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An Evaluation of a Chronic Disease Outreach Program (CDOP) – A Primary Care and Tertiary Care Kidney and Cardiovascular Prevention, Detection and Management Program

Ivor Jonathan Katz

A thesis submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in fulfilment of the requirements for the degree of Doctor of Philosophy

Johannesburg 2010

DECLARATION

I, Ivor Jonathan Katz, declare that this thesis is my own work and it is being submitted for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. Where I have received assistance, it has been acknowledged in the acknowledgements, section.
It has not been submitted before for any degree or examination at this or any other university.



_____

____20th_____ Day of _____January_____, 2010

ETHICS APPROVAL

The protocol for this study was approved by the Committee for Research on Human Subjects (Medical) of the University of the Witwatersrand, Johannesburg (protocol number 03-10-17)

HUMAN RESEARCH ETHICS COMMITTEE CLEARANCE CERTIFICATE

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

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DATE 04-04-07	**CHAIRPERSON** ..... (Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor :

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.**

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ABSTRACT

Background: Chronic diseases have increased worldwide. Despite the significant advances in medical science, the management of chronic diseases continues to be poor. To meet this challenge, we need to try to implement existing chronic illness models of prevention, early detection, and risk factor management. This is achievable in part by linking primary health care clinicians, such as primary health care nurses (PHCNs) and hospital-based medical specialists. This study evaluated a 'real life' chronic disease outreach program (CDOP), which assisted PHCNs with the early detection and management of chronic illnesses known to cause chronic kidney disease (CKD) and cardiovascular disease (CVD). PHCNs are critical in the management of chronic illnesses but they require ongoing support of and links with specialists. This will ensure that current guidelines reach the people receiving primary health care (PHC) and detection of those needing referrals.

Aims: The study aimed to determine if CDOP was an effective method for the early detection and management of diabetic and hypertensive patients at high risk for complications like stroke, ischaemic heart disease and CKD. It also aimed to evaluate the PHCNs' knowledge and motivation, and to elucidate the challenges facing the current health system in the management of patients with chronic conditions.

Methods: Patients at risk for complications were enrolled for increased monitoring and clinical support and management, at 20 clinics in Soweto, South Africa (SA). CDOP used a paper-based support and patient care system, modelled on the Wagner Chronic Illness Care Model (CICM). The components for evaluation included: (i) Focus on monitoring functional and clinical outcomes (ii) Health system interventions, such as increased 'decision support' and the development of a 'prepared motivated health care team' and (iii) Enhancing PHCNs' knowledge and motivation. The evaluation followed the various elements of the Wagner CICM, as well as drawing on the WHO Innovative Care for Chronic Conditions (ICCC) Framework. A cohort analysis of functional and clinical outcomes in enrolled patients was conducted. PHCN knowledge and motivation was assessed through self administered questionnaires. Health

worker knowledge was evaluated through the use of case scenarios and multiple choice questions. On the theme of health worker motivation, Franco's model, with Penn-Kekana's adaptation, was used to develop the questions and analyse diary recordings. Diary recordings of PHCNs and meetings with regional and provincial health managers' discussions were collected by CDOP staff during follow-up focus groups and feedback meetings. Diaries were analysed thematically. The CDOP evaluation is thus a triangulated analysis of clinical and functional outcomes, diary recordings, and the self-administered questionnaire.

Results: The CDOP ran from 2003-2006, during which time 618 patients (61% females, 39% males) deemed at risk of CKD or CVD were enrolled; 55% had uncontrolled hypertension (HTN), 45% DM with HT and/or proteinuria. Patients were followed for 2 years. In total, 108 patients completed 2 years of follow up, most of whom were referred for specialist support (n=69, 11%), more intensive medication regimes or because were not available in the PHC system. Most did not require referral (515, 82%), 35 (6%) were referred but never arrived at the hospital and 6 (1%) died. Twelve percent had advanced CKD, 2% required dialysis, 6.9% required medications not available to primary care clinics, and 1% died. As a tool to detect those needing referral, the program was successful. The sensitivity and specificity for detecting those needing referral was 95% and 100%, respectively.. However, although PHCNs were able to detect high risk patients, not all those referred arrived at the hospital. Hypertension, blood glucose, cholesterol and proteinuria control significantly improved in those followed ($p<0.01$) over 2 years, but no improvement was noted with weight control. Importantly, proteinuria and kidney function, in patients with static stable renal function, measured by estimated GFR equations and urine dipstick or albumin creatinine ratio (ACR), did not worsen significantly. Of the remaining 510 patient enrolled but not followed up, 213 (35%) were reabsorbed into the routine clinics, and a further, 123 (20%) of patients enrolled were lost to follow up completely. The diary recording thematic analysis revealed the problem of poor patient follow up, attributed to the poor existing health system in the clinics, competing demands on PHCNs, staff shortages, high staff turnover, and the low motivation and morale of clinicians. The analysis of the health worker questionnaire showed improved motivation and statistically better knowledge in those PHCNs involved with CDOP compared to those who were not exposed to the program ($p<0.0034$).

Conclusions: CDOP was successful in supporting PHCNs, detecting patients with advanced disease and ensuring their early referral. Such programs are able to correctly detect people with disease, but this is dependent on the health and program systems being intact. It also improved patient risk factor control in the sub-set of referred patients and impacted on PHCNs' existing knowledge and motivation for caring for patients. Its weaknesses were related to the poor existing health systems and infrastructure, and the poor integration of chronic illness care in the region. The PHC clinics had poor follow up compared with that in the hospital setting. The study also revealed an overworked, poorly supported, and frustrated primary health care team. This was despite the fact that the PHCNs were willing and motivated to deliver a good service.

PREFACE

The Chronic Disease Outreach Program (CDOP) began its life in a highly specialised renal unit of a tertiary hospital, located in Soweto, South Africa. The program was driven by the fact that many patients developing end stage renal failure (ESRD) in Soweto are not offered dialysis or transplantation. This is because of the scarce resources and an established protocol that limits access onto renal replacement therapy (RRT) programs. After learning about an Australian program for Indigenous populations, and recognising similarities between the communities, it was decided to establish an early detection strategy in Soweto. This program aimed to provide nephrologists with an alternative to refusing people dialysis and intervening downstream from the problem. Its focus on primary and secondary prevention, aimed to prevent people developing ESRD, or to facilitate early detection of ESRD and provide appropriate interventions to prevent early death from cardiovascular disease (CVD). The Chronic Disease Outreach Program (CDOP) would also link the primary and tertiary care systems.

The program was established jointly with the Directorate for Chronic Disease of the Johannesburg Metropolitan Health Department (JMHD) in 1999. It was inspired by, modelled on and motivated by the CDOP in Australia, but its introduction in Soweto required adaptation and significant scaling up. The Australian CDOP was developed in response to an 'epidemic' of chronic kidney disease and cardiovascular disease in indigenous Australians. This same epidemic was suspected as being a problem in communities in South Africa, particularly in disadvantaged communities such as in Soweto and Southern Gauteng. This was confirmed by a pilot CDOP study (Phase 1), conducted from 1999 to 2003, known as the Primary Prevention Program (PPP). The pilot program informed this study, known as the 'paper based' version of CDOP or Phase 2. The program has since developed into a 'web based' version, Phase 3, not discussed in this thesis (https://www.medicaldatabanks.net/cidoppp/).

Initially, as indicated above, the program was referred to as the Primary Prevention Program, where the term 'primary' referred to the primary health care setting where the program was implemented. In public health terms, the program was developed around secondary prevention but did include some aspects of primary prevention with respect to patient education. However,

the motivation of CDOP was not only about prevention among indigenous people in Australia and South Africa (SA) who could not afford expensive technologies. Instead it provided an opportunity to establish an argument for good secondary prevention, which is a good practice in any health system.

The program in SA was tailored around resource realities, and included the use of simple diagnostic techniques for early detection and vigorous treatment to prevent the development of ESRD. A screening method to detect people with CVD and CKD, and attempting to arrest the disease process among an African population, needed to be developed, implemented and evaluated. Soweto and its surroundings reflect a typical setting of Black Africans. Like Australian Aboriginal people, black South Africans have suffered under colonialism, discrimination, marginalisation and inequality.

The impetus to start this program, for South Africans in Soweto, began in 1996 when I met Wendy Hoy, the Australian CDOP creator, at an African Association of Nephrology (AFRAN) meeting in Abidjan, Ivory Coast. At this meeting Professor Hoy presented compelling evidence indicating the effectiveness of her program in reducing deaths and dialysis starts (Hoy et al., 2000, Hoy et al., 2003b). The program took place in a small Australian Aboriginal community of 2000 people on the Tiwi Islands of the Northern Territory. Compared with European Australians, Aboriginal Australians in the Northern Territory require a disproportionate amount of dialysis. The program aimed to reduce the number of people requiring dialysis, an expensive treatment for the 'end stage' of chronic kidney disease (CKD). Prevention strategies had not been developed in these areas and, at least, secondary prevention strategies were an attractive option. Hoy's program not only resulted in a decrease in the number of people starting dialysis but also in a reduction of 'all cause' mortality from cardiovascular disease (CVD), such as strokes and heart failure, because it targeted the primary causes of ESRD i.e. diabetes (DM) and hypertension (HTN). The benefits of renoprotection have the benefit of all risk cardiovascular protection. The program has since expanded elsewhere in Australia, an outreach program, run in a context of disadvantage and social transition, similar to that of most black South Africans (Hoy et al., 2003a).

The possibility of a similar program in Soweto was even more compelling because of the sophisticated primary health infrastructure developed around Chris Hani Baragwanath Hospital (CHBH). This hospital is a tertiary, academic teaching hospital on the outskirts of Soweto. The latter is an extensive collection of suburbs to the Southwest of Johannesburg, established as a result of the forced removal Apartheid policies of the former Nationalist Government. The clinics were developed following the 1976 'uprising,' with the aim to win back 'the hearts and minds' of the local black population. Although the 'uprising' was concerned firstly with the language policy in schools, it was interpreted more generally as a rise against Apartheid policies. After the protest the government sought to create a façade of improving the quality of life and living conditions of people in Soweto. As a result, numerous primary health care clinics were established. The Soweto-based South African CDOP program took advantage of this fact.

A major challenge was whether a program such as Wendy Hoy's could be scaled-up in Soweto, with a population of between one to two million and an average chronic disease clinic population (HTN and DM) of 2000 to 4000 people per clinic, compared with the total Tiwi population of 2000 people. The Soweto program aimed also to develop the program using established chronic illness models, and to draw on the knowledge and experiences of nephrologists running CKD prevention and early detection programs elsewhere in the world. This thesis is an evaluation of this experience to establish a CDOP program in Soweto and Southern Gauteng.

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I also wish to thank those people who assisted me in establishing and running the program in the Johannesburg Metropolitan Health Department Region B which includes Soweto. These were Sisters Dudu Mthombeni (Deputy Director of Chronic Disease in the Gauteng Health Department), and the two South African CDOP Nurse Coordinators, Sister Eugine Shezi and Sister Golebemang Mdleleni from the primary health care service in Soweto. I appreciated the hard work and support of Mr Omar Butler (Clinical Information System and Data Manager), for organising the data base and doing interim analysis during patient follow up.

I think it is important to acknowledge the support and inspiration provided by Professor Wendy Hoy, the founder of the Australian Outreach Program. She has supported the program from the outset, with training, protocols and by allowing her Australian program nurse coordinators to come to South Africa. The two Australian Outreach Program Nurse Coordinators, Sisters Jo Smith and Suresh Sharma, showed inspirational skills, dedication, commitment and

support during their eight months in Soweto, training our two local nurse coordinators. These skills included program management, computers and chronic disease management. Sisters Jo Smith, Suresh Sharma and Dr. S Kondalsamy-Chennakesavan (Australian Outreach Program Director) also helped us during our visits to the Australian Outreach Program in the Northern Territory. Dr. S Kondalsamy-Chennakesavan, the Australian program director, provided both advice and assistance with the evaluation of the pilot phase of the Outreach Program and with the development of the second phase of CDOP. This is the phase on which this research is based.

Others, who assisted me and supported the program and provided permission to carry out the program in their region, were Dr. Sehularo Gaelejwe (Director of the Johannesburg Metropolitan Health Department) and his management team. He showed great vision and insight, but despite this was moved after only a short time of managing the regional office. I also acknowledge the fantastic work and dedication of the primary health care nurses who work, under trying conditions, in the primary health care services in Region B. I especially appreciated the work and dedication of those who volunteered to actively participate in the program. I acknowledge the assistant nurses, health promoters and health workers in all the clinics who participated as part of the Outreach Program teams. Dr Andrew Truscott and Sr. Melita Mahlo and Dr. Leon Pein, from the PHC School at Lillian Ngoyi clinic, were critical for ensuring that CDOP developed a relationship and trust with the PHC teams in the clinics. Their input, enthusiasm and dedication to PHC care in Soweto are unrivalled and they have gained great respect from the PHC nurses and me.

I also wish to thank my own department, the consultants, nurses, registrars and medical officers who managed all the patients referred to the specialist clinic at the Division of Nephrology at Chris Hani Baragwanath Hospital. The CDOP patients now comprise twenty percent of our total renal clinic population. I also thank Professor Huddle and Professor Blumsohn for proofreading my thesis and for their comments and suggestions.

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ABBREVIATIONS

ACEi	Angiotensin converting enzyme inhibitor
ACR	Albumin-Creatinine Ratio
ARB	Angiotensin receptor blocker
CDOP	Chronic Disease Outreach Program
CD-PHCN	CDOP Primary Health Care Nurse Group
CHBH	Chris Hani Baragwanath Hospital
CICM	Chronic Illness Care Model
CKD	Chronic Kidney Disease
COMGAN	Commission for the Global Advancement of Nephrology
CVD	Cardiovascular Disease
DM	DM
DOH	Department of Health
EDL	Essential Drug List
ESRD	End Stage Renal Failure
eGFR	Estimated Glomerular Filtration Rate
GFR	Glomerular Filtration Rate
HGT	Finger prick haemoglucotest
HIS	Health Information System
HTN	Hypertension
HWM	Health Worker Motivation
ICCC	Innovative Care for Chronic Conditions Framework
ISN	International Society of Nephrology
KDIGO	Kidney disease: Improving Global Outcomes
K/DOQI	Kidney Disease Outcomes and Quality Initiative
JMHD	Johannesburg Metropolitan Health Department
MetS	Metabolic Syndrome
NCD	Non-communicable Diseases
NC-PHCN	Non CDOP Primary Health Care Nurse Group
NGO	Non-Governmental Organization
NKF	National Kidney Foundation
NKFS	National Kidney Foundation Singapore
NPC	Nurse Program Coordinator
OSD	Occupation Specific Dispensation
PAR	Participatory Action Research
PCR	Protein-Creatinine Ratio
PET	Program Evolution Timeline
PHC	Primary Health Care
PHCN	Primary Health Care Nurse
PMT	Program Methodological Timeline

QA	Quality Assurance
ROPD	Renal Outpatient Department
RRT	Renal Replacement Therapy
RSA	Republic of South Africa
SADTS	South African Dialysis and Transplant Registry
SAHS	South African HTN Society
SARS	South African Renal Society
SPHS	Soweto Primary Health Care School
CICM	Wagner Chronic Illness Care Model
WHO	World Health Organization

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1 INTRODUCTION

Rationale and Approach for Chronic Disease Outreach Program

No nephrologist working in a developing world setting can provide care for all those people in the community who develop end stage renal disease (ESRD). Many people developing ESRD in South Africa are offered neither dialysis nor transplantation, i.e. renal replacement therapy (RRT), because of scarce resources and established protocols for accepting only patients without significant co-morbid disease onto the RRT programs (Moosa and Kidd, 2006, Dirks and Levin, 2006). When the program on which this thesis is based was conceptualised, there was a need to establish an early detection and prevention strategy to provide nephrologists with an alternative to prevent people developing ESRD or early death from CVD. CDOP provided the opportunity of early detection through screening high risk patients with HTN and DM. It provided a link between the primary and tertiary care health systems. The initiation of this program was an attempt to start changing the approach of managing chronic illnesses in Soweto. This included highlighting the future challenges of initiating similar programs, which includes scaling up a program and motivating primary health care clinicians to participate.. The improved recognition of kidney disease globally can be attributed to some important developments, which included re-defining and re-classifying CKD, culminating in a coherent conceptual model of kidney disease (National Kidney Foundation, 2002, Levey et al., 2003, Levey et al., 2005) (As illustrated in Figure 1).

A key reason for the new definition of kidney disease and the model is that CKD encompasses a range of conditions, including its early forms and final failure. This definition highlights the natural history of CKD, providing a systematic description of the course of the disease over time unaffected by treatment. CKD staging highlights the phases of susceptibility and increased risk. It has brought focus on the pre-clinical phases, where kidney disease has begun but is asymptomatic. The earlier manifestations may include HTN, proteinuria or reduced kidney function, but the presence of disease may not be identified unless a clinician screens for it. Unfortunately, when a person reaches the ‘clinical phase’ of kidney disease, it is usually too late to impact on its progression.

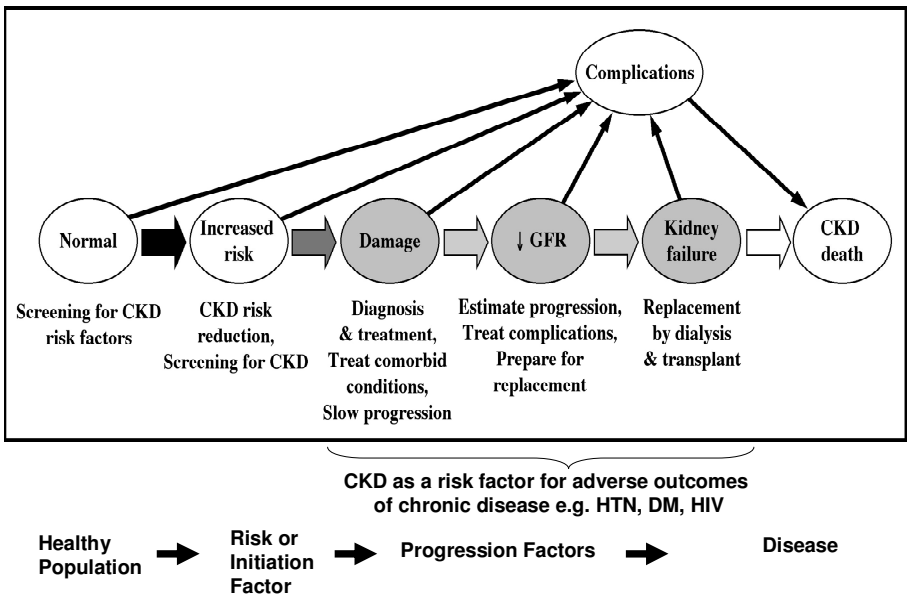


Figure 1. Conceptual Model of Chronic Kidney Disease

Note: The model covers the course of CKD and the therapeutic strategies. Shaded ellipses represent stages of CKD; unshaded ellipses represent potential antecedents or consequences of chronic kidney disease. Thick arrows between ellipses represent risk factors associated with the initiation and progression of disease that can be affected or detected by interventions. Interventions for each stage are given beneath the stage. 'Complications' refer to all complications of chronic kidney disease and its treatment, including complications of decreased GFR (HTN, anaemia, malnutrition, bone, and mineral disease) and cardiovascular disease. Increasing thickness of arrows connecting later stages to complications represents the increased risk of complications as kidney disease progresses (Levey et al., 2007a).

At the final stages, a person may present in a 'uraemia' state, with symptoms of vomiting, confusion and fluid overload. In this state, the chances of recovery or remission are unlikely and the person will require preparation for dialysis or transplantation. These expensive therapies are often unavailable in developing countries and are very costly in general (Barsoum, 2006).

This new knowledge of the development and progression of kidney disease served to highlight the problem, leading to greater awareness of the burden of kidney disease and understanding of factors influencing its progression and outcome (Coresh et al., 2003, El-Nahas, 2004). Most kidney disease specialists have focussed on kidney disease phases specifically. To a large extent, this is driven by funding from pharmaceutical companies or Kidney Foundations, but also by the general lack of awareness that kidney disease is fundamentally a genuine public health problem (Schoolwerth et al., 2006, El Nahas and Bello, 2005, Levey, 2006). Some programs have focussed on screening people at highest risk for CKD, which would include those with DM

and HTN, but also other susceptibility and risk factors such as obesity, dyslipidaemia and race. However, in general these programs have failed to cross the divide to true integrated prevention and cure. They have not been able to highlight the closeness of the challenge facing chronic non-communicable and communicable diseases, both of which require ongoing treatment. They have also not highlighted the close link between CVD and CKD.

Whilst these studies have detected those at risk, highlighted the problem and shown us what can be done, they have not necessarily answered the challenge of implementation and delivery on a large scale, especially in developing countries. They have also not elucidated the necessary changes required to existing health systems. The improved focus on CKD as a public health problem and better detection of those with disease should be met with an improved system of integrating prevention and treatment within the existing health system. This type of integration needs to find its way into the mainstream practices of kidney disease management. Unfortunately, in chronic illness care primary and secondary preventive roles tend to be separated. Clinicians continue to see their role as treating those already sick, rather than preventing illnesses. An associated problem includes the fact that the definition of prevention has also become quite confusing (Starfield et al., 2008), often incorporating established disease and this includes kidney disease. An integrated system has good communication and coordination between different components of care (Bachmann, 2007). Vertical integration is about linking the different levels of care, linking primary care, the first point of first contact with the health service e.g. clinic or general practitioner, with secondary care, the first level of care to which problematic cases are referred, e.g. regional hospital. If disease progresses or requires the next level of care, then patients are referred to the tertiary care level. In the case of severe renal dysfunction or end stage kidney failure, higher specialist care level referral to the regional dialysis unit would be required. An amalgamation of the conceptual model of CKD and its integration with the different levels of care in the health system is discussed further in Chapter 2.

Figure 2 demonstrates its amalgamation with the public health levels of care and prevention strategies. This figure highlights the fact that any program hoping to tackle a chronic illness requires a well functioning health system, including clear referral protocols and a sharing of clinical information. Importantly horizontal integration of different curative and preventative

services is imperative. Success in the area of coronary artery disease has been shown in Australia, England and the United States (Rose, 1981), yet despite the benefit of integration being clear, the approach has not been adapted to other settings.

