types
	• Staff training
	• Budget
	  ○ Source
	  ○ Expenditures
	• Communicate with other levels
	• Community involvement
	• Patient knowledge
		• Goals
		• Challenges
		• Patient
		  ○ Information
		  ○ Self-management
		  ○ Compliance
		• Health care worker
		  ○ Types
		  ○ Support
		  ○ Training
		  ○ Incentives
		• Medication supply
		• Services provided
		  ○ Promotion
		  ○ Prevention
		  ○ Curative
		  ○ Rehabilitation

2.5 Limitations

This research was conducted with the hope of informing the Gauteng province about the current services offered by their clinics. It was not representative of the entire Gauteng province due to the selection of clinics in the Johannesburg Metropolitan area only. In

addition, for reasons of access, only provincial (rather than local) government clinics were evaluated. Another limitation was the variation in the types of key informants interviewed at each clinic. Attempts were made to interview the same type of health care worker, such as head nurse, at each facility. This was difficult, however, as each clinic was unique in its worker composition. As a result, the key informant was selected according to who was most knowledgeable regarding chronic disease management. Patient interviews were not a part of this research.

A final limitation was found within the researcher's ability to verify information derived from key informant interviews. Trust and openness, on the part of respondents, would have been diminished if the researcher was seen to be deliberately "checking" their responses against those of other colleagues. There was also the danger that key informants represented their services overly favourably and thus reflected what *should* be done according to the guidelines, rather than what was provided in reality.

It is acknowledged that the interview methodology is a subjective (rather than objective) assessment of the nature of chronic disease care services. However, the manner in which various actors describe chronic disease services (for example, what they include or exclude in the definition of chronic disease care) provides useful insights into the nature of practice. Secondly, by triangulating responses from several stakeholders on the same phenomenon (e.g. information systems) it is possible to deduce fairly confidently what happens in reality.

Other types of bias are possible with this type of study. The method used to select the key informant allowed for selection bias, simply based on who was working at the clinic on that particular day and to whom the researcher had an opportunity to speak. With the qualitative and semi-opened ended nature of the interviewer technique, there exists also the

possibility of interviewer bias, where rapport is more easily established with certain interviewees than others. The researcher was careful to ask the questions in the same manner, during different clinic visits, and to ask the questions in the same order.

2.6 Data Processing Methods and Data Analysis Plans

The researcher, who has satisfactorily completed Masters level courses in empirical methods and statistical analysis, processed all data. All interviews were recorded and transcribed by the researcher. The responses in the transcripts were then coded thematically according to the ICCC level and subject matter (Table 1).

2.7 Ethical Considerations

This research used health care workers as informants. All informants were informed they would remain anonymous to both the researcher and in the report. They were made fully aware they were participating in research by supplying them with a one-page information sheet summarizing the nature of the research and their role in the project. The name of the health facility was coded and not reported in the research. Informants were informed that a tape recorder was used during the interview and the data would be destroyed after data was collated. The informed consent sheet (Annexure 4) was attached to the information sheet (Annexure 5-7) and was signed before research commenced. The informant kept the information sheet and the researcher kept the signed consent form. Organisation names and other identifying characteristics are not included to ensure anonymity. Ethics approval (R14/49) was obtained from the University of the Witwatersrand's Human Research Ethics Committee (Annexure 8).

Chapter 3: Results

In this chapter, the results of the interviews are presented according to the three levels: macro, meso and micro. Information from the regional (district) and provincial manager interviews are presented first (macro), followed by community-based organisations (meso) and finally PHC clinics (micro). All information is categorised in tables based upon interviewee's response and topics common to all three levels. These include: challenges in chronic disease management, goals for chronic disease management, financial and human resource issues and patient information.

3.1 Research Participants

The sampled sub-district was located in Soweto and all interviews took place within the sub-district, with the exception of the manager interviews. The sub-district is densely populated and contains two community health centres and four primary health care clinics that are provincial (rather than local) government owned. A major hospital is also located within the sub-district. These facilities are the major providers of health education, treatment, and rehabilitative services for chronic diseases.

The Provincial Chronic Disease Care Manager was interviewed at the Provincial Headquarters Office and the regional manager (in charge of supporting the Johannesburg Metro District) was interviewed at her regional office. The five interviews with CBOs took place at the their offices or at the nearest clinic if they did not have an office. All CBOs operated within the sub-district and served approximately 100 individuals, although two had a much greater scope. Those interviewed at CBOs held leadership positions in the organisation and had been involved for many years, or since the organisations inception in

the case of newer organisations. All interviews with PHC providers took place at the health care facility.

3.2 Macro Level – Chronic Disease Managers at Regional and Provincial Level

Two managers, one at regional (district) and one at provincial level were interviewed to gather data regarding Gauteng's policy environment for chronic disease care. The first interviewee had formal management and administrative training as well as clinical training as a nurse (Table 2). She had previously worked for the district nursing service as a chief professional nurse and had operated in her current position for two months, which had been vacant for the previous year. The second interviewee formerly worked as a head matron within a community health centre and had held her current position for a number of years. The managers held various responsibilities with respect to chronic disease care. The provincial manager reported that her main task was receiving policy from the national level and handing it down to the district level, as well as ensuring that this policy is implemented. She implemented by hosting workshops and visiting individual clinics. The regional manager cited her responsibility as ensuring national policy, regarding chronic disease, is adhered to in the region's 27 clinics. She was also in charge of eye care and geriatrics.

Table 2. District and provincial managers: profiles and responses

	Manager 1 (Region)	Manager 2 (Province)
Respondent's background	Degrees in management and administration, former chief nurse for district nursing service	Previously served as head matron at Community Health Centre, served in current position for numerous years
Respondent's current responsibilities	In charge of region's old age homes, chronic disease and 2020 eye sight initiative in 27 clinics	Conduit for policy and procedure between national and district, ensure implementation via workshops, support districts
Goals in managing chronic disease	To promote healthy lifestyles and prevent disease, to prevent diseases from progressing once occurs, to enable citizens to live full life with no stigma and discrimination from employers	To decrease prevalence of chronic diseases and complications
What are the greatest challenges in managing chronic disease?	Money to buy medication, reaching out to people, no system to ensure patient compliance	Human resources (national policy is not realistic), when clinics do not have drugs it is their fault

The regional manager reported two main goals for chronic disease care. The first goal was a healthy lifestyle for everyone. "To prevent (chronic disease) if possible or to manage it once it happens. Even for people who are affected, to have a full life, to be able to live with this disease…and have no stigma". The second goal was to ensure that employers do not discriminate against workers with chronic disease who, "every month are asking for a day to go to the clinic". For the provincial manager, "The goals of the province are to reduce the prevalence of these chronic diseases and the complications. Unfortunately diabetes is going up everyday, but what is happening nobody knows".

Each interviewee was also asked about the greatest challenges in managing chronic disease. The regional manager stated the high cost of medication and the lack of a system to track patient compliance because, "there is much research on patients who have their medication and keep them at home and they are not controlled". She also cited the inability to reach out to people "in the back of the beyond", to bring more people to the clinic who are sick and not currently attending. The budget was another challenge; "…it is never enough to do what you want to do, but that is understandable". The last challenge she mentioned was the erratic availability of a car; "There are not enough of them for sometime now, for years. In fact, this morning I was to go [location] to collect some things and take them to Lillian Ngoyi, but I found there is no car. I'll see in the afternoon, otherwise I won't go".

The provincial manager responded that human resources pose the greatest challenge, specifically the inability to implement national's policies regarding the numbers of caregivers. "…the national policy says we must have educated staff for non-communicable disease. But it is not happening because people cannot desert other patients and now look at this diabetes. If you have got 5 or 4 nurses in the facility, where will you get the nurse to look strictly at diabetes and hypertension? But the policy says we must have dedicated staff for chronic diseases. That is the major problem". The manager volunteered that medication supplies are "running very well, we have a very good system running. If a clinic does not have a drug, maybe they did not order in time".

Interviewees were asked questions to gain a better understanding of their financial and human resources and decision-making authority. The regional manager stated that they write their own annual budget by looking at the number and type of activities they wish to conduct. This is then submitted to the provincial level, which determines the budget based

on number of outpatients within the previous year. The province will cut the district's budget if the budget is not completely used. "National just gives. Province gives everyone however much. They are prioritising. What methods they use, I don't know. But you will never run out of things in which you are really in need" (referring to medication, etc).