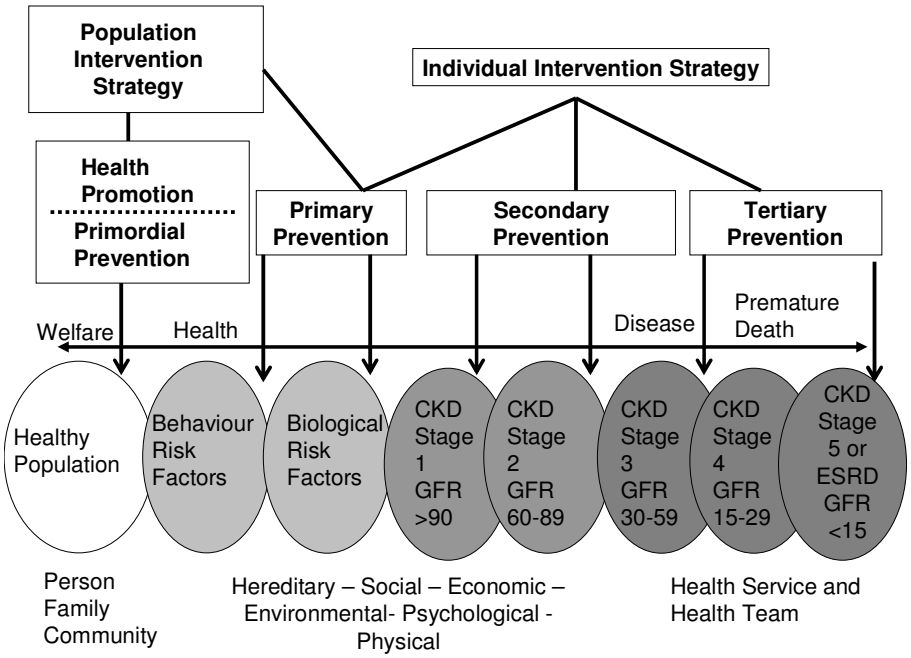
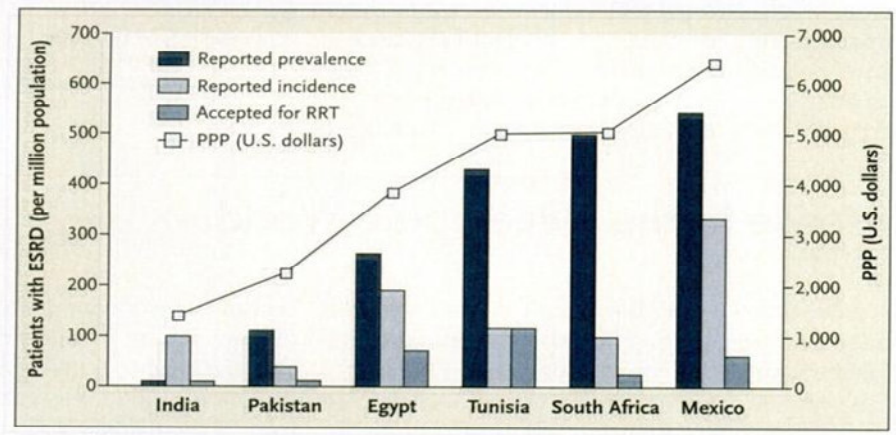


Figure 2. Linking Levels of Care and Prevention Strategies for CKD
Adapted from KDIGO and Cuban conceptual models (Levey et al., 2007a, Almaguer et al., 2005). CKD – chronic kidney disease, GFR – glomerular filtration rate ml/min; ESRD – End Stage Kidney Disease or CKD stage 5

Advances in medications and improved technical developments in dialysis have failed to resolve the growing burden of kidney disease. Countries around the world are challenged with problems of inadequate resources and treatments are extremely expensive. Figure 3 demonstrates the low rate of acceptance onto RRT programs.

Globally, there continues to be an increasing burden of chronic illnesses like HTN and DM. This means a greater number of people succumb to ESRD or die of cardiovascular complications with kidney disease (El Nahas and Bello, 2005). Developing countries have a dual burden of chronic non-communicable diseases like HTN and DM, and 'chronic' communicable diseases associated with kidney disease like HIV/AIDS. In the United States, HIV renal diseases is a common cause of ESRD in African Americans (Szczech et al., 2003). While no data exists for South Africa, HIV/AIDS is widely perceived by nephrologists to already be or soon to become the largest cause of ESRD in this country. The true numbers are difficult to determine, however,

because many patients with HIV are not referred for RRT because of restrictions on resource allocation (Fabian et al., 2007).



Reported Prevalence and Incidence of ESRD and Rates of Acceptance for Renal-Replacement Therapy (RRT), in Relation to Wealth.

ESRD denotes end-stage renal disease. Purchasing power parity (PPP) is an economic measure that compares annual incomes per capita on the basis of purchasing power for goods and services. Data are from the World Bank, 2001.

Figure 3. Select Countries ESRD Prevalence, Incidence and Acceptance to RRT
Note: Figure taken from Barsoum et al. NEJM, March 2006

In developing countries, these problems are aggravated by higher rates of malnutrition and primary risk factors for chronic illnesses, e.g. obesity and smoking. So despite improvements in the early detection of kidney disease and our greater knowledge of treatment of established kidney disease, we are far from achieving any real success in reducing the burden of disease.

A number of studies have highlighted that CKD is not only an unrecognised public health problem, but a marker of an even greater and also more recognised problem; cardiovascular disease (CVD) (Go et al., 2004, de Zeeuw et al., 2005, Parikh et al., 2006). In reality, these two major causes of morbidity and mortality are closely linked. Epidemiological surveys have highlighted that CKD and CVD share common susceptibilities and risk factors (Coresh et al., 2007, Fox et al., 2004a) such as race, obesity, and proteinuria, HTN, DM and HIV. Although the principles of prevention need to be tailored according to available resources, the emphasis in all settings needs to include simpler diagnostics, early detection with appropriate screening approaches, and vigorous treatment using primary health care clinicians rather than dialysis or

transplantation (Epping-Jordan, 2005). Kidney disease program strategies have highlighted that an integrated prevention strategy may have a major impact to improve outcomes for CKD and CVD (Rossert and Wauters, 2002, Hallan et al., 2006c). However, because CKD and CVD are so closely linked, it would be more sensible to focus more broadly on improving management of the chronic illnesses (Epping-Jordan, 2005, Beaglehole et al., 2007).

There is, therefore, a need to move away from an organ specific focus and rather, to focus on all organs and specialities associated with a higher risk of CVD and CKD. This integrated strategy must be shared by all specialists involved in chronic disease care (e.g. cardiologists, nephrologists, endocrinologists and HIV specialists) and by primary health care clinicians (doctors and nurses). If we focus upstream of the end organ damage, then we will focus on the same problems. Risk factors like obesity, HTN and DM are as important to treat as the end point. Certain medications, like angiotensin converting enzyme inhibitors (ACEi) and lipid lowering agents like statins, have proven particularly valuable for managing risk factors and diseases associated with CKD and CVD (Ruggenenti et al., 2001b, de Jong and Brenner, 2004).

However, prevention and good primary health care is not established without a cost, and programs for primary and secondary prevention require organizational skills and human skills to be established (Barsoum, 2006, World Health Organization, 2008). A first step is to establish the networks and build alliances among all clinicians addressing the problem of chronic illnesses at different levels in the health system. To achieve this we have to look to existing systems and models for managing chronic illnesses. The World Health Organization (WHO) has highlighted the approach of starting with simple strategies and adding to these with improved resources and skills. This comprises an initial focus on lifestyle measures (reducing tobacco smoking and obesity), and then moving to more specific measures such as proteinuria detection and ultimately dialysis and transplantation (Epping-Jordan, 2005, Epping-Jordan et al., 2005) . Immediate integration of the primary, secondary and tertiary health care sectors provides the links, support and integrated strategies for managing chronic disease, rather than focusing on one sector of public health as more important than another.

One popular model adopted predominantly in the developed world, specifically by the United States Family Medicine fraternity, is the Wagner Chronic Illness Care Model (CICM)

(Figure 4) (Wagner, 2004, Wagner et al., 2001). However, other models in developing countries have been successfully implemented for combating chronic infectious diseases. Such models include those used in Cambodia which integrated the management of HIV, diabetes and hypertension and improving PHC response to chronic NCDs (Janssens et al., 2007, Coovadia and Bland, 2008). The development of chronic care services that cut across conventional categories of infectious diseases and NCDs (Setel et al., 2004), and the incorporation of indicators of program outcomes and access to service are components used to measure program success. Strategies for managing tuberculosis and HIV have included the use of evaluation and reporting treatment outcomes (Harries et al., 2008), and these models can be adapted for all NCDs, including CVD and CKD.

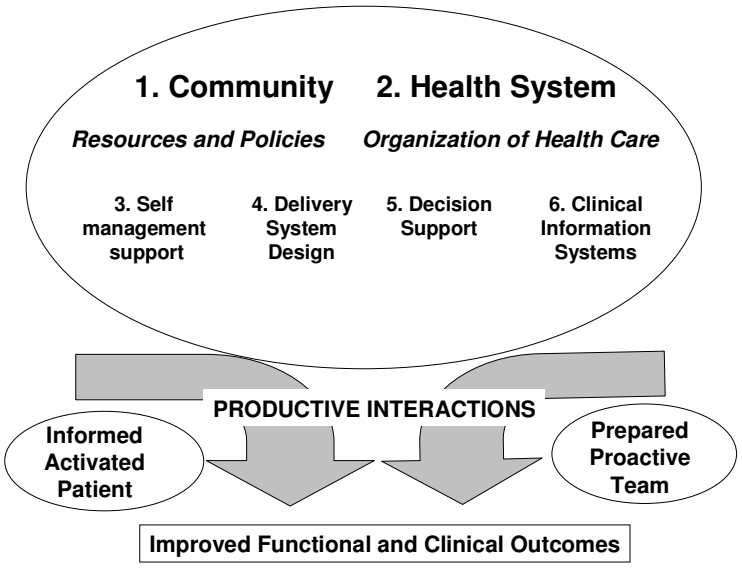


Figure 4. Wagner Chronic Illness Care Model (CICM)

This Chronic Illness Chronic Care Model adds to the stepwise approach by acknowledging a health system paradigm shift when approaching ongoing chronic care. It recognises that the current dominant reactive health system – waiting for people to present with disease – does not deal with this contemporary challenge of chronic illnesses. In the Innovative

Care for Chronic Conditions Framework (ICCC), the WHO highlights the importance of the correct support for a health system, which includes better resources and policies to support chronic disease management. CICM and ICCC, in essence, call for the same advances, an improved integrated method for managing chronic illnesses. These models potentially provide a platform for the Rose Philosophy (Rose, 1981) of integrating prevention and treatment into a single platform, resulting in improved knowledge to detect and manage CKD, and a better understanding of its close links with CVD. We have the skills to manage both problems by chronic illnesses programs for prevention, detection and management (Hoy et al., 2003c, de Jong et al., 2003, Brown et al., 2003b), We also need to tackle the problems of implementation and scaling up programs for managing chronic illnesses. This includes linking the tertiary specialist systems (hospitals) with the primary health system to develop a comprehensive strategy to manage chronic illnesses.

Health systems have developed around the specific need of diseases prevalent at the time (World Health Organization, 2000a), primarily communicable, infectious diseases like measles, smallpox, malaria and poliomyelitis. Infant and child mortality and maternal mortality rates were, until the last 5-6 decades, very high. Health systems tended to develop around the typical and health care management, the 'find it and fix it' model (Epping-Jordan et al., 2004, Epping-Jordan, 2005), in which health providers waited for people to present with an acute illness to a hospital, clinic or general practitioner . This model acknowledges that our existing health system focuses far too much on specific specialised problems. The CICM model goes further, by arguing the need to reorganise our health systems, and improve decision support, communication and information to facilitate the management of chronic disease. These improvements would result in both the patient and health care team being more empowered to manage chronic diseases. Enabled, knowledgeable patients and health workers are essential requirements to improved patient adherence, follow up and clinical outcomes, as illustrated in the WHO Innovative Care for Chronic Conditions (ICCC) Framework (World Health Organization, 2002a) (Figure 5).

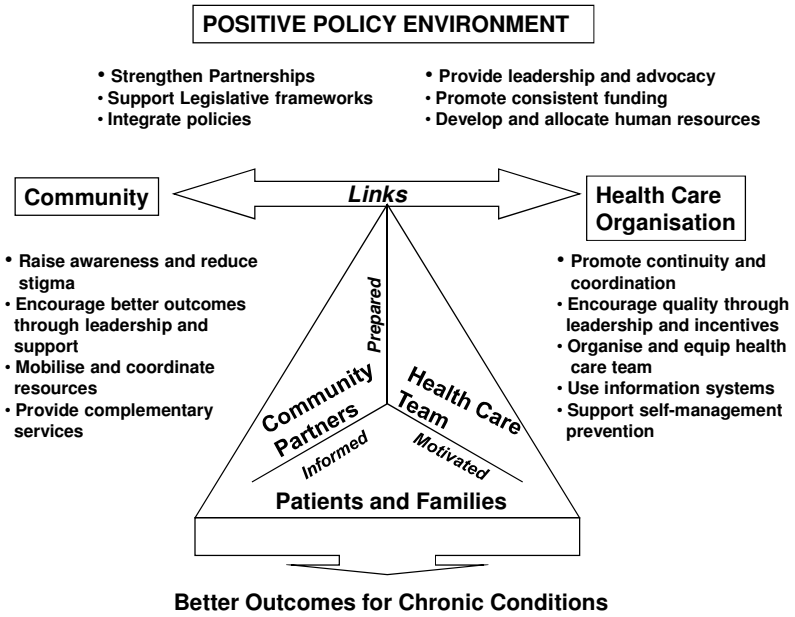


Figure 5. Innovative Care for Chronic Conditions Framework
Note: This model was developed by the World Health Organization based on the Wagner CICM model

Contemporary societies face new burdens associated with lifestyle problems around tobacco use and poor nutrition and the development of chronic, non-communicable diseases (NCD). The shift was assumed to be from a high prevalence of infectious diseases (tuberculosis, malaria), in poorer societies, to a high prevalence of NCDs (hypertension, diabetes, cancers, obesity and cardiovascular disease) with economic development. 'Health transitions' are dynamic, complex and not easily simplified (Manderson, 2008), as evidenced by declining survival and deteriorating health conditions in some countries e.g. Zimbabwe, and the existence of high burdens of non-communicable diseases like diabetes, hypertension and obesity in communities in developed countries e.g. Aboriginal Australians.. Chronic illnesses currently are best defined as non-communicable diseases like heart disease, hypertension, diabetes, asthma and epilepsy (Couper, 2007), but now communicable disease like HIV/AIDS and TB could be included in the overall framework of chronic illnesses. Chronic illnesses are broadly defined as health problems that require ongoing management over a period of years or decades (World Health Organization, 2002a), or more specifically as illnesses that last longer than 3 months and are not self-limiting (Wagner et al., 2001). The transition from primarily communicable acutely

treatable disease to chronic illnesses requires a more integrated health system, able to deliver high quality care over time.

The emergence and re-emergence of disease is often related to poor infrastructure, poor socioeconomic and physical conditions and where there has been an inability to provide accessible health services and sustainable disease control (Manderson, 2008). Over the past century, health systems have undergone overlapping generations of reforms but definitions and conceptual models of disease lag behind existing knowledge and practice.

Kidney disease is not seen as part of the CVD continuum like coronary artery disease or stroke, nor is it seen as part of the continuum of chronic illnesses. It would be advisable to ensure that all chronic disease, like chronic kidney disease, are included in order to achieve the goals of improved detection, management and outcomes (Schneider et al., 2006, Si et al., 2008, World Health Organization, 2000a) (see Figure 7). Health systems are defined as comprising all the organizations, institutions and resources devoted to producing health actions. A health action is defined as any effort, whether in personal health care, public health services or through intersectoral initiatives, whose primary purpose is to improve health (World Health Organization, 2000a). We have to evolve these early health systems from their 'radar' like approach to a chronic ongoing integrated care model. Figure 6 explains the relationships and relatedness between the various chronic diseases and their early risk factors, which needs to be understood when developing services tackling these illnesses (Beavers and World Health Organization, 2003). This figure highlights the commonality of risk factors such as hypertension, diabetes and obesity on the risk of developing chronic illnesses like chronic kidney and cardiovascular disease, with the resultant complications which could include ESRD and or a stroke.

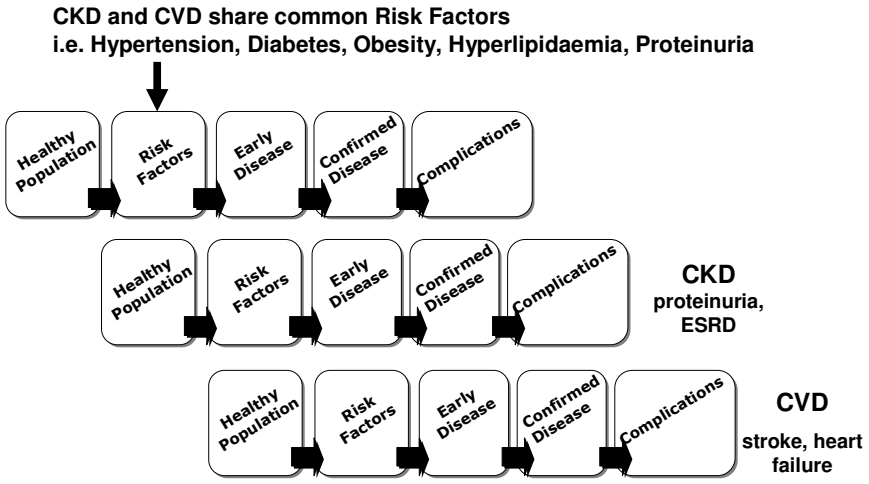


Figure 6. An Integrated Model of Chronic Disease
Note: The kidney is an organ which illustrates this 'interactive model' of chronic illnesses. Adapted from 'Healthcare Decision making in the Western Pacific Region: diabetes and the care continuum in the Pacific Island Countries (Beavers and World Health Organization, 2003).

Figure 6 also highlights the need for integrated and intersectoral initiatives which require health systems to be developed in a horizontal manner, focusing on common risk factors, preferably at the source, rather than vertically on specific illnesses or 'organ systems'. Ideally, disease should be prevented in the community, through health education and other interventions, e.g. discouraging smoking or poor lifestyle resulting in obesity. It is often the case that a problem occurs before prevention can occur and a person's first point of contact with the health service will be a primary health care (PHC) clinic. In these cases, interventions will be required to prevent the disease worsening, i.e. secondary prevention. In the case of DM, for example, good primary DM glucose control should prevent HTN or proteinuria. Either of these complications could increase the chances of disease progressing to CVD (strokes) or CKD (end stage renal disease). Secondary prevention intervention will also be required to prevent proteinuria progressing, such as initiating treatment with an angiotensin converting enzyme inhibitor (ACEi). The most cost effective method for secondary prevention would include a screening program in the community or clinic, and the education of primary health care providers. Often the knowledge and skills for best treatment reside in the tertiary specialist

referral centres, but the greatest impact for treatment rests at the first point of contact at the PHC clinic and with the primary care clinician.

Background to Study Site

This section provides an argument for the need to evaluate the extent of the burden of chronic illnesses in South African in general and specifically in Soweto. It highlights the importance of the PHC sector in dealing with this problem, providing the appropriate skills and support to PHC clinicians and an argument for developing a chronic disease outreach program.

In South Africa, and especially in Soweto, the nurses working in PHC clinics are known as the Primary Health Care Nurse (PHCN). They are most often the primary source of contact for most people who are ill and they form the backbone of primary health care in South Africa (Health Systems Trust et al., 1999). It was recognised in 1988, by Edelstein in Soweto, that nurses were not adequately or appropriately trained to meet the needs of primary care services. One of the most obvious gaps was the small number of nurses with post basic training in skills to diagnose and treat common complaints. To meet these needs, a number of post basic courses and in-service training programs were developed in South Africa (Health Systems Trust et al., 1999). Many of these programs were highly effective, including the program developed by the Primary Health Care School in Soweto (Pein et al., 1999), which bridged the knowledge-skills gap left from basic training. The nurses trained with this skill, were referred to as Primary Health Care (PHC) nurses, or later known as the 'PHCN'. Although most people working in South Africa use and understand this term, many prefer "nurse clinicians" or "nurse practitioners" and the official Nursing Council term is not PHCN.

The need to evolve health systems requires a move away from a reactive model towards an early prevention and treatment model. Models like the CICM or ICCC provide the tools to link primary care to specialist care, and offer an opportunity to investigate how to best link specialists with primary health workers. Early disease management can be achieved by providing better communication, knowledge and motivation for primary care clinicians. Acknowledging the key role played by the PHCN in managing chronic diseases, and what would be required to improve their knowledge and motivation, remains largely unaddressed. Evaluating the impact of the

chronic disease program on improving kidney and cardiovascular outcomes, by utilising the PHCN as an important link in the health system, requires investigation.

In 1999, a Chronic Disease Outreach Program (CDOP) began in Soweto, South Africa. Soweto is an acronym for “south western townships”. Soweto is on the outskirts of Johannesburg, and was established as a result of the Apartheid system whereby black South Africans were forcibly moved since the 1930s. Soweto remains a largely black urban township, of crowded houses, backyard rooms, shacks and hostels, situated 20km from Johannesburg (Rispel et al., 1996). For political and practical reasons, the population has never been counted accurately, but an official figure of one million was given in 1996 and it is now possibly 1.6-2 million or higher (Doherty et al., 1996). After the 1976 uprisings, some people believed that improved primary health care service were established to try and win over community support, others thought it due to doctors feeling unsafe. No evidence exists for either assertion. it appears that the PHC services were primarily driven by the need to diagnose and treat common complaints instead of referring them to directly to Chris Hani Baragwanath hospital (Health Systems Trust et al., 1999). The resultant PHC clinics and nurses allowed the primary care service to be linked with the only hospital in the vicinity. Chris Hani Baragwanath Hospital is Soweto's only regional hospital and was established in 1941 as the Royal Imperial Hospital, Baragwanath, in what is today Diepkloof, for convalescing British and Commonwealth soldiers (Wikipedia Contributors, 2008, Brodie, 2008). The hospital was named after John Albert Baragwanath, who owned the land at the time, and changed to Chris Hani Baragwanath Hospital (CHBH) in 1996, in memory of the murdered anti-apartheid activist. Today it has 2800 beds, serving the needs of the Soweto population and others in the South Western Gauteng area, the nearby North West Province and even regional Southern African neighbouring countries such as Botswana, Mozambique and Zimbabwe. The hospital acts as both a local referral hospital for the clinics in South Western Gauteng province, but also has a regional, tertiary and even quaternary service. The local or secondary hospital function results in it accepting first referrals from the surrounding primary health care centres and it is the primary referral centre for primary health care nurses and doctors working in the public health clinics and for private general practitioners in Soweto and the region. CHBH and its primary health service development mirrored that of

primary health care development taking place worldwide in the 1970s (Segall, 2003). Although it is the only regional hospital, the care provided in Soweto has remained largely fragmented, with multiple health authorities, local regional and government health departments, taking on the responsibility for the provision of care to the population (Rispel et al., 1996). A newer clinic system, with some improvements in regional management and upgrading of some clinics to community health centres, was developed in 1996 after South Africa's liberation, but the hospital today remains largely unchanged (Rispel et al., 1996, Doherty et al., 1996). The referral system has remained the same for the past 20 years, and there is no secondary hospital in the area, so CHBH receives referrals directly from PHC clinics to its casualty department. Patients are then triaged to a specialist clinic at the discretion of the casualty doctors.

There is a lack of information regarding the disease burden, population size and health service needs and utilisation in Soweto (Doherty et al., 1996). Like other parts of sub-Saharan Africa, Soweto residents' face multiple burdens of CVD and CKD risk, non-communicable disease such obesity, HTN and DM, and communicable diseases like HIV and TB (White and Dalby, 2008, Sliwa et al., 2008, Beran and Yudkin, 2006). In 1999, CDOP was established in a number of primary care clinics in Soweto (Figure 7).

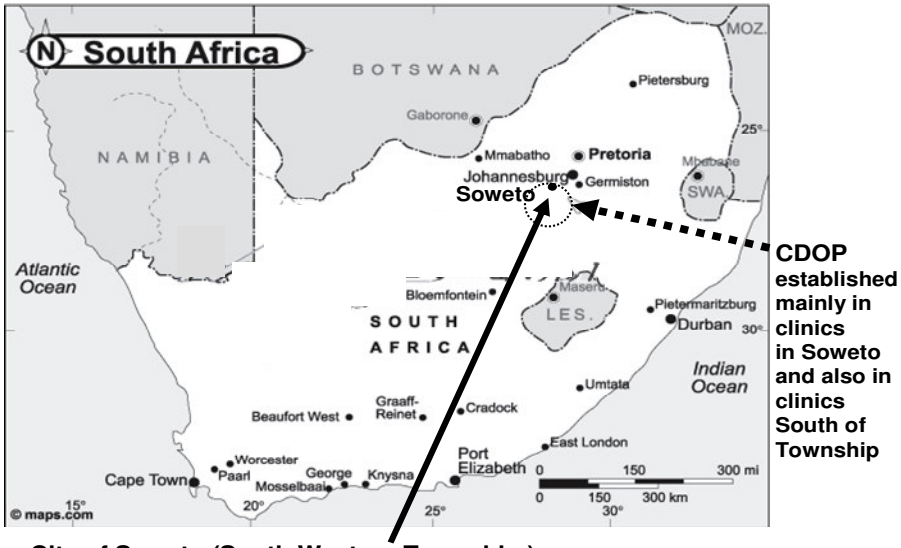


Figure 7. Location of Chronic Disease Outreach Programs

The approach by CDOP in Soweto has been to stratify the high risk population groups within the DM and HTN population (Katz, 2005b). This recognises the lack of resources to screen all people attending chronic clinics. This strategy, in keeping with that followed by others (Hallan et al., 2006a, Hallan et al., 2006c, Brown et al., 2003a, Naicker, 2003), recognizes those at highest risk of CVD and CKD are patients with uncontrolled HTN or with DM, HIV and proteinuria. The approach of focussing on early risk factors, common to both CKD and CVD, like uncontrolled hypertension and albuminuria supports the emphasis of developing integrated, rather than disease-specific, surveillance programs. It also supports a unified approach for primary and secondary prevention. The Chronic Illness Care Model (CICM), discussed earlier, served as a good model in Soweto for the Chronic Disease Outreach Program, as screening for CKD matched the processes carried out by the PHCN when managing hypertension, diabetes and HIV. It also provided an opportunity to focus on PHC clinicians as the 'prepared and proactive team' (Wagner et al., 2001), who manages the risk factors associated with CKD and CVD and specifically the PHCNs in Soweto, who are the foundation on which the service is run.

These chronic illness care models measure both the progress and outcomes of care, encourage follow up, and can enable ''stepping up'' or ''stepping down'' care from PHC to specialist care (Gask, 2004). Deciding where patients can be best managed is not always well researched. An effective health care system relies on all components being intact, and those clinicians working in the PHC sector have to be able to recognize and implement appropriate strategies for managing disease, and if disease is advanced, to refer the patient to the next tier.

Chronic disease programs also facilitate the long-term social processes that involve capacity building of both the communities and health workers. The strengthening of health systems in developing countries remains a key challenge, especially in the wake of the existing epidemics of "chronic" infectious illnesses like HIV and TB together with chronic non-communicable diseases, often co-occurring. CKD and HIV share similarities in that their risk factors can be effectively detected and treated, but their treatment is complex and often, at some point in the course of the illness, will require specialist support to ensure effective management. The major constraint with chronic illnesses is that life- long therapy is required, often with

multiple drugs. The aims of establishing Outreach Programs should not be to develop a program specific for kidney disease but rather to integrate kidney disease management horizontally into established chronic disease systems within the existing PHC services. Programs for HIV and antiretroviral (ARV) therapy in South Africa demonstrate the difficulty in establishing and integrating into the existing poor health systems. Programs for HIV are developed in parallel within health systems, and this weakens rather than strengthens the overall health system (Victora et al., 2004, Schneider et al., 2006). Whilst a focus of the study is to highlight CKD amongst chronic illnesses, it is not the aim to achieve this to the detriment of other chronic illnesses. It is recognised that the improvement of CKD and CVD as a whole will rely on improved primary health care services. This is clearly supported by evidence that countries, with good health policies and organization and with a strong service for primary care have better health outcomes at a lower cost (Rawaf et al., 2008). Both Couper (2007) and Rawaf (2008) highlight the importance of certain key principles and a person orientated approach to deal with the overlapping problems associated with chronic illness, and this approach is supported.

The need for integration and more broad-based improvements in population health, such as preventive measures, primary care services, and health workforce development ('horizontal programming') (De Maeseneer et al., 2008), is endorsed, despite the fact that CDOP was initiated in a vertical manner. The need for integration is supported by most but it is acknowledged that the implementation of this framework remains a challenge (De Maeseneer et al., 2008, van Weel et al., 2008, Couper, 2007, De Maeseneer et al., 2007), and this is evidenced by the desire to implement such a strategy as part of the '15 by 2015' campaign (De Maeseneer et al., 2008). It is envisaged that CKD would be detected and managed as part of an overall approach to a patient with the risk factors for chronic illnesses (hypertension and diabetes), and that this would include screening for proteinuria and an estimated the glomerular filtration (eGFR) rate at the PHC consultation. This thesis acknowledges that decreasing the chronic non-communicable disease (NCD) burden requires the implementation of the multisectoral policies aimed at decreasing population-level risks for NCDs, and effective and affordable delivery of primary care interventions for patients with chronic NCDs. This framework for a public health approach is informed by experience of scaling up interventions for chronic

infectious diseases (tuberculosis and HIV) (Couper, 2007). However, as was commented by Couper (2007), page 4; “unfortunately a major opportunity was lost, in planning this vertical program” for HIV. The ultimate integration of CKD screening would have to take this into account, and ensure that it is part of the overall management of patients at high risk for CKD and CVD, and falls under the gambit of chronic illnesses.While focusing on the technical and structural aspects of the health systems is important, supporting and developing staff, is a key element of all chronic illness programs. Continuing care needs to be delivered by a well functioning team (Epping-Jordan, 2001).The Wagner CICM and WHO ICCC models both call for an informed, activated and motivated health care team. Unfortunately there is little investment in the development of staff (Franco et al., 2002). This sentiment was expressed by Hongoro and McPake (2003), who have found health workers in developing countries to be underpaid, demoralised and underproductive, and noted problems with health worker training, deployment, and retention. In order to achieve the successful delivery of chronic disease care, attention to the conditions of health workers needs to be addressed.

In Soweto, there was a need and motivation to establish an early detection and prevention strategy, to provide nephrologists with an alternative to refusing people RRT, and to prevent people developing ESRD or early death from CVD. However, prevention strategies are costly, require a degree of sophistication and expertise to establish, and are seen by many as a long term rather than a short term solution (Kober and Van Damme, 2004, Dirks and Levin, 2006). CDOP was established to try and answer some of these questions.

Soweto a Transitional Community

‘Transitional communities’, through colonisation, urbanisation and western dietary influences, have undergone dramatic changes over very short periods of time, who, prior to these developments, had lived very different life styles (Figure 8). We are reminded by Manderson that the epidemiological shifts in disease, termed health transition, cannot be explained so simply (Manderson, 2008). The Soweto community, like industrialised and urbanised societies, show a concurrent increase in non-communicable illnesses and in Soweto also new infectious diseases. These variations in patterns of disease and life expectancy reflect

the complexity of factors affecting health transition and include the social, cultural, and behavioural factors, belief systems and practices, geography and economic factors (Manderson, 2008). It has been suggested that biological factors may play a role in chronic disease prevalence (Burrows et al., 2008), as whilst their lifestyles and diet have been altered in many ethnic populations, bodies and genetics adaptation may differ in response to the same transition (Karter et al., 2002, Hsu et al., 2003, Hong et al., 2004). Findings have suggested that the genetic difference between racial or ethnic groups seem to relate more to differences in susceptibility to factors which promote CKD. The result of these factors is a higher burden of CVD and CKD in black or indigenous communities discussed earlier (Cass et al., 2004, Lea et al., 2008). Such dramatic societal transitions are behind the high burdens of CVD and CKD in black or indigenous communities discussed earlier. Transitional communities and the changes in their 'way of life' form part of a greater worldwide problem, reflected in the metabolic syndrome (see also figure 13).

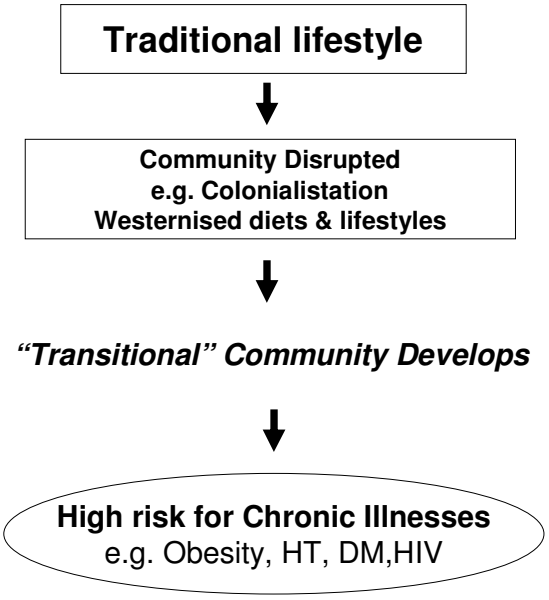


Figure 8. "Transitional" Communities and the risk of Chronic Diseases
Note: Developing world and 'minority' communities appear to be at particular risk for cardiovascular (CVS) and chronic kidney disease (CKD).

Overweight and obesity, central obesity, sedentary lifestyle, higher visible fat intake, and higher social class were significantly associated with DM in an Indian study (Ram et al., 1998).

In SA, data from the THUSA study (Transition and Health during Urbanisation in South Africa) showed increases in overweight, obesity and several risk factors for NCD (Vorster et al., 2005, Vorster, 2002, THUSA study et al., 2007). The changes in dietary habits amongst poorer rural and urban Africans have been documented for some time in Southern Africa (Walker, 1995, Steyn et al., 2005). In city dwellers, prevalence of obesity, HTN, and DM have risen and remain true for 'transitional communities' like Soweto (Katz et al., 2006b). The 'way of life' of these communities has changed significantly. With increasing smoking, excessive drinking, and impoverishment, these factors remain potent continuing health challenges.

The higher risk for CKD and CVD among 'minority' disadvantaged communities like African Americans and Australian Aborigines is influenced by poverty and other structures of violence (Ward, 2008, Burrows et al., 2008, Cass et al., 2004, Spencer et al., 1998). African Americans have a 3-7 times greater risk of kidney disease than Euro-Americans, even for the same diagnosis (Lopes et al., 1994, Brancati et al., 1992, Cass et al., 2004). Disparities in HTN and DM control also exist in disadvantaged and minority communities (Duru et al., 2008, Mainous et al., 2004), and disparities between rural and urban areas are well documented internationally (LuXia et al., 2008, Abdul-Rahim et al., 2001, Ram et al., 1998) and locally (Walker, 1995, Vorster et al., 2005). In these studies risk factors and morbidity of CVD and CKD differed in rural and urban areas, and often in relation to poverty and gender. The association of CVD-CKD and HTN with DM was greater in urban than rural subjects.

Unfortunately the greatest burden of non-communicable chronic disease is also felt by countries with a high burden of infectious diseases (Global Forum for Health Research, 2002, Abegunde et al., 2007, Strong et al., 2005), leading to additional and aggravating effects on non-communicable diseases e.g. HIV and HIV associated kidney disease can cause ESRD, and HIV is a cause of heart disease. Research has highlighted this epidemiological transition from infectious diseases to NCDs experienced in middle-income countries with growing economies, but in South Africa, this transition has been joined by the HIV/AIDS epidemic (Manderson, 2008, Vorster and Kruger, 2007). The impact of this double burden is on health resources and services with increased demands on the clinicians facing these epidemics, the interpretation of trends of

morbidity and mortality have been difficult. However, the recent study in rural Agincourt in South Africa by Tollman et al. (2008) was able to demonstrate this impact and concluded that mortality from NCDs was prominent despite the increase in deaths from chronic infectious disease.

The high prevalence of obesity, DM, HTN and other kidney diseases like infectious glomerulonephritis and HIV glomerular diseases, suggests that like other “transitional” and minority communities around the world, South Africans have an increased susceptibility to kidney disease and its aggressive course. Hemodynamic and metabolic factors, perhaps aggravated by existing poverty and the high prevalence of low birth weight (related to intra-uterine malnutrition), are also factors to be considered (Barker et al., 1989, Huxley et al., 2000). This strong causal relationship between DM and the resultant lethal CVD complications leads to an underestimation of the primary importance of CKD and, hence, under-reporting in official mortality statistics (Pugsley et al., 2003).

The epidemiological transition in CVD in Soweto is evident in statistics of hospital admission. In 1993 at Baragwanath Hospital, Soweto, only 42 cases of CVD (coronary artery disease or myocardial infarction) were diagnosed from a total of 23,000 hospital admissions (Walker, 1995). In a recent follow up evaluation of 4162 patients, the presence of CVD and its risk factors was found to be high, including 616 cases of coronary artery disease (Sliwa et al., 2008). This health transition, including the significant burden of non-communicable disease, despite the growing infectious disease burden, was recently described in a rural community in South Africa (Tollman et al., 2008). The implication of this transition is the need for the delivery of effective primary health care. Almost all the studies call for the establishment of programs that are holistic, integrated, but trans-disciplinary and multisectoral. This is required to break the vicious circle of poverty and under-nutrition and the long-term prevention of CVD and CKD.

Soweto Chronic Disease Outreach Program

CDOP was initiated as the Primary Prevention Program (PPP), as a pilot secondary prevention strategy, in June 2001. As already indicated, the program was modelled on an outreach program run with remote indigenous communities in Australia (Kondalsamy-

Chennakesavan et al., 2004, Katz et al., 2006a, Hoy and Kondalsamy-Chennakesavan, 2004). PPP was established to detect people at high risk for CKD and CVD, but also to curb the high incidence of end stage renal disease (ESRD). The pilot program aimed to compare progression, morbidities and rates of dialysis and death in two separate regions in Johannesburg. The CDOP pilot program ran in Soweto Wits Health Region B of Gauteng Province, which included Chris Hani Baragwanath Hospital (CHBH) and another region, Region C. These Region C clinics are closer to central Johannesburg and have a different specialist referral hospital, Johannesburg Academic Hospital. The pilot program aimed to compare progression, morbidities and rates of dialysis and death in the two regions. Chris Hani Baragwanath hospital was chosen for this study, as it is the tertiary 'specialist referral' facility for PHC clinics in the region. This allowed the two regions to run independently and be compared.

The people enrolled into the pilot CDOP, PPP, had the same profile of underlying chronic diseases as those who participated in the current study i.e. HTN (BP$\geq$140/90) or DM and HTN or proteinuria. They were enrolled at 12 intervention clinics (IC) and 4 control clinics (CC). The IC clinics used CHBH as their referral hospital and CC clinics did not. At the intervention clinics, the patients were managed with the early use and quicker up titration of an ACE inhibitor and a diuretic, and received specific health education. BP targets were set at a lower value of 120/70mmHg. The health education included information about HTN, DM, CKD and the appropriate lifestyle and management for these diseases. The treatment targets, developed from existing established guidelines, were also simplified. Instead of providing clinicians with algorithms of management, nurses were requested to focus on a specific target for a CVD or CKD risk factor. In HTN, where different targets exist for HTN alone compared with DM and proteinuria, we chose a single blood pressure target. In DM management, targets were also divided into three different zones e.g. HbA1c level <7 is optimal; 7-8 acceptable and if >8 additional action. This target was simplified to <8. This strategy was taken in view of the poor control in the pilot project at baseline where glucose serum levels were >10mmol/L (Figure 9).

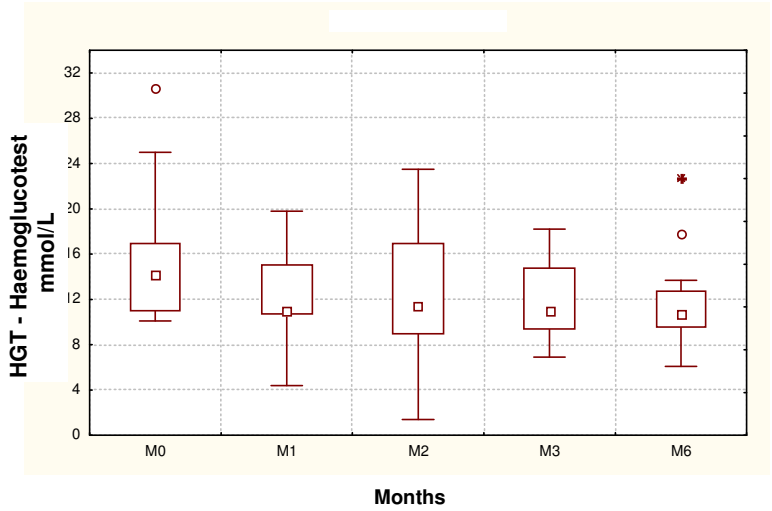


Figure 9. Glucose levels on Pilot CDOP (PPP*)
HGT – haemoglucotest (finger prick serum glucose mmol/L);M0=baseline; M1=month one;M2=month two; M3 = month three; M6= month six
Note: Treatment group patients with HGT>10mmol/L at baseline. At 6 months nearly 75% had finger prick HGT of less than 10mmol/L; *Primary Prevention Program

Control clinics (CC) managed their patients according to established 'normal' practice guidelines and were also monitored, but there was no assistance with management or interference in care, unless advanced disease was detected. Here BP was managed primarily with a thiazide diuretic and goals were standard (<140/90mmHg). In the IC clinics PHCNs could contact the program director at any time, they visited the referral centre every 4 weeks for reports on progress, individual cases were discussed, and patients needing specialist care were referred. Before and after data were collected and compared between intervention and control sites. A total of 871 patients (527 females, 268 males) were enrolled onto the pilot program at baseline (645 IC, 226 CC). Age distribution was significantly different between IC and CC clinics, with more people >60 years in the IC clinics. Gender distribution was similar. Control clinics also had significantly more DM patients and IC clinics had more HTN patients. Comparisons of baseline characteristics are shown in Table 1.

Table 1. Baseline Parameters of Patients enrolled on the Pilot PPP

Parameters	Control Clinics		Intervention Clinics		p
	N		N		
Age *	219	51.4 (10.0)	625	57.5 (11.9)	<0.001
Male	226	78 (34.5%)	645	201 (31.2%)	0.353
Diabetics *	226	110 (48.7%)	645	234 (36.3%)	0.001
Hypertensive *	226	178 (78.8%)	645	622 (96.4%)	<0.001
Smokers *	201	19 (9.5%)	577	86 (14.9%)	0.051
Alcohol	201	24 (11.9)	569	98 (17.2)	0.078
Height, cm *	165	161.9 (12.8)	583	158.1 (10.5)	<0.001
Weight, kg	219	78.1 (14.6)	631	80.3 (19.0)	0.083
Hips, cm	192	109.5 (13.7)	587	111.1 (19.1)	0.218
Waist, cm	189	96.2 (14.3)	583	97.5 (18.8)	0.366
BMI, kg/m2 *	162	31.0 (8.3)	581	32.7 (8.6)	0.026
Obese by WHR	187	86 (46.0%)	583	256 (43.9%)	0.619
SBP *	221	147.8 (22.2)	619	153.0 (21.6)	0.002
DBP	221	93.4 (12.6)	619	93.6 (12.5)	0.826
MAP	221	111.5 (14.8)	619	113.4 (14.1)	0.094

Data are Mean (SD) or proportions; * Significant difference between the 2 groups
BMI – body mass index, WHR – waist-hip-ratio

Significant differences in some parameters at baseline indicate the non-homogeneity of the different regions, making direct comparisons of the intervention difficult. In the Soweto IC clinics, there were significantly more smokers, alcohol users, and patients had higher systolic blood pressures (SBP). There was also a slightly higher BMI and obesity by waist hip ratio, although it was not significant. No significant difference could be noted in blood glucose level, haemoglobin and serum creatinine levels. However, the proportion with proteinuria by dipsticks was significantly higher in CC group (53%), compared with 32% in IC group; $p<0.001$. This probably related to the greater number of DM in the CC group. However, the median levels of

the protein to creatinine ratio (PCR) did not differ in the two groups, but blood lipid levels (cholesterol and LDL) were significantly higher (Table 2).