The provincial manager emphasised the difference between budgets at the clinic level and those at the provincial level. "They are managed in the facilities and they are budgeted in the facilities. Here in central office we have our own operational plans we develop". Most of the budget goes to cover the costs of petrol when she visits clinics, salaries, training, workshops and awareness campaigns. "I am given R 600,000.00 to see that I do my little things up here in the central office. But the major budget is down there in the districts".

Table 3. Resources for chronic disease care

	Manager 1 (Region)	**Manager 2 (Province)**
Budget comes from…	Provincial approval based upon last years number of outpatients and expenditures	Own budget comes from central office, no involvement in clinics' budgets
Money goes to…	Support groups, awareness campaigns, salaries of region-level staff and medication	Training, staff salaries, workshops and petrol for clinic visits
What do you think of the skill mix?	Mix is adequate, but not enough workers	Good mix, but not enough workers
How do you support health care workers?	Being encouraged to attend workshops, but mainly at clinic level	Speak with clinic staff and in-services, but mainly at clinic level

Some money goes to buy necessary equipment clinics cannot afford. "We are not to buy it for them, but we must make sure the patients get quality care" (speaking about buying glucose testing equipment for a clinic). Donations from pharmaceuticals and other companies are an important part of the budgeting process. The budget is to be completed

only after donations are arranged. This ensures that an excess of money is not budgeted to an area that will receive donations, and therefore, can be used elsewhere.

In reference to the different types of health care workers available to provide services, both managers felt that there was an adequate skill mix. They each divulged the problem of staff shortage. Manager 1 stated, "At this level I think it is OK. But [at the clinic level] patients come looking for help, then they find out they wait for a long time". When asked how they support health care workers, both managers responded that such was really the responsibility of the clinic level, "…basically it is from the coordinators in the clinics". The managers reported that they do lend support by encouraging paid workshops and being willing to listen to nurses when they visit the clinics.

Pertaining to how the needs of the community are recognised, one manager cited the role of awareness campaigns. Many people attend these campaigns and are screened for chronic diseases. Some are referred and become new patients at their local clinic. Also, an awareness campaign for hypertension may uncover another chronic problem such as diabetes. The other manager believed that community-based organisations and community health committees were the best ways to identify the needs of the population.

Table 4. Communication with other stakeholders

	Manager 1 (region)	**Manager 2 (province)**
How do you identify the population's needs?	Referral cards from awareness campaigns and school nurses	Through CBOs and health committees
What patient information do you collect and how is it used?	None. All kept at the clinic level in registry	# of uncontrolled patients each month
What partnerships exist between the health sector and other stakeholders?	Private sector donations	Private sector donations
How do you receive feedback from clinics?	Clinic visits	Monthly reports including: # of support groups, any problems, projects and # of uncontrolled patients
How do you judge clinic's performance?	Head count vs. catchment area, surprise clinic visits	Surprise clinic visits, suggestion boxes
How do you communicate with upper level management?	Monthly report ("theoretically")	Call when necessary

With respect to the recording, as well as the management and analysis of patient information, managers reported that any patient information collected at clinics is mostly confined to each patient's individual card. This card is kept in the possession of the patient and is not stored, at any time, within the clinic. Each clinic claimed to maintain a chronic disease registry that is updated daily by the head PHC nurse. This registry contains the name, surname, date and disease state of each chronic patient. Each clinic sends a monthly report to the management level. This report contains a headcount of chronic patients, the status of the clinic's support group and any problems encountered. The chronic registry is used mainly for budgeting purposes. Each clinic is allocated funding based on the population it serves. In fact, the district manager cites budgeting as her primary responsibility. Patient

information, such as a monthly blood pressure reading, is recorded on the patient's card and is not available to be aggregated or analysed at any level. Neither manager felt the need for any more information than the monthly headcount to be necessary at their level.

Partnerships between the government and private sector are important in aiding the health sector. In addition to the role of donations from the private sector in budgeting, private sector employees also volunteer at awareness campaigns. They donate equipment as well as healthy foods to be used at such campaigns and they train health care workers to use new equipment. One manager states; "We work very well with the private sector, especially pharmaceuticals" (obtaining extra supplies or supplies at a reduced price).

Both managers used spot-checks to monitor clinics during clinic hours. In this way, they were able to note whether or not the diabetes support groups were meeting and whether they were indeed being educated. Some clinics recorded the time on the patient's card when they entered the clinic, allowing for managers to spot-check patients' cards to monitor how long they had been waiting to see a nurse. The visiting manager may call a brief meeting during clinic hours to discuss a problem with the staff. The staff can relay their frustrations to the manager at this time as well. Suggestion boxes were also used to monitor clinic performance. Typical suggestions by the community included, "the nurses take tea and leave us unattended", "not talking nice" and comments to the effect that the patient did not receive appropriate supplies.

Both managers felt the macro, meso and micro levels were operating together. One described the relationship as follows: the patient goes from the hospital to the clinic. The clinic calls the CBO, who is then able to receive information about the patient and begin home-based care. The other manager described the relationship as "one long thread" and

"they remote control us" and " there is someone on top of the other; they make the guidelines and give it to us".

The ICCC calls for community involvement if chronic disease is to be managed properly. Both managers felt the community must be involved. One manager stated the community must "be truthful to themselves…and take ownership of their condition". The other manager cited a different role for the community and emphasised the community's responsibility to inform the health sector if something was wrong, while at the same time protecting community health workers. She also stated, "if you don't involve the community, it will not go well".

Table 5. Opinions regarding other stakeholders

	Manager 1	**Manager 2**
How are the three levels operating?	"It is 1 long thread, they remote control us…tell us what to do"	Described hierarchy of a patient in a hospital, the clinic, the CBO then the patient
What is the community's responsibility?	To be truthful to themselves, come for treatment and take ownership of their condition	To report what bad things are happening and to protect health care workers
How should patients help themselves?	Health promoters in clinic waiting areas	Problematic because patients are not provided with any equipment
Are CBOs/CBOs active?	Yes, run by pension nurse	Home-based care and hospices all government funded

It is important that patients with chronic disease learn to manage their illness outside the clinic environment. While one manager cited self-management as a problem, "we don't provide them with the equipment", the other manager cited health promoters as the primary means of helping patients manage their own illness. These health promoters were present in the waiting rooms to speak on a wide array of health issues and were available for questions.

Community-based organisations play an active role in providing care for patients with chronic disease. According to both managers, the primary role of CBOs is providing home-based care to patients with chronic disease and/or HIV/AIDS. They both stated the primary patients of most CBOs are those suffering from HIV/AIDS. Clinics contact CBOs when they have patients who they know are unable to come to the clinic for treatment and medication. CBOs also come to the clinic when they have too many patients in one area, or have patients that need more extensive medical care. One manager said they try not to encourage the use of home-based care too often because patients and their families become too reliant on them. Retired nurses on pension play a large role in such home-based care organisations. All the CBOs discussed by the managers were funded by the government.

3.3 Meso Level – Community-Based Organisations

Five community organisations were identified by asking PHC clinic staff about CBOs working in the area on patients with hypertension and diabetes. CBOs 1 and 2 worked exclusively with diabetic and hypertensive patients. All others dealt more with HIV/AIDS, though they did also work with patients who had other chronic illnesses. There are very few organisations working exclusively with chronic disease; and for that reason the organisations working on both HIV/AIDS and chronic diseases were included in the study. All organisations are based and operated in Soweto. Two of the organisations focused specifically on diabetes, while the other three focused on HIV in addition to chronic diseases such as stroke, cancer and any patients who might be bedridden.

The interviewee for Organisation 1 had been involved in chronic disease care for 22 years. He was a layman, though he exclaimed:, "Many of the nurses, they think I am an expert. But I just listen and learn all the time". His job was to travel to the more than 20 clinics in the Soweto area and to help establish diabetic support groups. He personally visited

these clinics 3-4 times each year to ensure the support groups continued to meet and operate. He also 'teaches the teachers' on an annual basis. At least 40 individuals for the various clinics come together once each year for training on how to best convey diabetic care to those attending support groups run within the clinics.

This organisation had no offices, phone or fax services. The interviewee was usually located at one of the government community health centres. The centre's staff knew him well and he has access to their offices as needed. However, he did not have access to their budget or supplies. The organisation was affiliated with a larger organisation operating throughout South Africa. The Soweto branch of this organisation stated their mission as, "…to see that people know about diabetes, and who is likely to have it and why. And then teach them that diabetes does not kill, but it is incurable…and to help as many educators as possible".