Table 2. Baseline Urine and Blood Lipid Profile

Parameters	Control Clinics		Intervention Clinics		p
	N		N		
Urinary Dipstick ≥1+	200	106 (53%)	604	192 (31.8%)	<0.001
PCR#	62	0.02	290	0.02	
Serum Creatinine*	51	79.5 (74.2-85.3)	424	84.9 (81.6-88.3)	0.270
Total Cholesterol	111	4.7 (1.0)	331	5.2 (1.2)	<0.001
HDL	107	1.3 (0.4)	321	1.2 (0.5)	0.240
LDL	107	2.7 (1.0)	315	3.2 (1.1)	<0.001
Triglycerides	111	1.5 (1.1)	323	1.6 (1.0)	0.098

#PCR - Median for Protein Creatinine Ratio *Geometric mean (CI) for Serum Creatinine
HDL – high density lipoproteins; LDL – low density lipoproteins

In the pilot phase of CDOP, nearly 90 percent of participants were overweight or obese by either BMI or waist circumference (Kondalsamy-Chennakesavan et al., 2004). Women were more likely to be in the higher categories of all parameters of body weight and fat than men. The average waist circumference was in the obese range for both CC and IC participants. More participants were classified obese by waist circumference than by either BMI or waist-hip ratio alone. As in other transitional populations, waist circumference has proven to be a better indicator marking obesity than BMI and better association with CVD, CKD risk (Alberti and Zimmet, 1998, International Diabetes Federation, 2005).

Using clinical outcomes and after 6 months of follow up, evaluation of the pilot phase of the PPP showed that the control of risk factors had improved. The program was successful in reducing risk factors and after a short period of follow up, achieved better treatment targets (Katz et al., 2006a, Katz et al., 2006b). Significant phase I reductions in blood pressure, blood glucose and proteinuria were achieved at intervention sites (Katz et al., 2002). Changing people's eating habits and lifestyle was more difficult than just adding medication to achieve a blood pressure target in HTN. A non-significant reduction in proteinuria was achieved in the intervention group

(0.057 to 0.049 g/mmol; p=0.45 NS), indicating that increased use of ACEi and improving blood pressure control may have had additional effects. An important finding was that hyperlipidaemia was more common in both the treatment and control sites than previously believed, suggesting that the lifestyle of Soweto people is continuing to change. It could also reflect an increase in the availability and consumption of cheap fast foods and high sugar carbonated soft drinks over the past few decades. This was particularly worrying given current restrictions and essential drug guidelines, whereby lipid lowering medications are not available in most primary care clinics.

Although PPP was found to be a simple and effective means of ensuring better risk factor control, this was for a very short follow up period, and its sustainability had not been tested. There was also a large drop-out rate of patients enrolled. These results must be considered against the poor overall follow up of patients. These facts prompted a more comprehensive approach and evaluation of CDOP. The challenge was to see if this could be improved and scaled up into the paper-based version, Phase II of the project, i.e. the component of CDOP used for this project. This resulted in the implementation of Phase II the ‘nurse coordinator’ and ‘paper based’ phase.

2 KIDNEY DISEASE AS A PUBLIC HEALTH PROBLEM

This chapter will argue that kidney disease is globally both a significant public health problem and should be considered part of an integrated approach to chronic diseases in the primary health care setting. It highlights the links between CKD and CVD, and establishes an argument for both improved management in patients with diabetes and hypertension and the early detection of serious risk factors and/ or complications in order to prevent strokes, coronary heart disease, development and progression of CKD. It also establishes a link between the global rise of chronic illnesses and the metabolic syndrome and its cluster of risk factors including the association between metabolic syndrome (MetS) and CKD. Finally it will provide an overview of key kidney disease prevention programmes established in various regions worldwide.

Global Epidemiology of Kidney Disease

Chronic kidney disease (CKD) is increasingly recognised as a global public health problem, as a result of key developments in our understanding and detection of kidney disease. The evaluation of kidney disease using an estimated glomerular filtration rate (eGFR), as well as the ability to monitor proteinuria easily with a single urine sample, has greatly improved awareness of the problem. These developments, coupled with existing methods for assessing risk and progression, resulted in conceptual models outlining the definition and classification of CKD which have been used to highlight the existing burden of kidney disease (National Kidney Foundation, 2002, Levey et al., 2003, Levey et al., 2005, Coresh et al., 2002, Coresh et al., 2005, El-Nahas, 2004, Schoolwerth et al., 2006) (see figures 1 and 2). These developments have allowed doctors, researchers, and public health specialists to focus on risk factors for CKD and CVD, and to encourage earlier diagnosis and better follow up people with CKD. The models have also enabled researchers to better determine background precursors to CKD, to identify risk factors for its development, progression and outcomes, and to test strategies for its early detection, evaluation, and management.

CKD is poorly recognised. It is not mentioned in the 2005 WHO Report on 'preventing chronic illness: a vital investment' as a chronic disease requiring prevention (World Health Organization, 2005c). This is despite the fact that CKD is common in people with CVD and with CVD risk factors (HTN, DM and obesity), and that the presence of CKD multiplies the risk for adverse outcomes in these conditions, and is often a precursor to CVD (Sarnak et al., 2003, Go et al., 2004, Zoccali, 2006) (discussed below). CKD is also a risk factor for adverse outcomes in other acute and chronic diseases such as infections (Hepatitis B and C, HIV)(Fabian et al., 2007). In the period 1985 to 1999, the percentage of haemodialysis centres providing care to patients with HIV in the United States increased from 11% to 39%, and the percentage of dialysis patients with HIV infection increased from 0.3% to 1.4% (Ahuja et al., 2002) (Figure 9). This information remains unknown for sub-Saharan countries most affected by infectious diseases and especially HIV/AIDS. Despite the link between CVD and CKD, and the high and growing levels of CKD associated with HIV, CKD remains unrecognised as an important chronic disease. In most cases, stroke and coronary artery disease are considered part of this continuum, but kidney disease is not. Equally, HIV/AIDS is still not considered by most countries to be part of the chronic illness continuum.

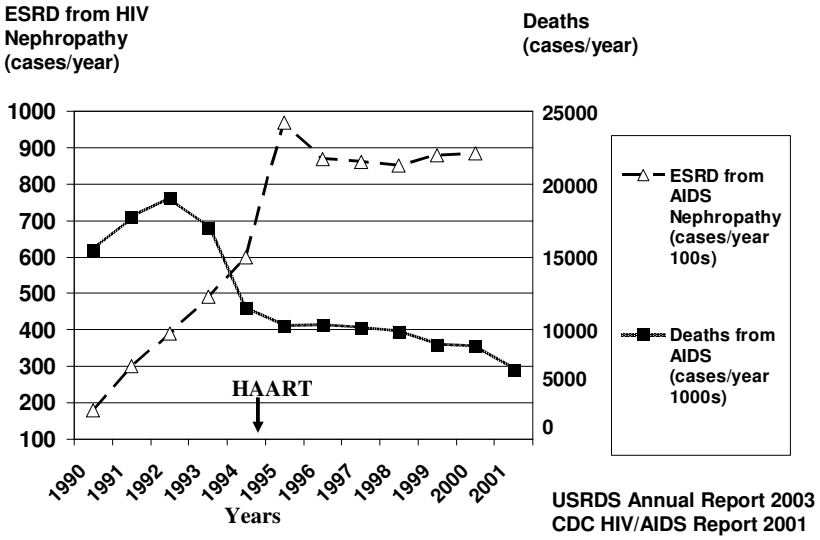


Figure 9 ESRD, Deaths and HIV Nephropathy
ESRD and AIDS Nephropathy and Deaths in black patients with AIDS
ESRD = End Stage Renal Disease, HAART – highly active antiretroviral therapy
Note: Information is for and Deaths in black patients with AIDS

In the United States, HIV renal diseases represent the third commonest cause of ESRD in African Americans between 24 and 60 years (Szczech et al., 2003). The incidence of HIV in South Africa is one of the highest in the world, and given this, it is possible that HIV/AIDS is a significant cause of ESRD, but no data exists currently. People with HIV do not easily qualify for dialysis or transplantation, and there is therefore no way to determine its impact on ESRD (Fabian et al., 2007). It has been advised that all HIV patients be screened regularly for CKD, but this is not being carried out[1]. Fabian et al. (2007) continue to suggest that an integrated management, similar to other high risk groups like HTN and DM, should be implemented to reduce the progression to ESRD. If one recognizes the conceptual framework of kidney disease, by which renal disease is initiated and then progresses (see figure 1), it is possible to develop the same framework for HIV CKD, as for the other chronic illness and risk factors (HTN, DM, obesity etc). This framework developed by the Kidney Disease: Improving Global Outcomes (KDIGO) group allows for the recognition of susceptibility factors[2], possible initiation factors and the progression factors associated with the development and deterioration of kidney disease (Figure 10). The greatest burden of NCD is felt by countries which also have a high burden of infectious diseases (Global Forum for Health Research, 2002), leading to additional and aggravating effects on the NCD burden e.g. HIV related renal diseases causing ESRD such as HIV associated nephropathy (HIVAN). There is a greater realisation amongst health workers who have a specific interest in CKD, that we must have a more realistic approach to the existing and increasing burden of CKD. This means changing the focus to earlier detection rather than trying to provide dialysis and transplantation for all patients.

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[1] The Infectious Diseases Society of America (IDSA) published guidelines in 2005, recommending that all individuals be assessed for CKD at the time of diagnosis of HIV infection, with a screening urinalysis for proteinuria and a calculated estimate of renal function. Therefore any patient with persistent proteinuria, persistent haematuria or (glomerular filtration rate) GFR <60mL/min per 1.73m2 should be referred to an institution where a specialist can evaluate this patient for further investigations Gupta SK et al., 'Guidelines for the Management of Chronic Kidney Disease in HIV-Infected Patients: Recommendations of the HIV Medicine Association of the Infectious Diseases Society of America', Clinical Infectious Diseases, 40 (2005), 1559–85.

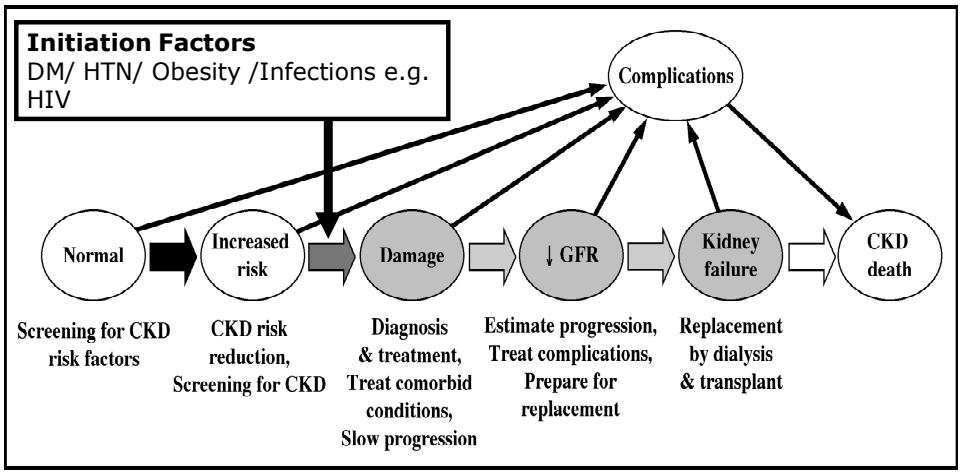


Figure 10. Initiation Factors of CKD

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Note: The susceptibility and initiation factors of CKD and CVD which form part of the KDIGO CKD conceptual framework which is a screening, risk reduction and management model.
DM - diabetes, HTN – hypertension, HIV – Human Immunodeficiency Virus

The implications of our ability to detect kidney disease is seen in the study of CKD in the United Kingdom (UK), revealing that the trend for CKD, as in other developed countries, is expected to continue to rise at an annual rate of around 5–8% (Lysaght, 2002). The factors influencing this rise include ageing populations, as the incidence of ESRD is higher in elderly people (United States Renal Data System, 2003), i.e. incidence of ESRD >1200/million per annum >65 years. The increased incidence of type 2 DM, which is closely linked to CKD will also directly impact on the development of CKD (Wild et al., 2004, Rossing et al., 2004, Friedman and Friedman, 2007), as is the rise of CKD from HIV in sub-Saharan countries like South Africa (Fabian et al., 2007).

Studies from Europe, Australia, and Asia confirm a global trend in the high prevalence of CKD (de Zeeuw et al., 2005, Chen et al., 2005 , Hallan et al., 2006b, Chadban et al., 2003, Iseki

et al., 2007). For example, screening surveys of representative samples of the whole population, using eGFR measurements, in Australia (Chadban et al., 2003), Japan (Iseki et al., 2007), and Holland (Hillege et al., 2001), identify between 6% and 11% as having some degree of CKD. The prevalence of CKD increases to 50–60% when at-risk individuals are screened (Brown et al., 2003b). In the United States, 9.6% of adults in the general population are estimated to have CKD (Stevens et al., 2006, Coresh et al., 2007) and kidney failure is being shown to be increasing. In general the outcomes remain poor, and the costs of managing end stage renal disease are high. The number of persons in the United States with kidney failure who are treated with dialysis and transplantation is projected to increase from 340 000 in 1999 to 651 000 in 2010 (United States Renal Data System, 2000).

Disparities in the incidence of ESRD (CKD stage 5) are strongly influenced by the racial and ethnic differences as well as by biological and social differences. In Australia and the USA, the annual incidence of ESRD is substantially lower in wealthier European populations compared with their poorer counterparts, i.e. indigenous Australians and African-Americans (United States Renal Data System, 2003, McDonald and Russ, 2003) (see Table 3). Studies have pointed to both biological and social causes for the differences (Hsu et al., 2003, Ward, 2008, Cass et al., 2004, Burrows et al., 2008, Karter et al., 2002). Some of these factors include difficulties with HTN and proteinuria control, and genetic differences between blacks and whites related to differences in susceptibility and likelihood of progression (Hsu et al., 2003, Karter et al., 2002, Ward, 2008). While the incidence of ESRD has been found to be greater in geographic areas with less educated populations and lower household incomes (Cass et al., 2001), studies that controlled for these factors found that African Americans DM had a higher likelihood of ESRD than European Americans with DM (Karter et al., 2002, Brancati et al., 1992). The persistence of ethnic disparities after adjustment again suggests a possible genetic origin, the contribution of unmeasured environmental factors, or a combination of these factors.

Table 3. Incidence and prevalence of ESRD, select regions and populations

	Incidence of ESRD (per million per year)	Prevalence of ESRD (per million)
Europe		
UK	101	626
European average	135	700
Russia	15	79
Australia		
White people	94	658
Aboriginal people	420	1895
USA		
Overall	336	1403
White people	256	1004
African-American	982	4432
Less Developed Countries		
India	34-240	Unknown
South Africa	99	Unknown
Nigeria	Unknown	Unknown

Adapted from (El Nahas and Bello, 2005, Naicker, 2003)

Differences in the access to dialysis and transplantation, the incidence of ESRD, and the number of people who require dialysis and transplantation (prevalence of end stage CKD) are largely determined by the availability of resources. There is a clear and direct relation between a country' s gross national product and the availability of RRT, with less developed countries unable to meet the increasing demand (De Vecchi et al., 1999). This huge inequality also stems from current differences in health-care resource allocation to programs of RRT. Disparities are also likely to reflect the racial and ethnic mix (El Nahas and Bello, 2005). These socioeconomic discrepancies are seen in South Africa, and with rationing of resources, these discrepancies make it difficult to ensure equity (Moosa and Kidd, 2006). Improvements in access to RRT and better quality care has been seen in previously disadvantaged racial groups, and this is suggested to be related to early detection and management of kidney disease (Burrows et al., 2008). Improvements in care stem from improved control of DM, HTN and other risk factors for kidney failure, as well as new pharmacologic agents (Burrows et al., 2008).

Overt kidney disease is only the tip of the iceberg of covert CKD. Although this is better recognised in the developed world by academics and possibly health services, the challenges in

the developing world are greater. Around 85 percent of the world's population lives in low-income or middle-income countries, and here the clinical, epidemiologic, and socioeconomic effects of CKD and CVD are the greatest. International comparisons of disease are therefore difficult. Data of people receiving dialysis and transplantation are better known in developing countries compared with all stages of CKD, so international comparisons must be based on ESRD (Barsoum, 2005). Drawing on mostly recently published data (Lamiere et al., 2005, Hallan et al., 2006b, Iseki et al., 2007, Horl et al., 1999), the prevalence of ESRD, or patients on dialysis, is higher than 2000 pmp (per million population) in Japan, about 1500 pmp in the United States, and about 800 pmp in the European Union. In developing countries, despite similar rates of incidence, the figures vary from less than 100 pmp in sub-Saharan Africa and India to about 400 pmp in Latin America and more than 600 pmp in Saudi Arabia (Barsoum, 2006). Differences in prevalence are largely a matter of survival made possible by RRT (dialysis and transplantation), which in turn depends on health care expenditures and the economic strength of different countries. The credibility of statistics from many developing countries is questionable, but some experts have suggested a low incidence of 150 pmp as the average for people who are receiving dialysis and transplants i.e. ESRD (Barsoum, 2005). This lower incidence more likely reflects poor data collection and fewer people receiving RRT in these countries. In countries like Australia, where resources are available to collect information, the rates of ESRD in the 'minority' Aboriginal populations are as high as 2000 pmp (Spencer et al., 1998). In the United States, incidence rates and progression rates of CKD to ESRD are higher among black and Hispanic compared with their white counterparts (United States Renal Data System, 2006, Volkova et al., 2008, Hsu et al., 2003, Burrows et al., 2008, Karter et al., 2002). The difference, discussed in chapter one, reflect ethnic origins, genetic and environmental factors (Barsoum, 2005).

In addition to placing an unaffordable financial burden on poor countries, RRT has negative social, economic and psychological effects on communities. In most developing countries, patients receiving regular dialysis are only partially rehabilitated, since dialysis is often delivered sub-optimally due to limited availability of dialysis machines, equipment to provide and purify the water, and people with skills for managing ESRD and its co-existing diseases

(Barsoum, 2006). This is aggravated by the challenges of transportation of people from their homes to treatment centres. These difficulties, together with household socio-economic burdens, often result in poor adherence to therapies (Moosa and Kidd, 2006, Dirks and Levin, 2006). In the words of Barsoum (2006; page 999), “families must often cope with a chronically depressed, sometimes aggressive, unemployed relative who must be escorted regularly to a possibly distant dialysis centre to receive care”. The great challenges of managing ESRD includes making health authorities in developing countries recognise the extent of the problem, and then to detect and treat CKD at the earliest possible stage.

Linking Kidney and Cardiovascular Disease

CKD is far more common in people suffering from CVD, and CKD is a risk factor for the development of CVD. CKD patients have a risk of CVD that is 10 to 30 times that of people without kidney disease (Sarnak et al., 2003). The likelihood of developing CVD is classically assessed on risk factor profiles that include age, gender, blood pressure, cholesterol, smoking, body weight, type 2 DM, physical inactivity, insufficient fruit and vegetables, and alcohol consumption (de Zeeuw et al., 2005, Dirks et al., 2006, Manjunath et al., 2003). These recognised risk factors account for 90% of CVD events, and the metabolic syndrome has been identified as a multidimensional risk factor for CVD. There is also a socio-economic gradient in the risk factors for CVD using, as examples, India and China (Liu, 2007). A study within 10 industries in India showed a direct correlation between educational status and five risk factors for CVD, namely smoking, regular physical activity, DM, HTN, and the metabolic syndrome (Reddy, 2004).

The specificity of risk factors allows clinicians the opportunity to initiate the most appropriate therapy. There is an overlap of therapies targeting CVD and CKD, as lowering blood pressure (BP) or controlling DM has an impact on both diseases. There is now also an overlap of methodologies to assess risk, which include an estimated GFR (eGFR) and determining the level of albuminuria. Considering that patients in all stages of CKD are at high risk of CVD, it is important to screen all those people at risk for both the traditional risk factors (obesity,

cholesterol, hypertension, diabetes) and non-traditional risk factors like albuminuria and eGFR (Menon et al., 2005). In a study by Go et al (2004), from the United States, there was a graded risk of developing a CVD event; this rose sharply for people with an eGFR less than 45 ml per minute per 1.73 m^2.

Recent data from several large, diverse populations have associated progressive decreases in kidney function (eGFR) with increased chance of death, cardiovascular events, and hospitalization (Go et al., 2004, Manjunath et al., 2003). People with CKD are more likely to be hospitalised and to die principally from CVD, than they are to develop kidney failure (Keith et al., 2004, Go et al., 2004), and have a greater likelihood of dying from co-morbidities of kidney disease than progressing to ESRD (Keith et al., 2004, Menon et al., 2005). In addition to reducing lifespan, CKD substantially reduces quality of life, yet it is often not recognised as a serious health problem. A person's baseline eGFR, the amount of proteinuria, the cause of kidney disease, race and gender, are more likely to result in kidney failure developing or progressing further, rather than resulting in their death. This is true, until a person is older than 65 years; at this age and beyond, death is more likely. Therefore, in patients with a lower risk of dying from CVD, screening is even more compelling to prevent the progression of CKD to ESRD (Menon et al., 2008). At older ages the clinician is also likely to prevent early death.

Major Breakthroughs in Kidney Disease Management

CKD Prevention and Early Detection Strategies

Some key initiatives and discoveries have resulted in health practitioners being in a position to have an impact on chronic illnesses like CKD and CVD. CKD prevention involves the early identification of individuals at risk, detection and treatment, so that adverse outcomes of CKD are prevented or delayed (National Kidney Foundation, 2002). The K/DOQI framework fits closely into the chronic illness models, as it recognises the need for early detection and good follow-up with appropriate interventions in PHC, but also highlights an integrated response between PHC and specialist care (Table 4) (National Kidney Foundation, 2002). In under-resourced health systems, the focus has to move from expensive 'end of the road' interventions

to early intervention and primary prevention strategies by integrating care between specialists, primary care clinicians and the community.

Because CKD and chronic illnesses are closely linked, a single initiative to combat them is convincing. Risk factors for CKD include an age of more than 60 years, HTN, DM, CVD, and a family history of CKD. Linking these risk factors with the determination of serum creatinine and a spot urine for albumin–creatinine ratio (ACR) are sufficient to detect CKD and evaluate risk for CVD (K/DOQI, 2002, de Jong et al., 2003, de Zeeuw et al., 2005)(figure 10**,** above)**.** As CVD and CKD share similar risk factors, common preventative strategies may extend beyond the kidney itself.

Table 4. Chronic Kidney Disease and Clinical Action Plan

Stage	***Description***	***GFR or eGFR mL/min/1.73m2***	***Action****
	At increased risk	**≥90 (with CKD risk factors)**	**Screening CKD CVD risk reduction In PHC sector**
1.	**Kidney damage with normal or ↑ GFR**	**≥ 90**	**Diagnosis and treatment of co-morbid conditions, Slow progression, CVD risk reduction**
2.	**Mild CKD ↓**	**60-89**	**Estimating progression**
3.	**Moderate ↓ GFR**	**30-59**	**Evaluating and treating complications**
4.	**Severe ↓ GFR**	**15-29**	**Preparation for dialysis and transplant Referral to a kidney specialist**
5.	**End Stage Renal Disease (ESRD)**	**<15 (or dialysis)**	**RRT started if uraemia present**

Note: Chronic kidney disease is defined as either kidney damage or GFR <60 mL/min/1.73 m2 for 3 months. Kidney damage is defined as pathologic abnormalities or markers of damage, including abnormalities in blood or urine tests or imaging studies. Minor adaptations have been made to the original table (K/DOQI 2002)

** Includes actions from preceding stages. GFR - glomerular filtration rate; CKD - chronic kidney disease; CVD - cardiovascular disease; RRT – renal replacement therapy

It is now possible to track CKD progression as well as the risk for further progression, and including the risk of CVD. The most sensitive test for early CKD is albuminuria. The earliest

stage of low-grade albumin leakage into urine is microalbuminuria. The clinical diagnosis of CKD, by measuring proteinuria and kidney function, is now simplified, with spot urine albumin-creatinine ratio (ACR) and an estimated Glomerular Filtration Rate (eGFR), carried out at the primary point of contact with people at risk. The GFR (the major kidney function test) can be reasonably estimated from serum creatinine using an equation validated in a large number of people with CKD in combination with the variables of age, sex, and race (Levey et al., 1999, Stevens et al., 2006, Cockcroft and Gault, 1976a).Therefore, CKD refers to a person with either proteinuria (protein leakage measure with urine ACR) or reduced functioning of any of the kidney's normal functions, such as toxin clearance, erythropoietin production, or acid-base balance, but is measured clinically by an eGFR, using these standard established formulae.

Clinical manifestations of kidney dysfunction may be HTN or anaemia, although there are often no symptoms until kidney disease is well advanced. Clearly CKD, HTN, DM and other CVD risk factors, if uncontrolled and undetected, can result in stroke, heart failure and/or progression of CKD to ESRD. As discussed above, people with a reduced GFR are particularly prone to CVD (Go et al., 2004), and are more likely to be hospitalised and/or die of CVD before requiring dialysis or transplantation. While chronic diseases such as HTN, DM and CKD tend to be separated by organ systems by specialists, this is not the case for PHC clinicians. However, chronic illnesses are generally poorly managed by PHC clinicians and a framework to approach these conditions is needed together with improved structures to manage these conditions (Couper, 2007), and CKD is one of those which needs to be integrated into PHC management. .

Current preventive care practices include maintaining stringent control of blood pressure to a target of 120/80 mmHg, using angiotensin-converting enzyme inhibitors (ACEi) and angiotensin II receptor blockers (ARBs) in both diabetic and non-diabetic kidney disease, maintaining good glycaemic control in individuals with DM, and following a low-protein diet (de Jong and Brenner, 2004, Hebert, 2006, International Society of Nephrology, 2005, Ruggenenti et al., 2001a, Rossert and Wauters, 2002). Treating dyslipidaemia, losing weight and quitting smoking, may also help to delay progression of early CKD (de Jong and Brenner, 2004, Ruggenenti et al., 2001a, Rossert and Wauters, 2002).

One study conducted in the Netherlands indicated that in the general population, the presence of albuminuria predicted both cardiovascular and non-cardiovascular mortality (Hillege et al., 2001). Amongst Australian Aborigines, there is an epidemic of type 2 DM, HTN, CKD, and CVD, and the incidence rates of people entering treatment programs for ESRD in some remote areas were – in the mid 1990s - 20 to more than 60 times those of non-Aboriginal Australians (Spencer et al., 1998). In response to this massive rise in CKD and ESRD, in one area of the Northern Territory, a CDOP was instituted to reduce the number of Aboriginal Australians starting dialysis. The Australian CDOP substantially reduced the number of people needing dialysis (end stage kidney failure) through 'CVD' risk factor control and all cause mortality, predominantly through a reduction in CVD such as heart failure and stroke (Figure 11) (Hoy et al., 2005b, Katz et al., 2006a). This was an integrative approach, focused on detecting and treating common risk factors for CKD (Hoy et al., 2005a). The program used random spot urine (ACR) to measure proteinuria, and this was shown to be a stable and robust marker of CKD, and determinant for other chronic disease morbidities. The broad base of shared risk factors probably explained the simultaneous emergence of the excessive CKD and CVD morbidities from which these populations suffer. Thus, albuminuria was a unifying marker for the harmful effects of the spectrum of chronic diseases. However Hoy and McDonald also argued that dipstick urine protein could be used as a surrogate for ACR when resources were constrained (Hoy and McDonald, 2004). This fits into the WHO models where a step-wise approach would be to use a cheaper urine dipstick measurement before progressing to ACR (Epping-Jordan, 2005).

Primary prevention depends on a multitude of changes, including socioeconomic advancement to changes in health care. However, even if these changes are successfully implemented, they will take time to modulate disease incidence, and therefore initiatives need to be implemented early on. The modification of existing disease is feasible. In the CDOP program carried out in this Australian high-risk community, it was demonstrated that systematic management with ACEi helped reduce ESRD and CVD deaths, with huge estimated cost savings (Hoy et al., 2005a). Albuminuria, both micro and macro, may simply be the renal

manifestation of a generalized abnormality of vascular function (Jensen et al., 1995), and therefore if targeted with simple measures can have a major impact.

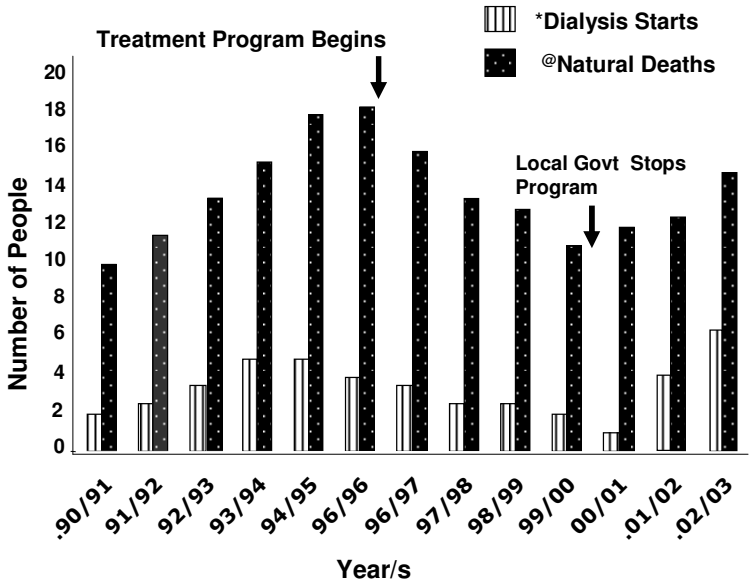


Figure 11 Impact of Integrated Approach in Australian CDOP
Dialysis Starts and Natural Deaths in Adults (18+ yr) being managed on Australian integrated CDOP measuring #Annual Rolling Average, to mid 2003. *Dialysis starts = patients starting dialysis, @Natural deaths = all cause morbidity, main factors affecting all cause mortality were strokes, heart failure and kidney failure (Katz et al., 2006a, Hoy et al., 2005b).

There is evidence that using an ACEi to treat individuals who are identified from screening as having microalbuminuria, or are at risk for CVD, results in a reduction in albuminuria, and reduces both progressive renal disease and cardiovascular events (Asselbergs et al., 2004, ADVANCE, 2007). Unfortunately, many patients with CKD still receive suboptimal care. Despite DM associations and CKD guidelines, ACEi or ARB are not used in patients with DM and co-morbid HTN or CKD (Cooke and Fatodu, 2006). CKD is both under diagnosed and under treated. The reasons for this suboptimal care are likely complex. The important aspects

highlighted here are that people at risk because of DM or HTN are often unaware that CKD can be caused by these conditions and are not made aware of the link between urine protein 'leaking' and kidney dysfunction, easily measured by an eGFR.

Global Rise of Chronic Illnesses

The impact of chronic illnesses is being felt in developing countries for two main reasons: the population is ageing as a result of social and medical improvements, but also rapid social and environmental changes is leading to an increase in common, preventable risk factors associated with chronic disease prevalence (World Health Organization, 2005c, Strong et al., 2005)Organization. In 2005, low-income and middle-income countries accounted for around 80% of the total burden of chronic disease mortality in developing countries, and in these countries, chronic diseases (including persistent communicable diseases such as HIV/AIDS and TB) were responsible for 50% of the total disease burden (Abegunde et al., 2007). In low- and middle-income countries, the increase in chronic non-communicable diseases (HTN and DM) is concurrent with unresolved communicable diseases (HIV/AIDS) (Strong et al., 2006). By 2020, the burden of DM and CVD will have increased by 130% in Africa alone, affecting nearly 21 million and 1.3 million people respectively, with concomitant increases in the prevalence of CKD, especially ESRD (also known as stage 5 CKD) (Schena, 2000).

The Australian Outreach program has documented that most people with chronic disease have more than one morbidity, overlapping morbidity, justifying integrated rather than disease specific programs (Hoy et al., 2005a) **(**Figure 12). The risk factors for CVD and CKD can be clustered into the metabolic syndrome (visceral obesity, dyslipidaemia, hyperglycaemia and HTN) or considered as separate entities. The paper by Hoy et al (2006) focuses on the value of screening people for multiple cardiovascular risk factors or if it is better to assess risk according to the metabolic syndrome definition (Hoy et al., 2006). It was found that an integrated approach, including primary and secondary prevention of all elements of the syndrome, rather diseases

specific approach was better. They also found that albuminuria had an important risk in non-renal risk, and these issues and the metabolic syndrome are discussed below.

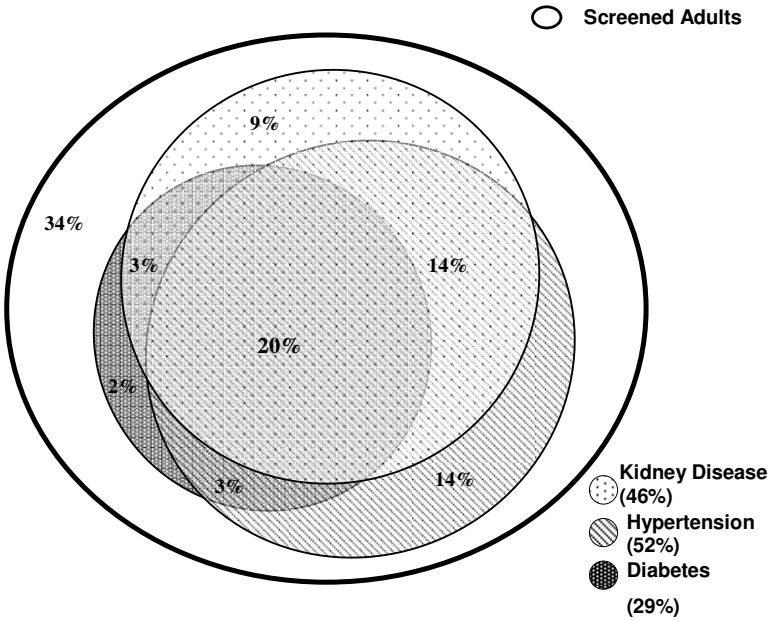


Figure 12. Overlapping morbidities of chronic disease
Note: Adults screened in a single Aboriginal Community in the Australian Chronic Disease Outreach Program

The Metabolic Syndrome and Chronic Disease

For the past two decades the metabolic syndrome (MetS) has referred to a constellation of diseases, and highlights the risk for developing type 2 DM and an increased risk for cardiovascular disease (Ballantyne et al., 2008). Metabolic Syndrome as an entity is recognised as a major public health challenge worldwide (Editor, 2005). It is a cause of both CVD and CKD but this term was originally recognised to help us understand how insulin resistance links with vascular disease, and if it could predict risk for developing CVD and type 2 DM (Sattar et al., 2008). There is no specific cause of this syndrome, but it includes cardiovascular risk factors and chronic conditions including visceral obesity, dyslipidaemia, HTN, and glucose intolerance or hyperglycaemia. The definition has undergone a series of changes over the last four decades, most recently by the International Diabetes Federation (International Diabetes Federation, 2005). This definition of Metabolic syndrome includes central obesity plus any two of the

following four factors: raised triglyceride levels or treatment for this lipid abnormality, raised cholesterol or treatment for this lipid abnormality, raised blood pressure (≥130/85mmHg) or treatment of previously diagnosed hypertension, and raised fasting blood glucose (≥5.6mmol/L) or previously diagnosed type 2 diabetes. Crucial to the IDF definition, to be defined as having metabolic syndrome, a person must have central obesity (waist circumference of a certain size which is ethnicity specific). No normal data for waist circumferences are available for Africa, and so European targets are used (>102cm for men and >88cm for women). The first published working definition was from the WHO and included the same cluster but also microalbuminuria (Alberti and Zimmet, 1998). Because of the regular re-evaluations of this syndrome, the central causative factor of insulin resistance has been challenged (Yudkin, 2007). The argument put forward is that central obesity, lack of exercise and tissue inflammation should be considered as the causative factors, resulting in the cascade of disease and complications. However, the clinical diagnosis of metabolic syndrome has always been in contention, since it was described by Gerald Reaven in 1988 (Reaven, 1988).

The pathogenesis of the metabolic syndrome is multi-factorial, with the major underlying risk factors being central obesity and insulin resistance (Reaven, 1988). Most patients with type 2 DM have insulin resistance, and most but not all are obese. A major contributor and possible cause is an excess of circulating fatty acids and an associated rise in cardiovascular inflammatory markers e.g. C-reactive protein (Festa et al., 2000, Ridker et al., 2003, Rutter et al., 2004). Inflammation affecting the vascular endothelium associated with dyslipidaemia and atherosclerosis causes the increase in stroke and coronary artery disease. Albuminuria is an early and dominant element of this symptom complex, and strongly predicts all-cause and cardiovascular illnesses and deaths.

The importance of diagnosing the metabolic syndrome is that it highlights the risk associated with cardiovascular disease. The combination of risk factors further increases this risk (Expert Panel, 2001, Ballantyne et al., 2008, McNeill et al., 2005). This has been examined in several large epidemiological studies (McNeill et al., 2005). In the DECODE study (Balkau, 2000, The Decode Study Group, 2003), European men and women without diabetes, but with metabolic syndrome, had increased risk from death from all causes as well as from

cardiovascular disease. In the United States, in adults 30-70 years of age, the metabolic syndrome was associated with an increased risk of coronary heart disease and total mortality. Those people with DM and pre-existing CVD had rates that were even higher. Even one or two metabolic syndrome risk factors confer increased risks of disease. Metabolic syndrome indicates an even worse prognosis than its individual risk factors (Meigs, 2003). Hoy et al. (2006) found that CKD and HTN were the most prominent and earliest features of the syndrome. There also appears to be gender differences; in the San Antonio Study mortality was more than twice as high in women as men (Meigs et al., 2003, Haffner, 2000). In the United States (US) Framingham Offspring Study elevated CRP levels were related to insulin resistance and the presence of the MetS especially in women (Rutter et al., 2004). In the ARIC study, again in the US which followed a cohort with low rates of coronary heart disease, stroke or DM, the men and women with the metabolic syndrome were 1.5 times more likely to develop coronary heart disease after adjustment for established risk factors (Ballantyne et al., 2008). Evaluating metabolic syndrome in Aboriginal Australians revealed high rates of kidney disease, HTN, and DM all increasing with age, and an overlapping of these risk factors (Hoy et al., 2006).

It is argued that the metabolic syndrome is not better than other models highlighting risks for cardiovascular disease. Wannamethee (2005) argues that it was better for predicting type 2 DM than coronary artery disease, and the Framingham score was a better predictor of disease than the metabolic syndrome constellation of risk factors (Wannamethee et al., 2005). The value of the metabolic syndrome as a clinical tool remains controversial and others have also added to this debate[3]. Here the conclusions were that the metabolic syndrome had a weak or no association with vascular risk in elderly populations, and defining risk for DM and cardiovascular disease had little real clinical value. It was felt that the clinical focus should remain on establishing optimum risk algorithms for each disease. Ultimately the metabolic syndrome serves well as a simple clinical tool for identifying high-risk subjects predisposed to cardiovascular disease or type 2 DM.. Risk factors identifying people with the metabolic

[3] Sattar et al (2008) argued that it was not as good as traditional algorithms that use continuous or categorical measures and which contain the key risk factors for cardiovascular disease: age, LDL cholesterol, and smoking.

syndrome may provide opportunities to intervene earlier in the development of shared disease pathways that predispose individuals to both CVD and DM.

The Metabolic Syndrome and CKD

The causes of the increased risk of CVD in CKD are most likely due to shared CVD risk factors, including DM, HTN, obesity, lipid abnormalities, and smoking (Manttari et al., 1995, Fox et al., 2004a, Muntner et al., 2000, Tozawa et al., 2007, Tozawa et al., 2002, Zoccali, 2006). It could therefore be concluded that established cardiovascular disease risk factors, or metabolic syndrome risk factors, are associated with the development of new-onset kidney disease and progression of CKD. This has been confirmed in a number of studies including among Japanese men, African Americans, Chinese and Southeast Asians (Tozawa et al., 2007, Lea et al., 2008, Kitiyakara et al., 2007, Chen et al., 2007). Interestingly, in the Southeast Asia study, the definition used to define metabolic syndrome influenced the likelihood of predicting risk for CKD, suspected to be similar to reasons for developing CVD.

Detecting and treating metabolic syndrome early on in the community will influence kidney disease and may also delay the progression or development both of CKD and CVD. In one study, there was a linear relationship between the number of metabolic syndrome risk factors and CKD (Tanaka et al., 2006). There is evidence too that the pathogenesis of CKD is linked to inflammation, measured by a serum C-reactive protein (Lee et al., 2007, Beddhu et al., 2005, Zoccali, 2006), and in the studies by Beddhu et al. and Lee et al. the metabolic syndrome and high CRP were independently associated with increased prevalence of CKD and the odds of CKD increased in the setting of high CRP and metabolic syndrome. Inflammation is increasingly prevalent in patients with CKD (Muntner et al., 2004), and the inflammation with associated obesity and atherosclerosis is most likely the cause of kidney damage as in other organs (Beddhu et al., 2005, Rutter et al., 2004, Zoccali, 2006). The development of insulin resistance, DM and HTN further activates the cascade of kidney dysfunction (Figure 13, see also figure 8**)**. Thus, associations of inflammation with metabolic syndrome and its component conditions, described in the general population, are also present in patients with moderate CKD. Risk factors do not act in single organs or compartments and can be targeted with primary prevention

strategies.

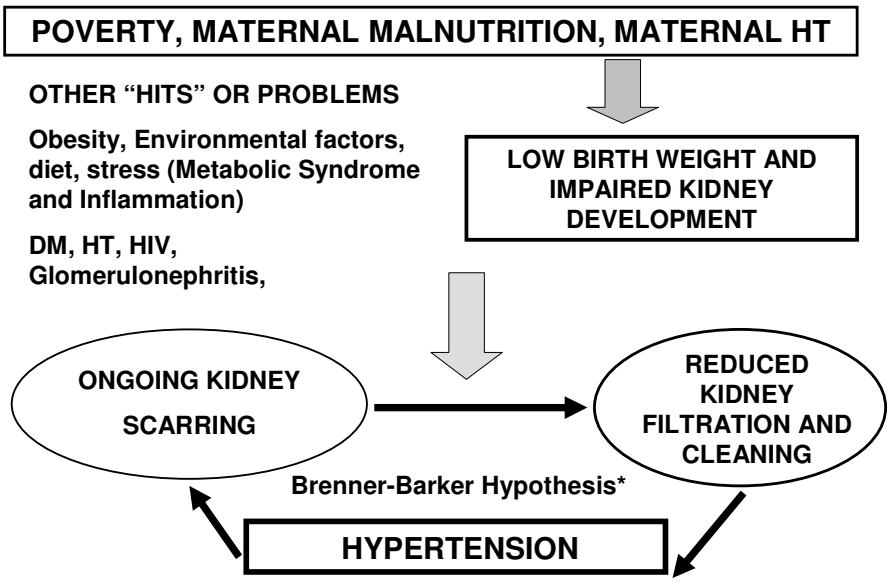


Figure 13. Metabolic Syndrome and Kidney Disease
Adapted from a lecture by Dr Valerie Luyckx – Abstract South African Renal Society 2002- "Why poor people get kidney disease" (Luyckx, 2002)*

CKD and CVD Risk Factor Control

Hypertension and Diabetes

Diabetes (DM) and hypertension (HTN), as already clarified, are the most common risk factors associated with kidney and cardiovascular disease. Lowering blood pressure (BP) in people with DM and HTN is associated with decreases in cardiovascular events and kidney failure (U. K. Prospective Diabetes Study Group, 1998, The European Study for the Prevention of Renal Disease in Type 1 Diabetes, 2001, Nosadini et al., 2000, ADVANCE, 2007). The seventh report of the Joint National Committee on prevention, detection, evaluation, and treatment of high blood pressure (JNC VII report) indicated that only 37% of all patients with HTN were controlled (BP<140/90mmgHg), and only 59% of patients with HTN are being treated (Chobanian et al., 2003), despite the availability of many effective, cost-effective and well-tolerated drugs in primary care.