The organisation's programs included weekly facilitated support group meetings at clinics as well as the conduction of approximately 24 awareness campaigns each year. Each clinic contained two executive members whose job it was to organize the weekly support group meetings. Each clinic had one or more days dedicated to the education of a particular chronic disease. Sisters encouraged attendance for those patients diagnosed with these conditions. Support group meetings were held on this day each week. Sisters and other health care professionals, such as dieticians, were asked to speak during these meetings to share information and educate patients. Patients were also encouraged to share their experiences and fears with one another so that they might support each other.

Table 6. Profile of community based organisations

Org. ID #	1	2	3	4	5
Interviewee	22-year caregiver and trainer within the organisation, ward committee member	Serves on organisation's executive committee & heads support group in one clinic	Caregiver working in the organisation for 3 years	Caregiver and former organisation supervisor for 2 years	Caregiver working in the organisation since its inception
Year established	1983	2004 (recently independent)	2000	2003(officially recognised but has been operating since mid 90's)	2004
Location	No offices	No offices	Church	Church	1-room office
Affiliation	Nationally recognized organisation	Independent	Church	Church	Independent
Mission	Awareness of diabetes	Awareness of diabetes	Fight stigma & discrimination of HIV/AIDS	Help people in need	Help DOH & community
Programs	Awareness campaigns and support groups	Awareness campaigns and support groups	HIV/AIDS support groups, HBC, OVC	VCT, HBC, HIV/AIDS support group	HBC
Focus	Diabetes	Diabetes	HIV/AIDS, chronic disease is secondary	HIV/AIDS, chronic disease is secondary	Even mix of HIV/AIDS and chronic disease
Number of patients	100's	100's	168	100+	114

Organisation 2 had operated in the Soweto area for more than 20 years as well. After much frustration, it declared independence from the larger organisation in 2004, due to a

promised office and budget that was never realized. Their mission is stated as, "…to make people aware that diabetes is there and it kills". The organisation is involved in establishing support groups as with the first organisation with whom it collaborates. It also works with Organisation 1 and other stakeholders on the monthly awareness campaigns, which are held at clinics located throughout Soweto.

A master schedule is made at the beginning of each year. Clinics take turns hosting the event, which runs from approximately 10 a.m. until 1 p.m. These events routinely attract between 200-400 individuals, with the last November meeting (Diabetes Awareness Month) attracting 1,600 patients, family members and other attendees. The campaign is social and educational in nature. Various speakers talk on subjects including: proper foot care, diet, exercise, and the role of insulin in the body. Refreshments are served during the meeting and lunch is served afterwards. In an effort to provide a healthier home-life, participants are encouraged to bring family members so that they might learn about diabetes care as well. Organisations 3-5 were established between 2000 and 2004. All were initially founded as organisations that would specifically tend to community members with HIV/AIDS. The scope of care was quickly broadened to include bedridden individuals stricken with cancer, stroke and other illnesses.

The Department of Health (DoH) was involved in funding all the organisations interviewed, though to varying degrees. Organisations 1 and 2 received funding, on a limited basis, in order to better assist with the large-scale awareness campaigns held each month. The guest speakers, charged with providing educational training during these events, were also supplied by the DOH. T-shirts were occasionally provided by the DOH and were given to participants at these functions in an effort to boost community awareness of health issues. These organisations also solicited members for monetary donations each year, but they are

not required. These funds go towards the provision of refreshments at meetings and to cover the cost of transport to and from the awareness campaigns. Transport was occasionally provided by the DOH when excessive distances are involved.

Interviewee 1 stated that under the former governmental structure, he had access to clinics' budgets. This was no longer allowed. He added that the current structure for accessing DOH budgets, "takes too long. It never actually happens". With no budget for copying and other administrative tasks, these organizations must depend on volunteers and informal networks; "…there are those people who have relatives who work in other places. Maybe policemen who work in offices with typewriters and copy machines. They say, how many copies do you want of this? Say 100, and they bring them". The DOH had promised to fund this organization on a regular basis if they submitted a business plan.

Table 7. Resources and personnel

Org. ID #	**1**	**2**	**3**	**4**	**5**
Financed by:	Member donations, occasional DOH	Member donations, occasional DOH	DOH, South African Bishop's Conference	DOH, private donors (businesses)	DOH, private donors (businesses)
Goes toward:	Food & transport	Food & transport	Stipends and administration	Stipends & supplies	Salary & supplies
# of workers:	Could not respond	32	14 (for HBC)	16	14
Worker types	Volunteers (lay and professional)	Volunteers (lay and professional)	Project manager, administrator, supervisor, retired nurse and health care workers	Supervisor, counsellor, volunteers & caregivers	Project manager, secretary, administrator & caregivers
Worker training:	Various	DOH 69-day course			

Organisations 3-5 were officially recognized by the DOH as community-based organizations (CBOs) and therefore were recipients of annual funding. This funding increased each year, with the initial amount depending on how many patients the organization served. This included both the number reached via home-based care as well as the number of patients who routinely attended support groups and other activities. Organisations 3 and 4 mentioned occasional monetary donations from corporations, as high as R50,000. Organisations 4 and 5 also reported weekly donations of supplies (soap, gloves, etc.), each from a large company. The DOH money budgeted to each organization was used to support the workers in the form of salaries or stipends. This amount was commensurate with the amount of training each worker had completed with the DOH. This money also covered administrative costs (Organization 3) and for the purchase of supplies (Organization 3 and 4).

Organisations 1 and 2 were operated entirely by volunteers. Some of these volunteers were trained professionals, such as dieticians and clinicians who spoke at awareness campaigns. The majority were lay workers, many of whom have been diabetic for years and were interested in passing on their knowledge gained through personal experience. Organisations 3-5 contained approximately 15 members dedicated to home-based care services. This included caregivers, a project manager, supervisor, and/or counsellor. Retired nurses also played a consulting role in Organization 3. The DOH 69-day training course was very well known by all organizations and many of their caregivers and staff attended this course. When asked about the content of this training course, one interviewee responded, "mostly HIV, not so much on things like diabetes. They don't focus much on that".

Questions were posed to discover the avenues of communication and information exchange between CBOs and the DOH, health clinics, the community and other CBOs.

The DOH was involved in all the CBOs included in this study. Four out of the five organisations submitted monthly reports to the DOH. These reports contained information including: number of patients served each month, any problems experienced, particular achievements, budget issues, and the number of deaths. For their own records, some organisations recorded patients' condition, house number, and the total number of inhabitants of the house. By calculating the amount of patients each organisation had served this had helped the DOH decide how much money to give to each organisation. Three of the organisations received yearly funding from the DOH.

Table 8. Relationship between CBOs and DOH, clinics and community

	1	2	3	4	5
Dept. of Health	Submit monthly reports, ask DOH volunteers to speak at awareness campaigns	Speak to clinicians in training upon request, attend monthly CBO/DOH meetings	Submit monthly reports, yearly funding, attend monthly CBO/DOH meetings, receive government-organized training, occasional visits by DOH to monitor the org.	Submit monthly reports, yearly funding, attend monthly CBO/DOH meetings, receive government-organized training, occasional visits by DOH to monitor the org.	Submit monthly reports, funding, attend monthly CBO/DOH meetings, receive government-organized training
Clinics	Facilitate communication between clinic and patients, hold meetings at clinics	Hold meetings at clinics	Obtain medication for clients, occasional meetings with clinic staff when needed	Obtain medication for clients	Clinic will call if need their assistance is needed
Community	Awareness campaigns and through health clinics	Door-to-door visits, radio, awareness campaigns	Door-to-door campaigns, radio and local newspaper	Word-of-mouth, church connections and luncheons	Door-to-door visits and pamphlets
Do other chronic disease CBOs exist? If so, how do you work with them?	1 health desk at a local church, coordinate efforts with one other chronic disease group for awareness campaigns	No others. Coordinate efforts with one other chronic disease group for awareness campaigns	One other-Working with them so they do not duplicate services	None.	One other - traditional healers

Three of the five organisations had staff members that participated in the DOH hosted 69-day training course. Caregivers were paid based on the amount of government-sponsored training they had completed. A monthly meeting was held in Soweto that included government representatives and representatives of the various Soweto-based CBOs. Four of the organisations had sent a delegate to this monthly meeting. Two interviewees reported that a DOH employee visited their organisation "occasionally" to monitor their services. One organisation stated that they had previously asked the DOH for volunteers to speak at monthly awareness campaigns, and the DOH was always happy to send someone. Finally, one respondent discussed the DOH having asked their organisation to occasionally send volunteers to help them train clinicians, to which they agreed.