DM control, and specifically the prevention of the vascular complications of type 2 DM mellitus, is a global health priority. Glycaemic control and the common association with HTN

make DM a double challenge. Despite access to diabetic medication like metformin, sulfonylurea's, insulin and newer agents (Turner et al., 1999, Koro et al., 2004), rates of glycaemic control have also declined, as defined by HbA1c levels≤7%. Control rates were 44.5% for the third National Health and Nutrition Examination Survey (NHANES III) (1988–1994) and dropped to 35.8% for NHANES 1999–2000.

The target levels of blood pressure for people with DM have changed in recent years. In a review, analysis demonstrated that only 25% of diabetic participants receiving antihypertensive drugs had their HTN controlled to the recommended BP of less than 130/85mmHg (Hajjar and Kotchen, 2003). With the increased prevalence rate of DM observed in this analysis, uncontrolled HTN with DM is an important health problem. Many patients do not have adequate blood pressure control, suggesting that inadequate HTN control may be a universal phenomenon (Berlowitz et al., 1998, Hajjar and Kotchen, 2003, Wong et al., 2007).

DM and HTN in association with kidney diseases are poorly recognised. In one retrospective study amongst people with evidence of CKD, the disease was only documented in 10% of patients with DM and less than 13% of hypertensive patients despite the presence of an abnormal serum creatinine and proteinuria (McClellan et al., 1997). More than 45% of people with ESRD had a diagnosis of DM and 26% had a primary diagnosis of HTN. It has been demonstrated that almost 33% of the US adult population has HTN and 75% of those with CVD have co-morbidities which include coronary artery disease, stroke, DM, and CKD (Wong et al., 2007). Despite treatment rates of 75% or greater in many cases, HTN was controlled to goal in only 30-50%. Moreover, given recent recommendations to reduce the BP goal to lower than before to reduce cardiovascular and kidney disease (Turnbull and Collaboration., 2003), the implication of these new targets is that control rates are a greater distance from the desired goal (Wong et al., 2007). However, in the African American Study of Kidney Disease (AASK) a lower BP target did not affect progression of kidney disease but ACEi were more effective than other classes of anti-hypertensive agents (Wright et al., 2002). Improved diabetes control and any treatment for HTN results in benefit, and generally lower blood pressure targets have been shown to reduce CVD risk further and the initiation of new onset CKD (ADVANCE, 2007, Turnbull and Collaboration., 2003, U.K. Prospective Diabetes Study Group, 1998). Target blood

pressure for people with HTN is <140/90mmHg but is lower for persons with high-risk (<125/75 mm Hg) conditions such as DM and CKD (low GFR or proteinuria) (Chobanian et al., 2003, Lenfant et al., 2003) .

A review of multiple randomised trials evaluating the effects of different blood pressure regimens on major cardiovascular events found that ACEi tended to perform better in people with high risk factors for CVD, but calcium channel blockers (CCB) were better in people with HTN only (Turnbull and Collaboration., 2003). In people with DM and HTN, again ACEi had better outcomes compared with people given only a CCB (Estacio et al., 1998). The Modification of Diet in Renal Disease Study (MDRD) investigated the role of diet and ACEi dosing in patients with CKD. It revealed that 91.5% of patients were on anti-hypertensive medication but only 54% had control less than or equal to 140/90 (Buckalew et al., 1996), a threshold above the target blood pressure of <130/80mmHg for a person with CKD and proteinuria (Chobanian et al., 2003).

This is also true in the general South African population. The South Africa National Demographic and Health Survey (Steyn et al., 2008) revealed that HTN was more common in less educated individuals and the elderly. HTN risk was lowest in rural blacks and significantly higher in obese black women than in women with a normal body mass index. Improved HTN control was found in the wealthy, women, older persons, Asians, and persons with medical insurance. Poorer, younger men without health insurance had the worst level of HTN control. HTN was only controlled in 21% of all adults (Steyn et al., 2001). Levels of HTN awareness, adherence with medication and control were also much higher for women compared with men. Adherence factors are important in blood pressure control. Factors affecting control may include the adherence of clinicians to guidelines for control. Suboptimal control and under-treatment of patients with cardiovascular risk factors in the primary care occurs (Zachariadou et al., 2008), and adherence remains a major obstacle in public health in South Africa as it is globally. Obstacles to adherence seem to be related to issues of the healthcare system, patients' knowledge about their chronic disease, beliefs and attitudes, and the relationship with healthcare professionals (Vermeire et al., 2007). Improvement of documentation of clinical information in the medical records, as well as clinicians training for implementation and adherence to clinical

practice guidelines, are potential areas of improvement. This problem in some ways may reflect that treatment guidelines, usually written by specialists and based on the results of clinical trials, do not take into account key issues faced in primary care. These include the amount of time and resources available to screen, educate, medicate, and reinforce regular, maintained blood pressure and glycaemic control.

Patient adherence factors involved with management of chronic illnesses like DM and HTN is very poorly researched and probably more important and even more complex than currently realised (Ingersoll and Cohen, 2008, Chapman et al., 2005, Cramer, 2004, DiMatteo et al., 2002). Patient's medication-taking, matching the prescribed treatment regimen, is influenced by many factors. Adherence factors include aspects such as depression, health literacy and the complexity of the medication regimen (Ingersoll and Cohen, 2008). Pill burden, regimen complexity, side effects, duration of needed treatment, and dosing schedule all further impact on patient adherence.

Adherence, as defined by the WHO, is clearly complex and is defined as the degree to which a person's behaviour corresponds with the recommendation of the health care provider (World Health Organization, 2003) . Adherence can relate to actions such as taking medication, following diet, and/or executing lifestyle (World Health Organization, 2003). Researchers have identified disease factors such as chronicity, symptom prominence, and response to treatment. There are also health care delivery factors such as the wait for appointments or medications, convenience of the pharmacy and clinic, in addition to environmental or contextual factors such as social support and socioeconomic status. Clinician factors such as clear communication and time spent explaining the disease and the treatment, and patient–clinician relationship factors such as trust are also documented as being important. Collaborative management, involving the doctor, patient, nurse, pharmacist and support from relatives, is an area which must be considered to achieve a significant improvement in treatment success rates with regard to HTN and DM. I will discuss this later in the thesis.

Obesity Risk Factor Management

Obesity greatly increases the risk of cardiovascular disease, metabolic syndrome, and DM (Yudkin, 2007, Hallan et al., 2006a, Hossain et al., 2007). In South Africa, obesity has a greater effect on women than men (Puoane et al., 2002, Vorster, 2002). Obesity is a complex disorder that is difficult to control. Lifestyle measures remain the cornerstone of management, but maintaining weight loss, even if achieved, is difficult.

Regulation of body weight is maintained by biological factors which favour weight gain and defend the body against weight loss (Sikaris, 2004). People must continually fight against biological factors and environmental pressures that encourage weight gain or provide the context that facilitates weight loss. Managing obesity firstly requires that a non-overweight person does not gain weight: a diet which is eucaloric, and regular daily exercise of between 30-60 minutes (Department of Health, 2001). If a person is overweight, this becomes more difficult, requiring a hypocaloric diet and 45-60 minutes of daily exercise (Merchant et al., 2006). A number of studies have been carried out evaluating obesity management and a person's ability to maintain weight loss. In the United States the Trial of HTN Prevention Phase II (TOHP-II) people were assigned to two groups. One involved usual care, diet and exercise, and the other was given additional support through group meetings and individual counselling (Stevens et al., 2001). In this study, if weight loss was maintained after 3 years, there was a 65% reduction of developing HTN. However, these positive results were dampened by the fact that reduction was only maintained in 12% of people. This challenge was similar in DM prevention studies, where considerable effort and resources were needed to achieve and maintain weight loss of around 4.5kg, although if the weight loss was achieved, it resulted in a 60% reduction of developing type 2 DM (Lindstrom et al., 2003, Diabetes Prevention Program Research, 2002). Achieving sustainable weight reduction in clinical practice remains challenging.

Managing Dyslipidaemia

Patients with HTN and especially those with type 2 DM have an increased prevalence of lipid abnormalities. This contributes to their high risk of CVD (Neaton and Wentworth, 1992) and

predicts the increased risk of kidney dysfunction. Treatment may impact on the development of kidney disease (Muntner et al., 2004). Hyperlipidaemia is also associated with a more rapid loss of renal function and the progression of established kidney disease (Manttari et al., 1995, Campese and Park, 2007, Ruggenenti et al., 2001b). For the past decade or more, multiple clinical trials have demonstrated significant beneficial effects of pharmacologic HMGCoA[4] reductase inhibitor or statin therapy on diminishing the risk of cardiovascular morbidity and mortality in subjects with coronary artery disease or type 2 DM and for primary CVD prevention (Baigent et al., 2005, Colhoun et al., 2004, Sever et al., 2005, Collaborators, 2008). Clinicians have been urged to regard CKD as a CVD risk equivalent and to manage patients in accordance with guidelines from the American National Cholesterol Education Program Adult Treatment Panel (Expert Panel on Detection, 2001), and there is evidence supporting these recommendations (Nogueira and Weir, 2007). Despite the multiple beneficial effects of statins on CVD risk in well resourced settings, only about a third of patients in general, and patients specifically with CKD and ESRD, are currently treated for hyperlipidaemia (Fox et al., 2004b, Stacy and Egger, 2006).

Screening for dyslipidaemia is advised annually in most DM and HTN guidelines (Society for Endocrinology, 2003, Southern African Hypertension Society, 2003, South African Renal Society, 2004, American Diabetes Association, 2008). Although goals for lipid control are similar to international guidelines (<5mmol/L) (Society for Endocrinology, 2003), in South Africa the target levels for initiating treatment for cholesterol are much higher than other guidelines. It should be noted that lipid modifying medications are not available in the PHC setting and are not included in the South African National Essential Drug List (EDL) Primary Care Guidelines (National Department of Health, 1998a).The use of lipid modifying drugs like the statins is seen to be too costly, and consequently the emphasis is on lifestyle modification, including reduced consumption of saturated fats and cholesterol, and increased exercise, until levels of cholesterol are >6.5mmol/L, LDL >4mmol/L or HDL <1mmol/L in men and <1.2 in women (Seedat et al.,

[4] 3-hydroxy-3-methylglutaryl coenzyme A reductase inhibitors

2006). In developed and developing country guidelines, and especially in relation to diabetes, clinicians are encouraged to initiate lipid modifying drug therapy only if patients are at particular high risk of cardiovascular disease, have had previous cardiovascular disease, or if their lipid levels are very high (Berger and Marais, 2000, American Diabetes Association, 2008).

As in the metabolic syndrome, the management involves a comprehensive targeting of the overall risk factors for CVD and CKD, with prevention focusing on avoidance of tobacco smoking, participation in regular exercise, and health-promoting diet, not dissimilar from obesity management. The Lipid and Atherosclerosis Society of Southern African goes further and calls for primary prevention strategies of CVD and CKD. It encourages community based public and professional education and the provision of community facilities for exercise and recreation. An integrated approach for managing dyslipidaemia, like other CVD and CKD risk factors, is advised.

Risk Factor Management and CKD Progression

Control of certain risk factors is important to prevent progressive renal function loss in patients with established renal diseases. Here, the primary risk factors to target are high blood pressure (Klag et al., 1996) and proteinuria (Locatelli et al., 1996, Ruggenenti et al., 2001b); both are associated with a more rapid decline in renal function. Lipid abnormalities have also been shown to cause the progression of kidney disease (discussed above). Genetic factors also appear to be involved, and people with the ACE DD genotype progress more rapidly to end-stage renal failure than those without that genotype (van Essen et al., 1996). This beneficial effect of angiotensin converting enzyme inhibitors (ACEi) in preventing the progression of chronic kidney disease (CKD) is clear from a number of evidence based clinical trials (Parving, 2001, Lewis et al., 1993, Bakris, 1993, Heart Outcomes Prevention Evaluation Study, 2000, Maschio et al., 1996, Kshirsagar et al., 2000). Several studies have demonstrated the potential for preventing or delaying the initial onset of diabetic kidney disease by treating patients who have DM with ACEi. ACEi prevent the development of microalbuminuria (ADVANCE, 2007, Asselbergs et al., 2004). In the early stages of DM, patients may have heightened renal function,

which manifests itself as a high GFR, sometimes called hyperfiltration. Such a state may precede the development of microalbuminuria in DM (de Jong and Brenner, 2004).
The specific targets for remission and regression of CKD, summarised in two publications (Hebert et al., 2001, Ruggenenti et al., 2001b), include the following clinical targets: excellent glycaemic control in diabetic patients, aggressive blood pressure control, correction of dyslipidaemia; reduction in proteinuria with ACEi and/ or angiotensin receptor blockers, reduction in cardiac risk factors, and appropriate diet and lifestyle modifications. These aspects mirror those advised in the approach to managing the metabolic syndrome, highlighting its commonality with CVD.

A number of factors are associated with progression of CKD in people with known pre-existing renal disease. Early detection and the ability to prevent progression are important factors motivating the development of kidney and cardiovascular protection programs, where standardised treatment strategies, simplified targets and early detection of risk factors can be evaluated (Coresh et al., 2003). As discussed above, studies have demonstrated the beneficial effects of numerous interventions and simplified targets to prevent or delay the progression of CKD.

Clinical diagnosis of CKD has become simplified. Current recommendations call for annual urine testing and monitoring of people with DM, HTN or HIV (de Zeeuw et al., 2005, Gupta et al., 2005). Testing for proteinuria in the risk groups of DM and HIV has not been as well established as that for HTN, where a simple dipstick method has been calculated to be cost effective (de Jong and Brenner, 2004). The Kidney Disease Outcomes and Quality Initiative (K/DOQI) Guidelines, discussed earlier and developed by the United States Kidney Foundation, have provided a framework for the diagnosis, staging, and evaluation of CKD (Eknoyan and Levin, 2002). These Guidelines recommend a stage-appropriate action plan that is independent of the type of kidney disease and can be taught to and carried out by non-nephrologists (Table 2). Importantly, this framework outlines interventions that address both CKD and CVD, and their risk factors; It includes the use of an estimated GFR calculated from a prediction equation, which incorporates serum creatinine (as opposed to relying only on serum creatinine), as the best measure for assessing kidney function in routine clinical practice. The guidelines acknowledge

and recommend the routine provision of an estimated GFR (eGFR) to facilitate identifying and staging individuals with CKD (K/DOQI, 2002). Improving early recognition of patients with CKD necessitates laboratory testing of people at increased risk. An albumin-specific method for testing spot-urine samples, albumin-creatinine ratio (ACR), will detect kidney damage earlier than standard urine-protein tests. Early identification widens the window of opportunity to put effective interventions to work, so benefiting patients and reducing costs both for patients and health care organizations. The development of this framework has proven to be a critical factor to stimulate research and provide a guide to those wishing to start early detection programs. It has impacted not only on our ability to affect CKD, but importantly, outcomes in CVD. However, the use of these methods to detect CKD and especially the ESRD group (CKD stage 5), has limitations. The number of patients with ESRD probably underestimates the entire burden of CKD because the numbers with earlier stages of disease (stages 1 to 4, Table 5) are likely to exceed by as much as 50 times those reaching ESRD (stage 5) (Coresh et al., 2003).

Table 5. USRDS CKD Staging and Incidence of CKD in each group

Stage	Description	GFR ($mL/min/1.73m^2$)	Prevalence*	
	At increased risk	$\geq$90 (with CKD risk factors)	N(1000s)	%
1.	Kidney damage with normal or ↑ GFR	90	5,900	3.3
2.	Kidney damage with mild ↓ GFR	60-89	5,300	3.0
3.	Moderate ↓ GFR	30-59	7,600	4.3
4.	Severe ↓ GFR	15-29	400	0.2
5.	Kidney Failure	<15 (or dialysis)	300	0.1

The data derived from the third National Health and Nutrition Examination Survey in the United States indicate that up to 11% of the general adult population (19 million) could have some

degree of CKD, including more than 8 million individuals with eGFR of less than 60mL per min (Coresh et al., 2003). An estimated 5·9 million people could have stage 1 CKD with normal renal function. These observations have substantial limitations, including basing prevalence estimates on single serum creatinine measurements, which are subject to variations owing to differences in calibration systems between laboratories (Clase, 2006, Levey et al., 2007b, Coresh et al., 2002). In addition, the data do not indicate which patients will progress to ESRD. Subsequently, the estimates based on serum creatinine were converted into estimates based on GFR by use of the formula of the Modification of Diet in Renal Diseases study (Hallan et al., 2004). This has not been fully validated in different populations and at different stages of CKD[5] (Coresh et al., 2002).

A discussion by Chen and Hsu (2003), based on the results of the third American National Health and Nutrition Examination Survey (NHANES), has questioned the need to change the classification of CKD used by the US National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (NKF DOQI). This classification is continually subject to debate, and some have argued that stages 1 and 2 would be better defined by the associated abnormalities (e.g. microalbuminuria, haematuria; panel 1) rather being classed as CKD. These improvements are believed to assist clinicians with daily clinical practice. Questions remain about the validity of using these equations to estimate GFR in population based epidemiological surveys. However, an eGFR remains an acceptable tool to evaluate kidney function.

Kidney and Chronic Disease Programs across the globe

The early identification of people at risk of CKD, and the prevention of progressive CKD, is likely to be key factors in alleviating the future burden of ESRD and the associated mortality. Ninety percent of people who develop ESRD and require dialysis in a developed world setting will receive it, while most people in developing world communities with ESRD will die (De Vecchi et al., 1999). The huge disparity in the prevalence of ESRD between

[5] The two most commonly used prediction equations for calculating an estimated glomerular filtration rate (eGFR) are the four variable Modification of Diet in Renal Disease (4-v MDRD) (Levey et al. 2000) and Cockcroft-Gault (CG) equation (Cockcroft and Gault 1976). The applicability of these equations for black South Africans is unclear. However, at the time of this study a 'South African' equation had not yet been formulated.

more and less developed countries probably stems from the inadequacy of health-care resource allocation to programs of renal replacement therapy (RRT), i.e. dialysis and renal transplantation.

The pattern of ESRD (CKD stage 5) has changed over time. In the 1970s, glomerulonephritis and pyelonephritis were the most widespread causes of ESRD. In the last decade, the prevalence of these diseases had declined relative to the epidemic increase of type 2 DM and vascular diseases such as HTN and generalized atherosclerosis. In South Africa HIV is also a major factor associated with ESRD. As discussed earlier, CKD and CVD have common risk factors and can be detected early by tracking albuminuria and the GFR (de Jong et al., 2003). Unfortunately, most patients are referred to a nephrologist only when renal function is close to the level where dialysis is required, when conservative reno-protective treatments will have little impact. In developing countries, this often means death, as no dialysis or transplant facilities are available. Initiatives should be undertaken to make health care providers and the general population more aware of the seriousness of CKD, its risk factors, and opportunities for screening. People identified with CKD should be provided appropriate educational materials to explain the treatment regimens and the benefits of undertaking therapy.

Currently, there are very few surveillance systems for tracking patients with chronic illnesses and especially CKD in stages before dialysis or transplantation. For this purpose, the International Society of Nephrology has designed guidelines adapted to the developing world (International Society of Nephrology, 2005). Recommendations, are based mostly on consensus procedures rather than hard evidence (National Kidney Foundation, 2002), and different screening strategies, have not been compared for their ability to detect chronic kidney disease or their efficiency. Screening only persons deemed to be at high risk is a viable option when mass campaigns are impossible and resources are limited. In one study, 20% of people had estimated glomerular filtration (eGFR) rates lower than 30 ml/min/1.73m^2, but only 1-2% of those with values of 30-60 ml/min/1.73m^2 progressed to end stage renal disease over eight years (Hallan et al., 2006c). This study helped simplify the screening task by showing that a simple screening strategy targeting people with DM, HTN, or age >55 had the highest detection rate for CKD and this was combined with a low number needed to be screened (Hallan et al., 2006c). This

approach of screening high risk patients for CKD is the approach currently proposed and followed by most people who focus on CKD and CVD (Hoy et al., 2003b, Rossert and Wauters, 2002, de Jong and Brenner, 2004, Ohmit et al., 2003). However, most patients detected had a low risk of progression to end stage renal disease. Whether screening is cost effective needs further research, as there are limited studies with longitudinal follow up and extending screening to people without DM or HTN cannot yet be recommended. Efficient screening might lead to an increase in workload for the health services as the patients detected are at high risk and need intensive intervention to prevent progression to ESRD and CVD complications. The costs of detecting patients and treating them might not be economically balanced in relation to possible expenditure on medical care as a whole. For this reason, control of DM, HTN, smoking, overweight, dyslipidaemia, infection, and pollution, and possibly the use of a single daily pill ("polypill") containing generic ACEi, statins, aspirin, and folic acid, should be on the agenda of many developing countries (Barsoum, 2006).

The options when establishing a CKD or CVD prevention program includes either screening an entire population, as in the Dutch PREVEND and in the Australian Aboriginal studies, or to detect a cohort of people at the highest risk of kidney disease (de Jong et al., 2003, Hoy et al., 2003c, Katz et al., 2002)(see Figure 14 below). The former approach is costly, less likely to be achieved in the developing world, and so is inappropriate.