Local health clinics were also involved in all of the organisations. Both diabetes-focused CBOs held their meetings at the clinics, which were used as unofficial headquarters since they had no offices of their own. They had built a relationship with clinic staff over many years. One organisation used contacts to secure medication for the clinic, "Most of what the community cries about is medication. They go to the nurse, then they say there's nothing we can do. But we have access to senior people. We say, 'down there, the nurses do not have these things (necessary medications)'". They also listened to patient's complaints during support group meetings and discussed these with the head matron. Interviewees were also asked how they made themselves known to the community. Organisations 1 and 2 responded that the community learns about their work through the health clinics and awareness campaigns. The other groups used local radio and newspaper, door-to-door visits and pamphlets.

When asked about the existence of other CBOs working on chronic disease, four were able to report of one additional CBO working on chronic disease. Noteworthy was that

all of them focused partially on HIV. One interviewee shared information about a health desk that operated out of his church. This health desk tended to the various needs of the congregation and surrounding community, including individuals suffering from dementia, stroke and HIV. Another interviewee reported the use of a group of traditional healers that were operating in a nearby neighbourhood. Only one reported they were working together with another CBO, "to work together to stop the problem (of duplicating services)". All respondents mentioned at least one organisation in the area working on HIV/AIDS and orphan issues.

Interviewees were asked a number of questions in order to gain insight into their opinions pertaining to the existence of a healthy relationship between community, clinics and the policy environment. When asked whether they felt patients were knowledgeable as to their medical conditions, all five replied negatively. One responded, "They have none at all. He is not told about diet, exercise, and medication. That is where we come in, to teach them about those tablets and about the insulin". Another stated, "…with the chronic diseases like diabetes and stroke, people are just clueless when it comes to that. They just don't have much information on what causes that or what they can do to prevent or control whatever chronic illness they have".

Interviewees were also asked their opinion in terms of the greatest challenge seen in managing chronic disease. The answers ranged from finances; "We fail people just because of funds", to issues concerning patient involvement and adhering to caregiver's advice. One said, "…you know what to tell them, that you mustn't take alcohol. Many people take alcohol and will just do as they please". One organization cited their caregivers' lack of chronic disease knowledge, "…not having much or adequate information on how to deal with someone who has stroke or something, because they will do more on HIV".

Table 9. Patient knowledge, challenges and community involvement

	1	2	3	4	5
Are patients knowledgeable?	No	No	No	No	No
Greatest challenge in managing patients with chronic disease?	Finances	Getting patients involved	No support at home & caregivers' lack of chronic disease knowledge	Not able to do enough to help patients	Patients do not listen & patients feel helpless
Overall feeling that the community is involved?	No	Yes	No	No	No
Are community leaders involved?	No	Yes	Yes – Church elders	Yes – Church elders	Yes – Churches
Does the triad function well?	No	Yes	No	Yes	No

Four of the five of respondents felt that the community at large was not involved in chronic disease management. One reported, "…the responsibility of our community is to take care of themselves, of their people. But there is negligence. People of the community were taken care of by people in the community. The community has no love, the community no longer takes care of their people".

Two respondents felt the relationship between the three levels (macro, meso and micro) was positive and functional. "We do sometimes meet together…the clinics come here and tell us so we can work together with them". The other three responded negatively, with one stating, "I would think so, but not much is really done. People do get much information about HIV/AIDS. But with the chronic diseases, how to deal with them exactly, with the diet and everything, it isn't something that has been dealt with that intensely. With a patient (that) has got stroke or diabetic, we do take those type of patients but there isn't

much a caregiver can do probably". Another replied, "It is just a loose relationship, but it does not work well. There is not communication between the committees and the community. National talks with provincial, provincial with local government, but it ends there. It doesn't go down to the community and the community doesn't know what is happening".

3.4 Micro – Primary Health Care Clinics

Six provincial primary health care clinics were visited. In all cases a PHC sister was interviewed. Respondents described two types of patients: those already diagnosed with diabetes and/or hypertension and those who were not yet diagnosed. The sequence of events, or care pathways, for each type of diabetic patient follows.

All new patients received cards (also referred to as 'bead letters') that they kept in their possession. The patient was required to bring this card to the clinic for each visit. This card contained a patient number (sometimes the patient's birth date) and full name. Some clinics included additional information such as employment status. The nurse reviewed this card during each visit and recorded all new observations such as weight and blood pressure.

A patient who had yet to be diagnosed was tested when a nurse heard traditional complaints, such as frequent thirst or urination, after which, they sent the patient home with instructions to not eat and return the following day for a fasting blood glucose test. The results of this test would confirm whether or not the patient had diabetes. Once diagnosed, the patient was instructed to return in one month and received education regarding diet, exercise, and medication. Some clinics provided pamphlets including this information as well.

Diabetic patients queue at clinics early in the morning (6-7 a.m.), which generally aim to finish seeing chronic patients by 11 a.m. Each patient visits a number of stations while at

the clinic. Nursing assistants are present at each station to record the patient's weight, perform urinalysis, monitor blood pressure, and to take a blood glucose reading. The data from each of these measurements is then recorded on the patient's card. The date was written at the top of these measurements in order to provide a chronological sequence of measurements. Two facilities cited the use of the 'chronic stamp' for recording clinical measurements in the patients' notes (Figure 2). Nurses are able to look back on a patient's card to note progress or regression. Patients keep their cards and no data from them is recorded at the clinic. The clinic does, however, collect a daily headcount of patients served.

		Diabetes	Asthma	Hypertension		Epilepsy	Control
Date	Urinalysis	Blood Sugar	PF Meter	BP	Failure: Yes/No	No. of Fits	Yes/No

Figure 2. Gauteng department of health non-communicable disease stamp

Over a series of visits a patient may become "controlled:. Such patients have consistently shown stable blood pressure, glucose levels and weight. PHC sisters make the judgment call as to when a patient is considered to be "controlled", and they refer to these patients as "repeats". At which time, the patient is instructed to return only to pick up medication each month. These instructions are written on their card, and this period of "medication-only pickup" lasts for a span of three months. On the appointment date of the fourth month, the patient rejoins the queue for all "non-controlled" patients. Some clinics

have "fast queues", which allow "controlled" patients to quickly receive their medication and bypass the normal queue for all other "non-controlled", chronic patients.

All micro-level interviewees were current PHC sisters at a PHC clinic, and one held additional responsibilities as an administrator. All sisters provided identical responses regarding their duties within the clinic (see Table 1). Responses were taken from questions posed regarding the sisters' goals for chronic disease management. Statements made focused on reducing chronic disease prevalence, keeping patients healthy, preventing complications, and highlighting the central importance of HIV and TB at that clinic.

All but one of the interviewees responded that issues involving patients were the biggest challenge in managing chronic disease. The health care workers appeared frustrated that patients did not comply with their medication regimes or heed diet and exercise advice. "The challenges we have are the patients. I don't think the patients are serious about it. It is always your [sister's] responsibility. Patients are smoking, and most of our patients are obese. They don't exercise. People will tell you, I don't have the money to buy these things [healthy food]". Some were quick to imply that this was not the patient's fault however, "They will tell you they are not working; they do not have good things to eat. With the male patients, they will tell you, 'Sister, I do not cook. My wife, my kids, they cook and they bring the wrong food [with salt]."

One of the more senior respondents felt that health care workers must also share in the responsibility for this situation. "The staff, I don't know how to put it. Just let me be open. As a primary health care sister, you feel your duty is just to see a patient and then 'next, next, next' and you do not realise that there are other factors you have to do despite saying next". Half of all clinics visited had a fast queue. This queue is reserved for those patients with no acute symptoms. "It is a straight queue to manage time". Those clinics that

did not have fast queues ask patients "who is special?" or something similar to identify patients who may need to be seen quickly for any particular reason.

Table 10. Basic clinic information, goals and challenges

	1	2	3	4	5	6
Interviewee's position	PHC sister	Administrator and PHC sister	PHC sister	PHC sister	PHC sister	PHC sister
Interviewee's duties	Attend to: chronic patients, paediatrics, acute, emergency cases and dispense medication and provide referrals					
What are the goals of the clinic in managing chronic disease?	Keep patients as healthy as possible	Reduce the number of patients with chronic illness	-	Promote PHC to the community and reduce TB/HIV	Decrease number of chronic illness we see and prevent complications	-
What are the challenges in managing chronic disease?	Compliance, traditional beliefs, staff/medication shortage	Administration & dealing with nurses	Patients not controlled (diet)	Smoking & alcohol	Patients not controlled (medication & diet)	Patients' food choices and smoking
Do you have a fast queue?	Yes	Yes	No	No	Yes	No

With patient compliance consistently identified as a key challenge in managing chronic disease, it is important to learn more about how the clinics monitor patient compliance. All respondents stated that they examined patients' cards to note whether or not they were practicing compliance. They use these cards to distinguish as to whether or not patients have been regularly attending clinic each month. Furthermore, they were able to track patients' clinical data such as monthly blood glucose measurement and blood pressure. Some also discussed the importance of asking patients whether or not they had completed their medication. Many patients told them they still had tablets at home and did not need more. As a result, they were careful to only dispense one month's supply of pills. This question was asked to learn if they were being compliant with medication. Again, no patient

information was kept at the clinic or transmitted to any other level for evaluation. The only information retained at the clinics was a monthly headcount.

Each interviewee was asked what they had expected patients to do on their own outside the clinic (reflecting on the concept of self-management). All responses pertained to patients listening to the education they had received in clinics regarding exercise, medication and diet, although some highlighted other issues. When asked what she meant by 'take care of themselves', one interviewee explained, "The person either has hypertension or diabetes and they don't know about their diseases. So outside the clinic, if they are going to eat sugars and salts and fats, they will not get better. And treatment, they take at home outside the clinic. There must be re-emphasis of education, self-care and hygiene".

If patients are to take care of themselves outside the clinic, how do clinics empower patients to make this possible? All those interviewed stated that patients were given education and pamphlets. It was difficult to determine how often these pamphlets were provided, but the provincial level delivers them to the clinics. PHC sisters give education while they are providing treatment, as well as health promoters. These health promoters spend mornings speaking about various health issues ranging from the proper storage of poisons in the home to breast-feeding to chronic diseases.

Table 11. Interaction with patients and management of information

	1	2	3	4	5	6
How do you monitor compliance?	Progress in patient's card	Examine patient's card	BP and sugar measurement on patient's card	Clinic attendance on patient's card	Clinic attendance on patient's card & if medication is finished	Clinic attendance on patient's card & if medication is finished
What do you expect patients to do on their own?	Education & 'take care of themselves'	Exercise & take medication as prescribed	-	Have proper lifestyle, attend follow-up visits, family support	Continue on with life	Comply with diet, exercise and medication
How do you help them self-manage?	Education about diet, exercise and medication compliance					
What patient information is collected?	Headcount of cases seen – broken down by age (under 5 and older)					
What do you give patients?	Pamphlets to aid in education					

Chronic disease is complex and requires skilled staff to manage properly. Two of the facilities mentioned in the study included medical doctors. Each clinic had various types of health care workers, including nurse assistants, enrolled nurses, registered nurses and PHC-trained nurses. Psychologists, social workers and retired sisters were present in only a few of the clinic settings. All but one felt the skill mix was adequate and a few answered hesitantly. At this point in the interview, all the respondents made mention of a staff shortage, that while there may be the adequate types of health care workers, there were not enough of them.

All health care workers felt their training was adequate and up-to-date. All discussed the weekly training sessions that took place at Lillian Ngoyi Community Health Centre on Wednesdays. This was run by the province. Each week a different topic was addressed, and when necessary, a particular topic spanned 3 to 4 weeks. Despite weekly training sessions, most of the interviewees felt they were not supported. They did not necessarily blame this on management however; "She (coordinator) is doing her best. It is just a big clinic with everything here. She is just the acting coordinator and has to train us from the cleaners up to the doctors".

Related to the issue of worker support was that of incentives for health care worker motivation. When asked what incentives were available, two stated that there were none. The other three commented on the self-completed performance evaluation form. All references to this were negative, as they were forced to share their rewards with all the other health care workers. They felt this was not a reward and viewed it as a frustrating management decision.

It is important to note that PHC sisters were not allowed to initiate patients on insulin. Only medical doctors were permitted to begin this treatment. Therefore, each time a patient needed to start insulin, he or she had to arrange transport and travel to one of the community health centres to see a medical doctor. One of the interviewees, at a community health centre, stated that once these patients began coming to the clinic, they continued to do so because they, 'like that a doctor is here'. She stated that this further increased their workload.

Table 12. Health Care Workers involved in chronic disease care

	1	2	3	4	5	6
Types of health care workers	Admin. clerks, nursing assistants, staff nurses, nurse clinicians, PHC sisters	Psychologist, social worker, security, all manner of nurses and nurse observers	Doctor, social worker, all nurses	Social worker, admin. clerks, nursing assistants, staff nurses, nurse clinicians, PHC sisters	Doctors, admin. clerks, nursing assistants, staff nurses, nurse clinicians, PHC sisters	Retired nurse, nursing assistants, staff nurses, nurse clinicians, PHC sisters
Is this adequate?	Think so	Shortage of trained sisters	Good skill mix	Good skill mix	Good skill mix	Adequate
Training	Weekly in-service meetings and workshops					
Do you feel supported?	No	No	No	No	No	No
What incentives do you have?	-	None – want uniform allowance	Performance evaluation form (self-completed)	Performance evaluation form (self-completed)	No	Performance evaluation form (self-completed)

Medication supply was extremely varied between clinics. While all stated that they received their supplies from the Hillbrow Dispensary, some reported that they never ran out of necessary medications, while others ran out on a monthly basis. Some had to wait up to a month to receive more. All respondents stated that they used the protocols when treating patients. These protocols were updated, and one clinic revealed that they did not have the newest version. "We are still waiting for it now. We have no idea (when we will get it). They are saying for months now. That is management's fault". One also replied that they sometimes used a telephone to receive outside advice when treating patients. Later in the interview, they revealed that they were unable to do so because, "…we don't have phones. There is no dialling tone for months now. It is just an internal phone".

Table 13. Resources for chronic disease care

	1	2	3	4	5	6
Run out of medication/wait time for more	Rarely/wait 1 day for more	Yes/up to one month	Yes/up to one month	No	Yes/3 days	Yes/cannot say
On-site materials to help you manage patients	Protocol	Protocol & telephone for help	Protocol	Protocol & knowledge from in-service	Protocol & knowledge from in-service	Protocol

Various services were offered by clinics, the majority of which were curative in nature. Only two clinics responded that they screened for chronic disease. Both replied that they screened using urinalysis. All interviewees spoke repeatedly about the importance of health education. None of the clinics provided rehabilitative services; these were all referred to either Chris-Hani Baragwanath Hospital, Lillian Ngoyi Community Health Centre or to the on-site doctor where they are present. All clinics provided identical tests and had the same equipment available.

Table 14. Chronic disease care services provided

	1	2	3	4	5	6
Do you screen	No	Yes - urine	No	No	No	Yes - urine
Health promotion	All respondents discussed the importance and need for educating patients regarding importance of follow-up visits, medication compliance, diet and exercise					
Rehabilitative services	All rehabilitative services are referred to Baragwanath Hospital					
Tests performed	Blood pressure, weight, urinalysis for protein, blood glucose level					
Equipment available	Blood pressure cuff, weight scale, urinalysis and strips (not always), 1 blood glucose monitor					
Refer to…	Baragwanath Hospital	Lillian Ngoyi & Baragwanath Hospital	On-site Dr. & Baragwanath Hospital	Baragwanath Hospital	On-site Dr. and Baragwanath Hospital	Lillian Ngoyi & Baragwanath Hospital

Chapter 4: Discussion, Conclusion and Recommendations

4.1 Discussion

The aim of this research was to examine the services provided, the role of management, community-based organisations and PHC clinics in chronic disease management. These groups are components of the three levels of the WHO's ICCC framework. Data was gathered from each level using in-depth interviews in order to better understand what services they provide and how they communicate with other levels. Service provision is discussed first, followed by the roles of each level in chronic disease management, which was preceded by discussions of patient information. The chapter concludes with study limitations and topics for further study.

4.1.1 Service Provision

The ICCC framework calls for the following types of health services: promotion, prevention, curative and rehabilitation. Chronic disease service provision in the study area was primarily curative in nature. Teams of nurses, with various training levels, integrated their skills to provide this care. These same nurses, as well as health promoters, provided health promotion and prevention services. The time and effort expended by these health care workers makes evident that curative services are emphasised. Efforts must be made to bolster health promotion strategies. Those who have come to the clinic and have already developed one or more chronic conditions receive the education delivered by nurses and health promoters. These patients are exposed to information because they have come for treatment. Once they are treated they leave the clinic and may or may not return for follow-up appointments. This is termed the "radar syndrome" by the developers of the ICCC. This is a problem because follow-up care can be sporadic and prevention is overlooked because those who are hearing the message already have developed the condition.