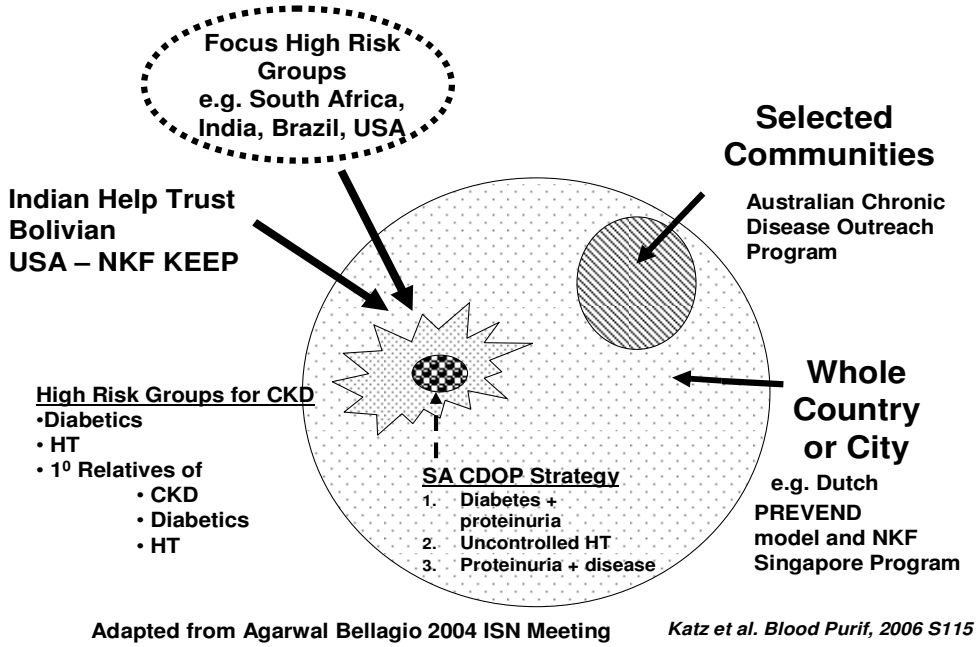


Figure 14. CKD Prevention Strategies

Evidence also supports a more focused screening approach. Mass untargeted screening appears to capture only a few percent, whereas targeted (e.g. HTN) screening is more effective, capturing 50% or more (Brown et al., 2003a, Littenberg et al., 1990, Boulware et al., 2003). Screening should target persons most at risk for chronic kidney disease: individuals with a personal or family history of DM or HTN, those from poor social circumstances, and high risk ethnic groups (Lei et al., 1998).

In Australia, Wendy Hoy and her team developed a number of programs in Australian Aboriginal communities, and had collaborated with teams elsewhere including India, Nigeria and South Africa (Katz et al., 2006a, Katz, 2005b). She has outlined the need to work together with communities to engage community interest in chronic illness management and prevention strategies, to help assess needs in the community, and to develop an agreement with the local community or health authority (Hoy et al., 2003a). Once these basic requirements are met, then one can proceed to help local staff implement the program, to try to ensure sustainability, and to provide a mechanism and skills to evaluate the processes and outcomes. Below, a few specific international programs aimed at preventing these diseases are discussed.

Kidney Help Trust Rural Project – India

Indian nephrologists were faced with the same problems as in South Africa. They had the expertise to provide dialysis but not the resources to deliver to all (Mani, 2006). The Kidney Help Trust was developed in 1985 in Chennai, originally to fund transplantation, and was one of the earliest programs tackling the overwhelming CKD problem in India. In India DM and HTN are widely prevalent, and the incidence is increasing steadily. The program was established to identify all people with DM and HTN as early as possible, detect those at risk, and treat risk factors well before the kidneys were damaged, at the least possible expense. It was the first non-communicable disease program in India, although programs existed for 'chronic' infectious diseases like TB and leprosy. This program focused on proteinuria, HTN and DM and included other common local renal diseases, e.g. kidney stones (Mani, 2003); it later included screening for kidney function. Persons at risk of renal failure were identified using the MDRD formula. The program needed to develop vertically, but was run by local community participants (health workers). The success of the project was its simplicity. It involved a cheap mass screening campaign, run over a number of years and aimed at early detection of kidney disease, it included 25 000 people in a group of villages and hamlets about 50 km from Chennai. It was also driven by primary health care nurses (PHCNs), who were trained to detect disease and give basic treatment under supervision. The problems of this kidney disease screening program included lack of long-term quantitative data and inability to evaluate the impact of the intervention. Mani (2003) noted that only 8% took ongoing treatment, indicating problems with adherence, and those health workers were only able to visit homes every 18 months. It also reflects the weakness of not focusing on those at high risk, as was carried out in other programs i.e. rationalising the screening process. However, the program had an impact on the communities' awareness of CKD, and detected and successfully treated people at risk for both CKD and CVD. The program's success was its modest and relatively simple goals, and its focus on the primary care setting, detecting people before they presented to hospital.

Bolivian Renal Disease Project

The Bolivian Renal Disease Project, a collaborative project run by Plata and Remuzzi with the support of the Bergamo Institute and International Society of Nephrology and Commission for the Global Advancement of Nephrology (ISN-COMGAN), involved a population based mass screening for urinary disease in 'healthy' subjects (Perico et al., 2005, Plata et al., 1998).The program was motivated for similar reasons to other developing country programs, i.e. shortage of resources and access to dialysis and transplantation. However, the purpose of the program was not only to detect those people with kidney disease but also to carry out an epidemiological survey to determine the extent of kidney disease in the country. About 14 000 patients were screened and urinary abnormalities were detected in over 4000. These people were referred to local health centres and were to be followed up for three years. Unfortunately only 23.9% were followed up (Perico et al., 2005). For those with positive screening for kidney disease, further investigations disclosed an array of kidney abnormalities, 1.6% having end stage kidney failure. The successes of this project outlined the basis to starting all such programs, i.e. gaining a good understanding of local problems using a simple and cheap test. This study helped define the incidence of asymptomatic kidney diseases in an unselected population. It showed that it is possible to screen a large population at relatively low cost, and provided a framework for further action to help prevent and diagnose kidney diseases. Aside from its scientific value, this study illustrates how, by rationalizing resources and investing in research programs, renal disease progression and cardiovascular risk may eventually improve, resulting in less demand for dialysis, and reducing cost of treatment and also death. However, the initiators of this program again saw the solution to future programs as in the hands of kidney specialists only. I will argue throughout this thesis that solutions need to lie mainly in the primary care setting in chronic disease clinics, with the support of kidney specialists.

Cuban Program for Prevention of Chronic Renal Failure

Cuba faces the same problems, but has greater resource challenges. Most people with end stage kidney failure are not offered any dialysis or transplantation. Cuban nephrologists have focused their efforts on developing a public health model integrating health promotion and

disease prevention (Almaguer et al., 2005). The Ministry of Public Health of Cuba launched the National Program for the Prevention of Chronic Renal Failure in 1996. The predominant focus of this program is around policy and health system changes rather than specific program development. The health ministry has analysed resources and evaluated the burden of kidney disease in the country. The program includes education for nephrologists, family doctors, and other health professionals, including the orientation of primary health care toward increased kidney disease surveillance and treatment. The Cuban program shows an excellent understanding of the need to link primary, secondary and tertiary prevention with the progression of kidney disease (see figure 2). Although no specific program has been developed, the aim is to integrate interventions within the primary health care system and focus on high risk people with CVD or CKD risk factors. What is unique about Cuba is that it has an excellent primary health care infrastructure with very high doctor to patient ratios.

The United States NKF KEEP

Moving to programs in developed countries, in the United States the concern over the doubling of its ESRD population who will require dialysis by 2010 from 300 to 600 thousand, prompted the National Kidney Foundation (NKF) to sponsor the NKF Kidney Early Evaluation Program (KEEP). KEEP screenings are conducted across the country, but the majority have been in South and Atlantic regions. The program relied on people volunteering to be tested. To maximize efficiency, this program also targeted those at high risk group: first order relatives of people with HTN, DM or kidney disease and those with a personal history of HTN or DM (Figure 14). The aims of the program were to encourage at-risk persons to seek evaluation and management from a healthcare provider (McGill et al., 2004).

The KEEP Pilot Screening Program demonstrated that targeted screening is an effective means to identify people at risk for kidney disease, and to identify them early enough to allow for effective intervention (Brown et al., 2003a). The screening identified risk factors for DM, HTN and/or kidney disease in 71.4% of individuals screened. The program also identified that the presence of anaemia, an eGFR <60mls/min per 1.73 m^2, and microalbuminuria were independently associated with CVD, and when all 3 were present, CVD was common and

reduced survival (McCullough et al., 2007). The program confirmed the link between CKD and CVD (Go et al., 2004), and the results supported the view that screening for CVD would be of high yield among people with these risk markers even if they do not admit any history of CVD symptoms (McCullough et al., 2007).

The KEEP program was effective in getting some people screened to see a physician, but not all. What was of concern were the findings after the primary care physician's review. Those referred with a possible problem did not know what their clinicians' management decision was nor what the findings were after they had been seen. Some clinicians advised patients not to worry about 'small' amounts of protein in the urine, or that 'slightly' elevated serum creatinine levels were not of concern. This highlighted the poor baseline knowledge of CKD by primary care clinicians. Education of primary care clinicians and health care providers regarding significance of abnormal test values and appropriate interventions emerged as particular areas of concern. In view of this, KEEP has since started a third generation version of the program which includes multiple interventions for the patient, to improve understanding and motivation to better manage their chronic conditions, but also to improve clinicians knowledge and management protocols for these conditions. KEEP highlighted the needs for people to embrace lifestyle behaviours that reduce risk, and adhere to medical recommendations in managing their existing conditions. At the same time, health care providers need to implement the latest evidence-based guidelines in diagnosis and treatment (Ohmit et al., 2003).

The Dutch PREVEND Program

In Holland the PREVEND (Prevention of Renal and Vascular End-stage Disease) study to investigated the impact of microalbuminuria in the general population in city of Groningen. The study organisers invited a potential 85 000 potential subjects, aged 28-75yrs, to participate and 41 000 agreed and sent their urine by post for screening. Seven percent were found to have significant microalbuminuria, a urinary albumin concentration of 20–200 mg/l. Amongst these 3000 subjects with microalbuminuria, 75% were not known to have either DM or HTN. Although the prevalence of microalbuminuria was higher in diabetic (16%) and hypertensive (11%)

subjects, still 6.6% of subjects without known risk factors appeared to have microalbuminuria (Hillege et al., 2001).

As a result of the PREVEND program, the authors invited those people screened with high normal proteinuria or significant proteinuria into a follow up study. This study also included additional people screened. Among this new group of just over 8500 subjects, it was determined that males, older age, obesity (Pinto-Sietsma et al., 2000a) and smoking (Pinto-Sietsma et al., 2000b) were important predictors for a higher risk for the likelihood of having proteinuria.

This cohort has been followed up for over ten years, making this a comprehensive screening and evaluation program which has shown how risk factors and CVD and CKD outcomes are connected (Bello et al., 2007, Halbesma et al., 2006). These findings are further supported by results from the same Dutch group, in the PREVEND-IT study. Here they found that when screening the general Dutch population for albuminuria, followed by empirical treatment with an ACEi (fosinopril), those people who were positive for proteinuria benefitted. The Dutch group questioned whether an empirical intervention with an ACEi in high risk patients was more cost-effective than screening (Atthobari et al., 2006). This has implications for developing countries where supplying appropriate treatment may be more important than screening high risk individuals. This last study provides an argument for 'simply' treating all high risk patients, and suggests screening may be an unnecessary costly exercise. However, this does not address the other values of screening which include determining the epidemiological differences which may exist in different countries and different population groups.

The Singapore NKF Screening Program

Singapore is a newly industrialized country with excellent access to dialysis when patients develop end-stage renal disease (ESRD). Seventy percent of the country's total ESRD population receives subsidized chronic dialysis care at the National Kidney Foundation Singapore (NKFS), a unique dialysis provider funded through charitable donations (Ramirez et al., 2003). The NKFS developed a comprehensive early detection and treatment of CKD because of the expected escalation in the burden of ESRD in the nation and the impact it would have on funding. The plan was aimed at ameliorating the continued increase in ESRD through

an early intervention and prevention program. This is possible because of the small population and geographic size of Singapore, and because renal disease and dialysis, through the NKFS, is a very popularly supported charity. The NKFS Prevention Program also incorporated a public health approach to the prevention of CKD. The strategy, like other programs described, was developed around the 'conceptual framework of the natural history of progression of kidney disease and its predisposing factors (see figures 1 and 2). Singapore has a central data base, and collects aggregates and reports data on kidney disease in the Singapore population. The NKFS prevention program combined both a population-based and a high-risk prevention strategy, educating doctors to screen people with DM and HTN, in order to use the program as both a primary prevention and secondary prevention strategy focusing not on all risk factors associated with high risk. This approach was cost-effective for high risk and it could be argued as being cost effective for a country like Singapore or Holland (de Jong and Brenner, 2004, de Jong et al., 2003), which could afford a population based screening program. However for most countries and with current evidence this would not be considered the most cost effective approach (Brown et al., 2003a, Sumaili et al., 2009, Hallan et al., 2006c), and a high risk approach would be more appropriate. Another criticism is that it did not remove the risk factors that lead to disease, and the approach therefore is largely palliative. The NKFS prime focus was on broad based general population primary screening, believing that a population-based approach would modify the determinants of disease in the population as a whole, and potentially have a larger impact on reducing the rates of disease. This latter approach relies heavily on public education, but also incorporates activities that remove obstacles to healthy behaviour.

Factors influencing the choice of program included firstly that Singapore could afford a broad based population approach, but the epidemiology of ESRD in Singapore was also a significant factor influencing the prevention program. Approximately 50% of incident cases of ESRD are attributed to DM and HTN. Surveillance data on the level of blood pressure and glycaemic control for patients with DM and HTN also demonstrated sub-optimal control, leading the NKFS to follow an approach which targeted these patients at high risk for developing renal complications and ESRD. The health care delivery system of Singapore is such that most chronic outpatient care is conducted by primary care practitioners paid at the point of contact,

and NKFS does not have access or control of these practitioners. This was a major deficiency in the program.

However, 450 000 patients have been screened since 1997. Analysis revealed important local information including racial differences in the risk factors among the major communities. Differences were found for proteinuria, systolic and diastolic blood pressure levels, which are not traditionally classified as elevated and associated with proteinuria. Proteinuria began to occur at markedly lower body mass index levels among certain racial groups. Malays were more likely to have higher proteinuria than Chinese (Ramirez et al., 2002), consistent with observations that Malays exhibit the highest incidence rate of ESRD, compared with other racial groups (Indian and Chinese). Differences in birth weights, related to socio-economic status, among these ethnic groups might also account for variations in HTN and renal disease (Ramirez et al., 2001). Malays are also more likely to be obese and have DM (Hong et al., 2004). Although this program focused on kidney disease, the close link of CKD with CVD risk factors helped with future approaches to chronic disease management. The National Kidney Foundation of Singapore incorporated a stepwise primary, secondary, and tertiary prevention strategy.

Components of the program included an aggressive public education program, routine surveillance for kidney disease and associated chronic diseases. The implementation of a disease management program to improve physician practice patterns, and the provision of comprehensive services in the community through a network of Prevention Centres was developed to optimize the care of patients at risk for kidney disease. The program also provided a baseline epidemiological survey against which future interventions could be measured.

The Australian Chronic Disease Outreach Program

The Australian Outreach Program is a Aboriginal Australian specific, predominantly rural based prevention program (Hoy et al., 2003c), with both screening and treatment. It started on the Tiwi Islands and has since extended to other Aboriginal areas. It involves mass community screening to detect and treat people at high risk (Figure 14). The communities range in size from a few hundred to a couple of thousand. These are small, allowing paid program staff the opportunity to screen the entire community, compared with at risk communities in Africa, India

and South America. Program nurse coordinators spend long periods of time living with the communities and training local health care workers to use algorithms and specific treatment targets for chronic illnesses. The program has significantly reduced morbidity and mortality of kidney and cardiovascular disease (see figure 11). It has influenced national protocols, becoming a government lobby group and galvanizing NGOs in Australia (Hoy et al., 2000). This program has been integrated into normal clinic activities in other Aboriginal communities. Its protocols have also been incorporated into standard care guidelines for Aboriginal adults in the Top End of the Northern Territory.

A major factor of the programs' success is the strength of the program management team and the funding it secured. These Aboriginal communities exist in a wealthy developed country, allowing the Australian CDOP the opportunity to seek out potential sponsors, including large mining corporations operating on or near Aboriginal land. The programs still rely on Aboriginal community support and in a context of considerable historical mistrust, have not always been forthcoming from the local health authorities. This appears to be changing with the program's success. However, it is still slow to influence day-to-day practice throughout Australia. Indigenous Australians are disadvantaged, relative to other Australians, over a range of socio-economic and health measures (Cass et al., 2004). The age- and sex-adjusted incidence of end-stage renal disease (ESRD) is almost nine times higher amongst Indigenous than it is amongst non-indigenous Australians. A striking gradient exists from urban to remote regions, where the standardised ESRD incidence is from 20 to more than 30 times the national incidence (Cass et al., 2004). Kidney specialists understand kidney disease and ESRD from a traditional, biomedical perspective, in which kidney disease is attributed to one of a range of discrete primary disease processes. However, work among the Australian Aboriginal communities has created the understanding that CKD and CVD is closely related to the social, cultural and environmental determinants of health in conjunction with the biology of kidney disease. It has highlighted the need for primary prevention strategies which include improved access to antenatal services to reduce the prevalence of intrauterine growth retardation, screening and intensive management of DM in pregnancy, prevention of obesity in childhood, training community members to improve housing, food supply initiatives to improve access to healthy

foods, cultural appropriate initiatives to improve nutrition and decrease smoking and physical activity programs to reduce obesity and likelihood of DM (Cass et al., 2004, Hoy et al., 2006). This research highlights the need for secondary prevention, covering the period from the development of albuminuria to ESRD, requiring a coordinated national program to provide community based screening and intervention for HTN, DM and albuminuria (Hoy et al., 2000, Hoy et al., 2003b). Early use of ACEi and starting oral hypoglycaemic agents and insulin for DM management is also recommended. Adequate resources and well supported staff are essential for sustaining such programs (Hoy et al., 2005b). This includes constant evaluation to follow outcomes and modify strategies in accordance with chronic illness care guidelines (Wagner, 2004, Wagner et al., 2001).

3 STRATEGIES FOR CHRONIC ILLNESSES MANAGEMENT

The objectives of this chapter are to investigate the current approaches for managing chronic illnesses. The discussion will take a critical look at the focus on prevention of risk factors, the associated diseases implicated in the chronic illness burden and whether it is appropriate and have the greatest impact on public health. It will critically investigate whether the 'prevention' strategy has lost its way. The argument will also focus on aspects of health systems which could have an impact on the chronic illness burden. Thereafter the focus will shift more specifically to kidney disease detection and management programs, evaluating the different approaches in the context of this discussion.

Many economically advanced nations have achieved major reductions in the toll of chronic diseases, especially of CVD, which researchers tend to attribute more or less equally to prevention strategies and health services (Unal et al., 2005, Kuulasmaa et al., 2000). From this experience, several evidence-based interventions have emerged for the prevention and control of chronic diseases. The global emphasis is on primary prevention, focusing on a few key modifiable risk factors e.g. unhealthy diets and physical inactivity resulting in obesity (World Health Organization, 2007b, Nestle, 2006) and tobacco use (Lancet., 2007). This appears to be both rational and cost effective.

For the past twenty years, strategies of primary and secondary prevention and treatment have been adopted and continue particularly in the areas of paediatrics and obstetrics, in the United Kingdom, United States and Australia (Rose, 1981). This combined application of primary and secondary prevention is achieved in obstetrics through good antenatal care, immunisation against tetanus and supervised delivery, and in paediatrics with childhood immunisation, weight monitoring, breastfeeding and other practices. This approach to health care has also been introduced in cardiovascular care, where clinicians are searching for ways to prevent deaths from stroke or myocardial infarction through early identification and treatment of diseases such as hypertension.

We now have to ensure that the integration of prevention and treatment finds its way into the mainstream practices of primary health care and that they include kidney and cardiovascular

disease management. It has been estimated that the implementation of integrated strategies in cardiovascular disease management in a few key developing countries could prevent around 18 million deaths globally over the next 10 years (Lim et al., 2007). Achievement of these health gains would need an average yearly investment of $4·7 billion or $1·10 per head, depending on the country. Medications would account for around two-thirds of this cost, but interventions for populations and individuals at high risk would almost meet the global goal for prevention and control of chronic diseases.

Failures of Existing Prevention Strategies

Medical science and public health have progressed appreciably over the past 50 years in managing CVD and CKD. We have an extensive understanding of the risks associated with these diseases and their complications, the treatment targets for disease control, and advanced medications to achieve these goals (Figure 15) (El-Nahas, 2004). The chronic disease threat can be overcome using existing knowledge. Yet we remain unable to control common chronic conditions like DM and HTN, which would decrease the incidence of CKD and CVD. Effective solutions require comprehensive and integrated action at country level, led by governments and involving local NGOs and actors at all levels of the health system.