Initiatives that access portions of the population that have not yet developed these conditions need consideration. Some CBOs are already utilising media campaigns, such as newspaper and radio, to make their message available to new audiences. Since no patient data is aggregated and analysed, it is difficult to determine whether the available treatments are consistently offered and/or whether they are successfully managing patients. All clinics reported that they test patients' urine, but on more than one occasion they stated they were not doing it that day because of staff shortages. Screening methods were poorly developed and lost opportunities to identify patients with chronic disease were evident

A common curative health service offered by health care workers is oral medication for diabetes; much less common was the provision of insulin. Health care workers mentioned at various times that patients do not want to be placed on insulin because they are scared of the needles and/or do not understand its effect on their body. This leads to other problems as well. Some nurses reported that patients consume traditional medications, directly before coming to the clinic, in order to artificially decrease their blood glucose level. This masks potential problems and allows serious complications to develop. The nurses reported that physicians could only initiate insulin therapy. They implied insulin is very dangerous and their training specified that only physicians have the knowledge to deal with this powerful drug.

While insulin management is dangerous, perhaps nurses can be made to feel more comfortable with insulin during their training. If they were given the knowledge and authority as part of their schooling, they may feel more comfortable, resulting in patients feeling more comfortable. Since most clinics do not have physicians, if trained nurses were able to fulfil this role, patients could avoid the hassles of arranging transport and scheduling appointments at a community health centre. Health care workers, at these CHCs, stated that

they are further burdened by the additional patient caseload caused by this influx of patients, many of whom they stated that they do not desire to return to their home clinic with no doctor. They reported that these patients like having a doctor at the clinic. This may be avoided if nurses at their home clinic were comfortable with, and able to initiate, insulin therapy.

Rehabilitative services, for patients with complications due to chronic disease, are not offered by the PHC clinics. Any patient requiring such care is referred to the hospital, and in some cases the local community health centre if deemed appropriate. Health care workers at PHC clinics learn about their patients' hospital treatment by examining their 'file', which the patient keeps in their possession along with their PHC clinic card.

4.1.2 Macro Level – Provincial and Regional Management

Much of the macro level's role in chronic disease management appears to be in handing down budgets and protocols, conducting surprise clinic visits and organising Health Awareness Campaigns. The language used by interviewees reveals a top-down management style. This applies to both regional and provincial managers. The regional manager used 'up there' numerous times when referring to provincial or national level decisions such as allocating funds and other budgeting issues. The provincial manager used 'down there' language when referring to the regional level. They saw themselves principally as conduits for instructions from the top rather than supporting and responding to problems from below. The regional and provincial levels work well together and appear to have excellent communication via telephone and written reports. Communication is welcome when necessary, such as when the regional level needs additional funding. This funding is always provided when needed and recommendations were made regarding budget adjustments for the following year.

While both managers agreed that the current types of staff workers are appropriate, they felt that there was not enough of each type of health care worker. Staff shortages are felt at this level as well. The regional manager's position was vacant before her arrival. After a brief orientation, she was left mainly on her own to establish her position. She appeared optimistic, yet overwhelmed by the amount of paperwork and how to utilize the computer system. These managers feel that the task of supporting clinic staff is at the clinic level. Both half-heartedly stated that they try to support personnel by allowing them to participate in training sessions, but there appears to be a disconnect between management and the clinic level staff.

It is important to identify management's goals in order to better understand current focus areas. Without knowledge of these goals it is impossible to ascertain whether or not progress is being made in areas management deems vital. This may also contribute to discovering issues that have yet to be dealt with, and therefore to set future goals. Both managers discussed the importance of chronic disease prevention in addition to treatment of these conditions. They both work towards this goal by their role in large-scale activities such as awareness campaigns and event planning for National Diabetes Month. Collecting data on the number of new diabetic and hypertensive patients each month, in addition to the headcount, may be yet one more method of illustrating the effects of their prevention efforts.

The managers also mentioned the goal of preventing conditions from worsening once patients develop them. Collecting information, like patient readmittance rates from referral facilities such as Chris Hani Baragwanath Hospital, may illustrate to what extent serious complications such as stroke or amputation are avoided. Neither manager expressed

an interest in collecting any patient data and analysing it at the macro level. Both were comfortable with monthly headcounts from each clinic.

4.1.3 Meso Level – Community-Based Organisations

The government (macro level) is highly involved in the CBOs' role in chronic disease management. It was extremely difficult to find CBOs dedicated to chronic disease care. The vast majority deal predominately with HIV/AIDS and only became involved in chronic disease as a result of the stigma associated with their workers entering patients' homes. These organisations receive most, if not all, of their finances from the government. They are held accountable to the government and communicate their actions via monthly reports. Their workers must receive government training and are paid with government stipends.

The two primary chronic disease CBOs receive no governmental finances. They do partner with the government in planning and participating in the monthly Awareness Campaigns and receive nominal funds to make arrangements. These Campaigns would not happen without these volunteers. The government supplies speakers and transport for participants when necessary. Both organisations operate out of government clinics and have a very comfortable working relationship with PHC clinic health workers.

This high degree of government involvement is countered by monthly meetings of all Soweto CBOs. Government representatives are present and all interviewees felt this meeting is very beneficial in that they are able to communicate their concerns and problems to the government; it provides a forum for them to come together and share common concerns. Despite this forum, the CBOs included in this study were unable to name other CBOs in the area working on chronic disease. Both managers also had difficulty in naming CBOs.

All CBOs worked hand-in-hand with the PHC clinics, though to varying degrees. One primary CBO's staff members use their position to voice patients' concerns to clinic staff. Some patients may not feel comfortable or empowered to discuss certain issues with clinic staff. The support groups can help them feel able to voice concerns to volunteers, who are then able to carry these concerns to clinic staff. It is important that patients' voices be heard, and this CBO may provide a primary vehicle.

These CBOs interact with patients on a daily basis and have more time to spend with them than PHC nurses. Their opinion, regarding patient knowledge, is therefore invaluable. All CBOs agree that patients are not knowledgeable regarding their conditions. This is most frustrating for many of the CBOs and is a primary reason patients remain "uncontrolled" and develop complications. The CBOs also present a unique perspective regarding the general community's involvement with chronic disease management. Only one CBO felt the community is involved, though four felt community leaders were involved. The ICCC places great emphasis on community involvement.

CBOs primarily address HIV/AIDS and orphan issues, with chronic disease being largely ignored. The two CBOs dealing exclusively with chronic diseases educate patients, motivate them to manage their own condition, while serving as a line of communication between the patient and clinic, and partnering with the government to lend grass-roots support to Awareness Campaigns. They supply clinic medication to those patients who are unable to attend the clinic. They do so with no funding; hence all work is performed by volunteers, most of which have diabetes and/or high blood pressure themselves.

4.1.4 Micro Level – Primary Health Care Clinics

The services provided by PHC clinics are primarily curative in nature and were discussed above. PHC nurses deliver curative care as well as education. These health care

workers do not feel supported by management and consequently did not view the self-reported performance assessments as an incentive. This is a monetary incentive that could be successful if it were implemented differently. The interviewees do not like the fact that were forced to share all money they receive, from this incentive, with the entire staff. It was not clear why they are made to share this money, but if they were allowed to keep it they may feel more valued.

A great cause of frustration and the primary challenge cited by PHC nurses is the fact that patients do not heed their lifestyle advice and education regarding medication compliance. These workers may feel more valued and heard if patients exhibited greater compliance. Improved patient education methods and greater community involvement may enable this to occur. All interviewees feel the proper skill mix of workers is present, but all agree that they are short staffed.

While some clinics run out of medications, none of the interviewees indicated that this is a serious problem and some implied that improvements have been made. All stated that they are free to communicate with regional and provincial management via phone anytime it is necessary. Some clinics stated that they do not have regular phone service, so this may not be a realistic option. They are also able to voice concerns at weekly in-service meetings, which are administered by the provincial government. None of the interviewees felt that collecting more patient data was necessary.

All clinics offer the same services and operate in a similar manner. However, not all clinics utilise fast queues or the non-communicable disease stamp. Where present, nurses very much value these innovations and claim they make their work easier and their time more efficiently spent. Those nurses at clinics that did not use these practices knew of them, but were unsure as to why their clinic does not use them as well.

Patient Information

Information pertaining to patient care is limited. Both and PHC clinics collect the number of patients treated for chronic conditions each month. No other patient information, personal or aggregated, is collected by anyone. The register, where the head count is recorded, is not regarded as being an important document. In fact, some interviewees felt it was indeed worthless. While all PHC nurses are to have a copy of the register that they complete during their workday, none was observed during interviews. CBOs record the names of their patients and in some cases the number of family members living in the house as well as and other socio-economic information. The only data they forward to anyone is the number of patients they see each month, as well as specific problems, projects or accomplishments that occurred that month.

However, patient information is generally available and frequently used at the point of care. Health care workers at clinics, and CBO workers examine patients' clinic cards to note progress. This includes vital information, such as how often they attend the clinic, as well as illustrating trends in clinical indicators such as blood pressure and blood glucose levels. CBOs, visiting nurses and other health care workers who enter the home would not be able to do their job as effectively if clinics retain this information instead of patients. Another support for this system is found in the fact that it reduces the burden of the clinic needing to transport the records to the hospital or CHC when a patient is referred. This responsibility is left to the patient and most interviewees agreed this is a good system. One mentioned that some patients keep separate records for different PHC clinics, which can be troublesome when trying to capture someone's entire medical history.

The current information collection system gathers a very small amount of data and makes it available to the macro level. This information is not analysed and utilised at lower

levels. If it were, information could be used to notify CBOs about areas that have a high concentration of patients who do not regularly attend clinic, or whose condition is uncontrolled. The macro level would have a better idea of which clinics may need closer supervision or additional spot-check visits.

In contrast, a system that still enables patients to retain their records but also keep a copy at the clinic may allow for greater data collection. This would be beneficial for numerous reasons, including that of analysis. Clinic managers could determine how many chronic disease patients return for monthly follow-up visits. If they find these numbers to be too low, they might examine why this is the case. If patients do not come due to long queues, they might try instituting a fast queue if they do not already use one. Upon a closer scrutiny of their data collection, they might even designate specific days for certain conditions to manage the numbers. Such information, as well as aggregated clinical indicators such as blood pressure and blood glucose level, would enable clinics to more effectively evaluate their clinics' performance.

Study Limitations

Only a portion of the ICCC framework was applied to a small sample size of managers and one type of health care environment (provincial PHC clinics).

4.3 Conclusion

Gauteng is working to address the burden of chronic disease. PHC clinics, CBOs and managers are working together to improve chronic disease management. Application of the ICCC framework shows continued efforts must be made if chronic disease is to be managed properly. There is a serious lack of prevention. Health promoters work primarily in the clinic, reaching those who have already developed chronic conditions. Clinics educate patients, but all three levels agree that most patients are not knowledgeable of their

condition. The clinic's primary services are curative, but nurses are not allowed to initiate insulin therapy. Patients must be referred to a CHC, many of whom do not return to their home clinic for care. This causes a great increase in the caseload at the few CHCs.

There is also a lack of patient information. Neither management nor health care workers feel the need to collect patient data. Without such data, there is no way to accurately determine whether current efforts are effective or how to best allocate resources. Patients are responsible for keeping their health records at their home, with no data retained at the clinic other than a monthly headcount that is sent to upper-level management. The most common challenges for chronic disease management are: finances and human resources (as cited by managers); lack of support at home and patient compliance (as cited by CBOs and PHC clinics respectively).

The government exercises great influence over chronic disease management at all levels. Government managers provide funding, write policy and ensure it is implemented with one yearly visit to each PHC clinic (visiting more than once if necessary). The government manages the PHC clinics, trains health care workers, and provides resources. The government also trains and pays CBO health care workers, collects monthly reports of the CBOs' activities and oversees a monthly meeting of all Soweto-area CBOs.

While communication between levels is present, there exists a top-down management style where workers feel unsupported. Regional and provincial managers talk of each other as being 'up there' or 'down there'. They also feel helpless in supporting PHC clinic staff and report that this job is the clinic managers' duty and, in fact, not in their repertoire of personal responsibilities. PHC nurses feel unsupported, overwhelmed by patient volume, and do not appreciate the current monetary incentive system.

4.4 Recommendations

- Those who receive education have already developed one or more chronic diseases. More health promotion strategies are needed, such as using schools to educate children about healthy lifestyles, chronic diseases and associated conditions. This will support a shift from reactive care to proactive education.
- PHC nurses should not be forced to share money, from incentives, with co-workers.
- Collect and transmit more patient data; a monthly headcount cannot enable evidence-based medicine or accurately evaluate a clinic's performance.
- Capturing each patient's blood pressure/glucose level or other clinical indicators will enable managers to better determine whether the system is performing well and able to meet their goals of reduced complications, proper disease management, etc.
- All interviewees felt patients were not knowledgeable about their condition. The methods used for patient education must be reviewed and reformed. Health promoters, situated in the clinics, could change their presentation style and/or content.
- Increase the amount of chronic disease information presented in the mandatory government training of all CBO health care workers.
- Construct a comprehensive list of all CBOs that includes: contact information, where they operate, services provided, current client addresses, etc. This will strengthen their ability to partner with one another and reduce overlap in patient care.
- Educate patients better regarding how insulin works. This will decrease the usage of herbal medicines that mask health problems and lessen patients' fear of insulin.
- PHC nurses could be trained and permitted to administer and/or initiate insulin

therapy.

- Enable managers to realise they can affect change in clinic staff, rather than feeling this responsibility belongs solely to the clinic manager.

Suggestions For Further Research

This research explored one aspect of each ICCC framework level. Further research would be necessary to fully examine the presence of all necessary components. Patients were one aspect of the framework not included in this study. Additional research, that explores how patients monitor their conditions and manage their symptoms, would be beneficial. Nurses repeatedly cited health promoters as the health care workers most responsible for promoting health education and distributing preventative information. A study could be conducted that more closely examines these health care workers and their role in the ICCC framework.

The Renal Unit at Chris-Hani Baragwanath Hospital is implementing the Wagner Chronic Care Model; it would be interesting to note the effect of this project on clinic capacity and health outcomes. The data captured by that project will better enable outcome-based guidelines, ability to judge clinic performance, and patient compliance. Finally, it would be helpful to note the interactions at the meeting of Soweto CBOs and government representatives. A close examination of the structure and issues of this monthly meeting would enhance the understanding of the relationship between the macro and meso levels.

Annexure 1 Clinic Interview Schedule

Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area

PHC Clinic Interview Schedule
PHC code _____
Date ___/___/___

Introduction

1. Please tell me about your position, such as responsibilities, day-to-day activities, etc.

2. What are the goals of this clinic in managing hypertension/diabetes?

3. What challenges does the clinic face in managing such patients?

4. Can you describe how you believe PHC clinics, community organisations and the regional/provincial level are working to manage chronic disease?

Staff and Training

5. What types of health care workers are used to manage chronic disease?

6. In your opinion, is the skill mix adequate for managing chronic disease in the clinic?

7. Can you please tell me about the chronic care management training available for health care workers?

8. What on-site materials are available to support health care workers?

Clinical Examination

9. What materials are used to diagnose and treat hypertension/diabetes?

10. What rehabilitative services are offered at this for facility diabetic amputees and those recovering from hypertensive related events?

Medication

11. Has the clinic run out of required diabetic or hypertension medication in the past 3 months? Y☐ N☐
    If so, for how long does this generally last?

12. How do you determine whether patients are adhering to their treatment protocol?

13. How long does a hypertensive/diabetic patient's prescription generally last until a refill is needed?

☐- 1 month
☐1 month
☐2 months +

Available Testing

14. What tests are available for hypertensive/diabetic patients?

15. Where is this information recorded?

Follow-up

16. Can you tell me about follow-up visits?

17. How many visits are expected from hypertensives/diabetics per month?

Information and Referral System

18. Can you tell me about what patient data you collect and what it is used for?

19. How do referrals for diabetic/hypertensive patients work?

20. How does information flow between the clinic and referral facility(s)?

Self-Management

21. Can you please tell me how the clinic works to enable patients to manage their own illness?

22. What are patients expected to do outside the clinic in terms of their illness?

23. Who outside the health sector is involved in chronic disease management?

24. What materials does the clinic possess to educate patients regarding hypertension/diabetes?

25. During consultations, on what topics do health workers provide advice?

26. What types of support groups does the clinic provide for patients?

Health Promotion

27. How does the clinic screen for patients with diabetes/hypertension?

28. Is there anything else you would like to add?

Annexure 2 Community Organisation Interview Schedule

Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area

Community Organisation Interview Schedule
Community Org. code _____
Date ___/___/___

Introduction

1. Please tell me about your position, such as responsibilities, day-to-day activities, etc?

2. How does your organisation support community members' chronic care needs?

3. Tell me about your organisation's mission and objectives?

4. What challenges does your organisation face in managing chronic disease?

Outreach Activities

5. Can you tell me how the organisation makes itself and its services known to the community?

6. Can you tell me about similar community organisations in the area and how your organisation interacts with them?

Organisation Structure

7. Please tell me about the interactions between your organisation and the formal health sector.

8. Can you describe how you believe PHC clinics, community organisations and the regional/provincial level are working to manage chronic disease?

Information System

9. How does the organisation learn about and track patients' health status?

10. What data do you collect and how do you use this information?

Resources

11. What resources does the organisation use in its activities?
    a. Workers/volunteers
    b. Funding

12. Are community leaders involved with the organisation's activities?

Services

13. Please tell me about the services offered by your organisation?
    a. Promotion
    b. Prevention
    c. Curative
    d. Rehabilitative

14. Can you tell me about the services offered by your organisation compared to those found in the health clinics?

15. In your opinion, what type of skills and knowledge do patients posses about their illness when they begin coming to your organisation?

Annexure 3 Manager Interview Schedule

Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area

Manager Interview Schedule
Manager code _____
Date ___/___/___

Introduction

1. Please tell me about your position, such as responsibilities, day-to-day activities, etc.?

2. Can you tell me about some current initiatives pertaining to chronic disease in the region/province?

3. What are the goals of the region/province regarding chronic disease and its management?
    a. Quality indicators?

Resources and Training

4. Can you tell me about the region/province's resources available for chronic disease management?

5. How are these resources allocated?

6. What are your opinions regarding the skill mix of the region/province's health workers?

7. Can you tell me about chronic disease education and training for health workers?

Health Sector Process

8. How does the district/province identify the population's chronic disease health needs?

9. How does the district/province judge a clinic's performance?

10. What is being done to increase patients' ability to care for themselves?

11. Can you describe how you believe PHC clinics, community organisations and the district/provincial level are working to manage chronic disease?

Policy

12. Do you feel current legislation contains redundancies or other aspects that impede chronic disease management?

13. Can you tell me how chronic care management is financed in the region/province?

Partnerships

14. Can you tell me about the various actors working to address chronic issues disease in the region/province?

15. In your opinion, what are the responsibilities of the community in managing chronic disease?

Information System

16. Can you tell me about chronic disease data that is collected and analysed at the regional/provincial level?
    a. Evidence-based

17. How do you feel the current flow of information might be improved upon?

18. Is there anything else you would like to add?

Annexure 4 Informed Consent

Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area

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Consent Form

I agree to participate in the study referenced in the attached information sheet. I understand the purpose of the study, that my participation is voluntary and I have had an opportunity to ask questions.

Name _____

Signature _____

Date _____

I allow the interview to be recorded (audio) provided that it is kept in the researcher's possession and destroyed immediately after data analysis.

Signature _____

Date _____

Annexure 5 Clinic Interview Information Sheet

Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area

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Dear Health Care Worker,

Introduction: My name is Chad Smith and I am a graduate student in the School of Public Health at the University of the Witwatersrand. I am conducting research in partial fulfillment of the Masters in Public Health. This research examines the management of chronically ill patients at the primary health care level in Gauteng Province. Hypertension and diabetes are used as examples of chronic illness. Your participation in this research is voluntary and appreciated.

Reason for study: The prevalence of chronic illness is increasing globally. Studies show the prevalence of risk factors for chronic disease, such as obesity, are extremely high in Gauteng. It is important to document the services made available to chronically ill patients in order to optimally serve the population.

Why I would like to interview you: This health facility was selected to capture the full spectrum of clinics in District 10. You were selected due to your knowledge of the health services provided to chronically ill patients. This research seeks to describe the current services offered to diabetic and hypertensive patients in your health facility.

What is expected of you if you participate: The research consists of an interview lasting approximately sixty minutes. A tape recorder will gather the information. This will be kept in the researcher's possession and destroyed immediately after analysis. The researcher will read questions from a questionnaire sheet and make notes. The research report will be made available to you once it is completed.

Cost/Benefits: There are no direct costs for the study. The nature of the research posses no harm to your person: either physically or mentally. By participating you gain the knowledge that you are helping improve the care provided to patients in Gauteng.

Withdrawal: Your participation in the research is voluntary. State your desire to stop if at any time you wish to discontinue. There is no penalty for withdrawal at any time.

Confidentiality: The information collected will **not** be connected to your name in any way. The researcher will **not** ask for, or record your name. If you volunteer this information it will **not** be included. The health care facility is coded, and only the researcher has this list of codes. This will remain in the researcher's possession and destroyed after the research is submitted.

If you have any questions please can contact me at any time.
Tel: 076 172 9317 Email: chadhsmith@gmail.com

Thank you,
Chad Smith

Annexure 6 Community Organisation Information Sheet

Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area

Dear Community Worker,

Introduction: My name is Chad Smith and I am a graduate student in the School of Public Health at the University of the Witwatersrand. I am conducting research in partial fulfillment of the Masters in Public Health. This research examines the management of chronically ill patients at the primary health care level in Gauteng Province. Hypertension and diabetes are used as examples of chronic illness. Your participation in this research is appreciated.

Reason for study: The prevalence of chronic illness is increasing globally. Studies show the prevalence of chronic disease risk factors such as obesity are extremely high in Gauteng. It is important to document the services made available to chronically ill patients in order to optimally serve the population.

Why I want to interview you: This community organisation was selected to gain an understanding of the services provided to individuals in the community. You were selected due to your knowledge of the services provided to chronically ill patients. This research seeks to describe the current services offered to diabetic and hypertensive patients in your community.

What is expected if you participate: The research consists of an interview lasting approximately thirty minutes. A tape recorder will gather the information. This recording will be kept in the researcher's possession and destroyed immediately after data collation. The researcher will read questions from a questionnaire sheet and make notes The research report will be made available to you once it is completed.

Cost/Benefits: There are no direct costs for the study. The nature of the research posses no harm to your person: either physically or mentally. By participating you gain the knowledge that you are helping improve the care provided to patients in Gauteng.

Withdrawal: Your participation in the research is voluntary. State your desire to stop if at any time you wish to discontinue. There is no penalty for withdrawal at any time.

Confidentiality: The information collected will **not** be connected to your name in any way. The researcher will **not** ask for, or record your name. If you volunteer this information it will **not** be included. The health care facility is coded, and only the researcher has this list of codes. This will remain in the researcher's possession and destroyed after the research is submitted.

If you have any questions please contact me at any time.
Tel: 076 172 9317 E-mail: chadhsmith@gmail.com

Thank you,
Chad Smith

Annexure 7 Manager Information Sheet

Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area

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Dear District/Provincial Manager,

Introduction: My name is Chad Smith and I am a graduate student in the School of Public Health at the University of the Witwatersrand. I am conducting research in partial fulfillment of the Masters in Public Health. This research examines the management of chronically ill patients at the primary health care level in Gauteng Province. Hypertension and diabetes are used as examples of chronic illness. Your participation in this research is appreciated.

Reason for study: The prevalence of chronic illness is increasing globally. Studies show the prevalence of chronic disease risk factors such as obesity are extremely high in Gauteng. It is important to document the services made available to chronically ill patients in order to optimally serve the population.

Why I want to interview you: You were selected in order to capture managements' perspective and role in chronic illness care. This research seeks to describe the current services offered to diabetic and hypertensive patients in your district.

What is expected if you participate: The research consists of an interview lasting approximately thirty minutes. A tape recorder will gather the information. This recording will be kept in the researcher's possession and destroyed immediately after data collation. The researcher will read questions from a questionnaire sheet and make notes. The research report will be made available to you once it is completed.

Cost/Benefits: There are no direct costs for the study. The nature of the research posses no harm to your person: either physically or mentally. By participating you gain the knowledge that you are helping improve the care provided to patients in Gauteng.

Withdrawal: Your participation in the research is voluntary. State your desire to stop if at any time you wish to discontinue. There is no penalty for withdrawal at any time.

Confidentiality: The information collected will **not** be connected to your name in any way. The researcher will **not** ask for, or record your name. If you volunteer this information it will **not** be included. The health care facility is coded, and only the researcher has this list of codes. This will remain in the researcher's possession and destroyed after the research is submitted.

If you have any questions please contact me at any time
Tel: 076 172 9317 E-mail: chadhsmith@gmail.com

Thank you,
Chad Smith

Annexure 8 Ethics Approval Form

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Smith

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER M060122**
PROJECT	Service Provision for Diabetes and Hypertension at the Primary Level in the Johannesburg Metropolitan Area
INVESTIGATORS	Mr CH Smith
DEPARTMENT	School of Public Health
DATE CONSIDERED	06.01.27
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Prof H Schneider

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

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