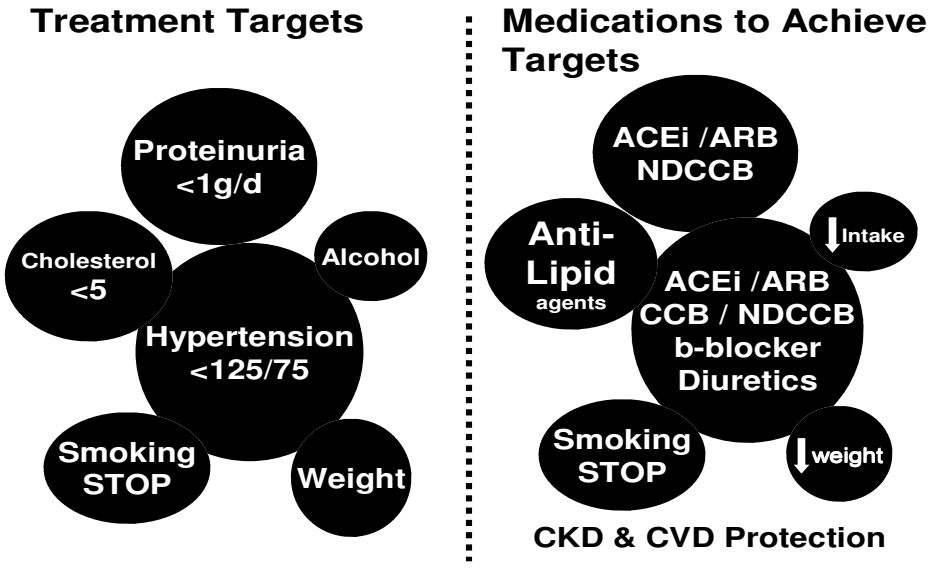


Figure 15 Treatment Targets and Medication for CKD and CVD
ACEi – angiotensin converting enzyme inhibitor, ARB- Angiotensin Receptor Blocker, CCB – Calcium channel blocker, NCCCB – Non-dihydropyridine calcium channel blocker, b-blocker – beta blocker

Life style factors, discussed earlier, impact on CVD and CKD. Prevention aimed at risk factors and early diagnosis and treatment have a striking effect on reducing CVD morbidity and mortality, but there is still little information to inform systematic implementation, the “how” of chronic disease programs (World Health Organization, 2007a). Surveys conducted by the WHO over the last five years show some early signs of progress. The proportion of countries with a national policy for chronic disease prevention and control rose from 42% to 70% between 2005 and 2006 (World Health Organization, 2007a). In this period, the proportion of countries with a chronic NCD unit or department in the health ministry also increased from 60% to 84%, and the proportion of countries with a specific budget line for chronic NCDs increased from 39% to 68% (World Health Organization, 2007a). Nevertheless, the proportion of the health budget spent, in general, on prevention and control of chronic NCDs remains very small. Although the scientific knowledge to achieve the global goals now exists, many low-income and middle-income countries must deal with the practical realities of limited resources and a double burden of infectious and non-communicable diseases. Integrated strategies, discussed earlier, as proposed by the WHO (Epping-Jordan et al., 2005), are always relevant for countries with budgetary and resource constraints. WHO has proposed an integrated stepwise approach to chronic disease prevention and control (Epping-Jordan et al., 2005), including secondary prevention strategies once a country can afford them. The main principle of this approach is a phased implementation of interventions, with core, expanded and optimum interventions, based on the availability of resources, political and community support, and the configuration of national health systems. Ideally, the interventions are comprehensive and balanced at every step, covering programs directed at the whole population and at individuals at high risk. As additional resources become available and support broadens, an expanded set and ultimately an optimum set of interventions can be implemented.

The concept and understanding of prevention has expanded and changed over the past few decades to include the management of risk factors, with risk factors being considered as “diseases”(page 580) (Starfield et al., 2008). Prevention has generally been considered as that which prevents disease (primary prevention) and that which prevents the progression of existing disease (secondary prevention). The World Health Organization did not include prevention as

part of the role of the health system (World Health Organization, 2000a), and prevention strategies now include primary, secondary and even quaternary prevention (Starfield et al., 2008). For some preventing morbidity on dialysis may not be considered prevention at all. The threshold for risk factors being treated and being termed disease is being lowered (Kaplan and Ong, 2007), which has implication to costs of healthcare and patient management. This has resulted in the treating of risk factors without strong evidence that they will have an overall improvement on 'population health'. It has also resulted in increased expenditure, as medications are directed at each risk factor, without clear evidence of its impact on cardiovascular outcomes (Ferreira-González et al., 2007) . Starfield (2008) has begun to question whether this approach is most appropriate and whether the shift should not focus on the 'population' as a whole rather than the individual with CVD risk factors. It was Rose (1981), who provided evidence for reducing coronary artery disease as a result on focusing on risk factors. However it was the intention of Rose to have a population orientation, and not on the individual patient focus. An example used for inappropriate use of research findings are when anti-lipid medication researched in males was recommended for females, without the supporting evidence (Kendrick, 2007). It is not enough to show a medication works in one population group and then recommend it for all others (S Ward et al., 2007). Population-based studies consistently show lower risk of disease or morbidity from single risk factors compared with clinical based studies (Fox, 1996). Prevention has always been to focus on diseases, and risk factors are being considered the same as disease. This has resulted in the boundaries between prevention and care becoming blurred. Starfield (2008), highlights the major challenges to establishing policy for appropriate interventions to reduce the burden of illnesses would be to focus on the success or failure in populations, prioritising inequities in health populations and improving health generally in the population, rather than focus 'disease by disease'. Population-attributable risk should be the priority over individual (relative) risk, and focus should be on defined populations with strong evidence to support an intervention. Interventions should be shown to be cost effective and reduce morbidity and not just the 'disease'. Population-based information systems make it possible to merge ''prevention'' and ''care'', and the full range of options must be considered to achieve the desired outcomes and these should be prioritised

according to maximum gain for the population as a whole. A compelling argument now exists for carefully reconsidering our approach to improving outcomes for chronic illnesses.

This WHO stepwise framework offers a flexible and practical approach to assist ministries of health in balancing diverse needs and priorities while implementing evidence-based interventions (Epping-Jordan et al., 2005). The WHO recognizes the difficulty in achieving the above ideal and has proposed that countries adopt a practical or a phased approach, tailored according to existing capacity. The WHO outlines the methods for achieving this approach by advising the development of a hierarchical framework to unify surveillance and prevention program activities, recognising that these should be flexible across a range of risks, conditions, ages and areas (Bonita, 2003). Standard methods and tools are adaptable to local settings. The aim is to start with primary prevention strategies and then to progress to secondary and tertiary level care according to existing resources. A key aim is to develop basic sentinel surveillance and treatment sites, and then to add on to existing systems (Figure 16).

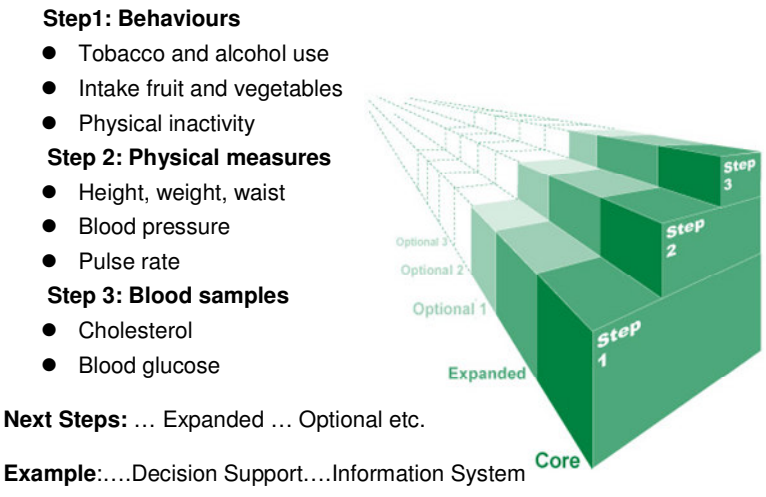


Figure 16. The WHO STEPS Framework

At the national level, government should provide a unifying support role for CD prevention and control, so that actions at all levels and by all stakeholders are mutually supportive. Broad based action, across different sectors, is necessary at all stages of policy

formulation and implementation because major determinants of chronic disease burden lies outside the health sector. As part of comprehensive public-health action, population-wide and individual interventions are combined, and this recognises that most countries will not have the resources to immediately do everything set out in the policy. However the implementation of these strategies is far more difficult to achieve than suggested and this strategy offers no practical approach or processes for implementing the framework. The barriers affecting implementation in clinical practice need to be corrected and effort needs to be directed to these ideals. It has also been proposed that certain key principles be implemented at the PHC level, clinic or family practice, during one on one consultations with patients who have chronic illnesses (Couper, 2007). The service needs to both appropriate and of a certain quality and certain key principles need to be addressed at this level of care. The "7 habits of highly effective carers" (page 6, Couper 2007), highlighted include those proposed by both the Wagner Chronic illness Care Model (CICM) and WHO Innovative Care for Chronic Conditions (ICCC) Framework. Fundamental strategies include commitment to the person who is ill, continuity of care, collaboration, a comprehension of the patients regarding their illness and how to manage it themselves. It also includes the ability of a patient to adapt to change, adhere to their new treatment and lifestyle changes. Finally it includes clear and simple guidelines for health providers and patients and the capture and tracking of clinical information in order to follow a person's progress. These overriding principles proposed by chronic illness guidelines are applicable on the macro level and micro levels of providing patient care. It is amongst these broader guidelines and PHC 'key principles', that collaboration and interaction with a specialist should be viewed. This small component of collaboration, amongst the many required to improve chronic illness care is the need for improvement of communication between hospitals and primary care. Improvement of follow-up of high-risk patients, particularly those identified to have problems and whose disease appears to be treatment-resistant, need to be flagged (Zoccali, 2006) and maybe even referred. New forms of collaboration between all those health workers concerned need to be planned and tested. It is in pilot 'outreach programs' that such approaches can be tested.

This approach suggests the need to move away from a radar approach to managing chronic illnesses, discussed earlier. In this model, by which most current health systems run, patients are only detected with a chronic disease in the advanced stages when they present to a doctor or hospital. Chronic disease management into the future relies on a better-coordinated system involving all components of the health care system in an integrated manner. Here patients are detected early in a PHC setting, and management support is provided by specialists if needed, together with effective systems for referral and an information data base to help support these systems. Public health decision-making is critically dependent on the timely availability of sound data. The role of health information systems is to generate, analyse and disseminate such data (AbouZahr and Boerma, 2005). In practice, health information systems rarely function systematically in an integrated fashion.

Large population based screening studies or programs initially focusing on screening should only be undertaken to identify people with disease if the criteria are met for it being a public health problem i.e. burden of disease larger or becoming larger, it is unfairly distributed, strategies must exist which could alter the course of these diseases, and such strategies are not yet in place (Schoolwerth et al., 2006).. Pilot studies or screening programs can determine the scale and nature of the problems and help determine health system requirements. While this approach may not be feasible or cost effective in all developing countries it may be for some diseases where prevalence is high. An alternative cost effective and sometimes more appropriate approach is to screen within the health system. This would allow for both primary prevention, e.g. screening for CKD in people with DM and a family history of CKD before they develop the disease, and secondary prevention screening can be followed, e.g. screening for microalbuminuria in people with DM and treating aggressively to prevent overt proteinuria or advanced CKD. This strategy utilizes the existing PHC system, developing skills and resources at the same time. The approach in SA CDOP has been to focus on the high risk population groups, as those with uncontrolled HTN or DM with proteinuria are at highest risk for CVD or progressive CKD**.**

Lifestyle measures remain the key to the epidemic of NCD and HIV, but these have to be matched with screening and treatment programs to impact on overall disease. This approach is

true for kidney disease too, as it recognises the continuum of CKD. Here we come to the point made by Rose (1981), discussed earlier, of the need to integrate prevention and treatment. Impacting on the primary care setting will affect the flow to the tertiary system. In our attempt to move the 'mean' towards improved management of chronic illnesses, specialists need to work with primary care clinicians and be involved with public education. This includes a commitment and sustained adherence to a healthy lifestyle. An integrated plan is essential, focusing on the susceptible and high risk groups along the entire continuum of kidney disease, with effective management at all levels of CKD.

Health Systems and Program Interventions

Attempting to integrate a kidney disease focus within a chronic disease management program is challenging. People's health status and quality of life will not be improved solely by medication and technical advances; and thus healthcare systems have to move away from the current dominant model of ''find it and fix it'' to a more integrated approach (Katz, 2005b, Epping-Jordan, 2005). Such solutions often require cooperation between government, private funders and non-governmental organizations. This is in keeping with the WHO definition of a 'health system' which comprises all organizations, institutions and resources devoted to producing health actions (World Health Organization, 2000a). Programs often rely on outside organizations and appropriate technologies to stimulate their development (Bachmann, 2007), but although non-governmental and private-for profit organizations are important players in stimulating innovation, they cannot carry out the central activities of the public health sector (World Health Organization, 2005a) . This responsibility has to fall on policy makers, government departments and the people and institutions that are responsible for public health care. Programs like CDOP require the acquisition of skills but also resources and funding. We have to balance our enthusiasm to initiate programs with the practical reality and recognition that most countries like South Africa, which need prevention and detection programs, are also those in which they are most difficult and time consuming to set up. Establishing these intervention

programs often require many years from the time of conception to implementation and even more time to scale up.

The strengthening of health systems in developing countries remains a key challenge, especially in the wake of the existing epidemics of HIV and chronic diseases. Fragmentation of health systems, by developing parallel programs, can lead to chaos (McCoy et al., 2005, Sanders and Chopra, 2001, Sanders et al., 2005). The energy and activism around HIV/AIDS should be joined with other chronic illness programs, providing an opportunity to strengthen and integrate health systems. Integrated programs are more likely to develop health systems horizontally across sectors and this will have a positive affect for all chronic illnesses. Chronic disease programs facilitate the long-term social processes of capacity building of both communities and health workers. CKD and HIV share similarities, their risk factors and complications can be effectively detected and treated.

In South Africa, nephrologists have had significant experience in CKD. As dialysis and transplantation are a scarce resource to which access is limited, great efforts have been made to ensure equitable access to this resource and better patient adherence (Dirks and Levin, 2006, Moosa and Kidd, 2006). The problems in strengthening health systems and scaling up therapies in the face of HIV and CKD include the scarcity of human resources, caused by an inadequate supply, maldistribution, the low remuneration health workers receive and the increased migration to more favourable environments (Schneider et al., 2006, Victora et al., 2004). Poor productivity and culture of service delivery is also a problem (Hongoro and McPake, 2003).

Another key challenge is insufficient financial investment into already weakened health systems. Although global funding has increased, adequate funding has been a challenge with scaling up of HIV programs. Even if there were adequate funding, the human resources required to provide treatment falls far short of what is required (Rosen et al., 2005, McCoy et al., 2005). Health system infrastructure is also inadequate. Such challenges cannot be reversed in the short term.

In chronic disease programs, it is critical to link treatment with prevention. Integrating the therapeutic and prevention roles has improved care provided by obstetricians and paediatricians (Rose, 1981). Integrating treatment and prevention is shown to have a greater impact on

outcomes than treatment alone (Salomon et al., 2005) (see figure 2). Success has been achieved in Australia and the United States from the late 1970s where this focus resulted in the reduction of mortality from coronary artery disease (Rose, 1981, Lenfant, 2003). For coronary artery disease, although both primary and secondary prevention and treatment components are necessary to maximise health care, the greatest benefit is seen with primary prevention (Unal et al., 2005). This may prove true also for other chronic diseases. Strategies should focus on primary prevention, particularly tobacco control, healthier diets and exercise.

People with chronic illnesses often present late in the natural history of their disease, when the disease is well advanced. An integrated health care system, involving all 'structures' including prevention and treatment components, is particularly appropriate for the ongoing care of any chronic illnesses, such as tuberculosis, DM, HIV (Epping-Jordan, 2005). Prevention strategies would include focusing on those at highest risk for disease and utilising a mass strategy of prevention and treatment to shift the whole population distribution of that risk variable (Rose, 1981). However, many questions have yet to be answered with regard to health systems and chronic illnesses: how to ensure the availability of low-cost generic drugs for people at high risk of CVD or CKD and their uptake and long-term use without financial burden. Other questions include how to identify people at high risk in primary health-care settings and ensuring appropriate referral. A simple set of indicators and good information systems for monitoring progress in implementing strategies to manage chronic conditions is also needed (Beaglehole et al., 2007).

In South Africa, chronic disease systems for managing HIV and TB have received a greater focus and are better funded and receive more attention for political and emotive reasons. But the management of all chronic diseases require a functioning health system and so tackling these problems should be integrated under the same banner (Epping-Jordan, 2005, Couper, 2007). The health system in South Africa requires significant strengthening given the epidemics both of non-communicable chronic disease and HIV. Research and evaluation of health systems has taken place in developing countries (Joint Learning Initiative, 2003, Sanders et al., 2005), and especially with regard to HIV (McCoy et al., 2005, Schneider et al., 2006) but also non-communicable chronic illnesses (Abegunde et al., 2007, Epping-Jordan, 2005).

Health Systems Evaluation

The evaluation of a health system is best approached by firstly understanding the environment in which it functions and then breaking the health system down into its components. The impact of a health system or program depends on socio-economic and social stratification factors such as race or ethnicity, gender and age, and because of this, quantitative evaluation of the outcomes may not provide all the answers to controlling illness. Despite the existence of many programs, a relatively small number of these are evaluated. Program evaluation determines which programs are needed, effective and utilised (Potter, 1999).

A prerequisite for effective implementation of any secondary prevention strategy, including early detection and prevention programs, is a functioning and equitable primary health-care system. The provision of affordable and reliable drugs for chronic disease is a major challenge, with many patients missing out on effective and cheap treatments. Proper planning and implementation of prevention and control strategies depend on reliable and comparable information to monitor the burden of chronic diseases and their risk factors. In the poorest countries, the availability and quality of health information systems are often inadequate to inform health policies and resource allocation at global, regional, and country levels (AbouZahr and Boerma, 2005, Murray et al., 2004). The rapid escalation of demand for chronic care services has been poorly documented, and major gaps in the supply of health information for developing countries are apparent. An information system allows for evaluation of challenges, and quick reaction to new methods to tackle problems. Good examples exist of the use of data for evidence-based decision-making leading to better health (Mubyazi and Gonzalez-Block, 2005). Inadequate health information contributes to the non-recognition of the burden of chronic diseases, inadequate resource allocation, improper planning of control strategies, and little means of monitoring the effect of health policies (Boerma and Stansfield, 2007).

The environment includes the policies and politics in which a system must function, the economic dynamics which prevail, and the underlying risk of disease in that community. In the case of a chronic disease like CKD, this includes risk factors associated with CKD like smoking, obesity, DM, HTN and HIV/AIDS. It also includes socio-economic factors. Evaluation has to take

into account the various components needed to ensure service delivery such as urine dipsticks measurements, blood HbA1c and eGFR measurements. It also includes the existing structures required to manage the disease, such as the clinics and PHCN staff. Finally, constant evaluation of the processes and outcomes are required, in keeping with the participatory action research methodology.

Models like the Wagner CICM and WHO ICCC recognise these complexities (Epping-Jordan et al., 2004, World Health Organization, 2002a), highlighting the need for adequate resources, appropriate protocols and systems, and for health workers and patients to work together. Integration can occur at many levels, including at the level of program management (Schneider et al., 2006, Si et al., 2008). This includes integrating the financing, procurement of resources and monitoring of the programs at the national level.

Models for Managing Chronic Diseases and Kidney Disease

Having outlined the great challenge of chronic diseases, the problem of CKD and its link to CVD, globally, in SA and in the setting of this study, I now consider some models which have been proposed to deal with these challenges. A core focus of this thesis is finding a solution to the management of chronic illnesses and developing strategies to deal with the problem. A key component to this 'solution' is to establish of programs and strategies to combat chronic illnesses. This includes primary care facility and clinician approach, and included in this approach is the linking of the primary health care and specialist care settings and the effective up and down referral. Health care delivery systems are generally poorly focused on dealing with chronic illnesses compared to infectious diseases. The approach is often unstructured, lacks systematic follow-up and monitoring of chronic clinical care, and provides little information about morbidity or mortality. Two key chronic illness models, the Wagner Model and World Health Organization Model, discussed earlier, have attempted to provide guiding principles for managing chronic diseases and must be considered seriously in any endeavour to tackle the problem. I turn to these now. Both are strategies based on reviews of innovative best practice and affordable healthcare systems (Wagner, 2004, World Health Organization, 2002a).

The Wagner Chronic Illness Care Model (CICM) and WHO Innovative Care for Chronic Conditions (ICCC) Framework models were designed to improve management of chronic illnesses like DM and HTN (see figure 4 and 5) (Si et al., 2008, Nutting et al., 2007, Solberg et al., 2006, Vargas et al., 2007, Tsai et al., 2005). The models are particularly valuable because they focus on clinicians as 'a prepared and proactive team' (Wagner et al., 2001, World Health Organization, 2002a). CICM and ICCC differ in that they strongly acknowledge the role of PHC clinicians, both doctors and nurses, and recognise the interaction required between the health care team and patients. They offer an opportunity to provide higher quality care by implementing a few fundamental changes. The models recognise the transformation needed in managing chronic illnesses from a reactive to proactive one. They acknowledge, although indirectly, the need to assist the PHC clinician with evidence-based guidelines, specialist expertise, and an information system which can track patients' clinical progress and outcomes.

A central role of these models is that they provide a methodology to measure both the progress and outcomes of care through an information system, encourage follow up and enable the ''stepping up'' or ''stepping down'' of care from PHC to specialist health care (SHC), according to criteria determined by data systematically collected (Gask, 2004). This concept of deciding where patients can be managed is not well understood by health professionals and especially public health care managers. In primary care settings where people with DM are managed, relatively little clinician effort is required to incorporate the elements of these models into daily practice routines (Nutting et al., 2007). Implementing the models has been associated with better incorporation of recommended clinical guidelines, reducing CVD risk in patients with DM, for instance. In one study (Vargas et al., 2007), over a 1-year interval, a total of 1170 DM patients were compared, using the CCM at intervention sites and 'usual care' management at 'control' sites. While there were improvements in both groups, at the intervention sites the risk factors for CVD, blood pressure, lipid levels and HbA1c were significantly lower than the usual care sites. Various other trials provide evidence supporting most of the components of the Wagner CICM, and in particular, broadening the care team by including nurses in chronic illness management (Peters and Davidson, 1998, Aubert et al., 1998a, Bodenheimer et al., 2005). This included involving nurses in patient management activities such as tracking patient care, (The

California Medi-Cal Type 2 Diabetes Study, 2004) with telephone follow-up (Nutting et al., 2007, Polonsky et al., 2003), and in self management support for patients e.g. glucose monitoring. In a meta-analysis of the value of the CICM model, it was found that interventions that incorporated one or more elements of the CICM had beneficial effects on clinical outcomes and processes of care for patients, with results consistent across various chronic illnesses (Tsai et al., 2005). However, most of these studies were conducted in small primary health care practice settings in the United States, and in small communities. It remains unknown if it is suitable in larger environments in lower income settings in developing countries.

Chronic illness care models recognise the importance of involvement of the patient and their family in patient care, for the delivery of effective health care for chronic diseases care. They however do not provide an effective implementation model or system. The “efficacy” (whether an intervention works under ideal circumstances) of these models has to be transferred in “effectiveness”(whether the intervention works under the conditions of a health service). Research based model are an exciting alternative to traditional randomised control trial (RCT) research, on which most chronic illness care is based, because of its pragmatic and ‘real life’ implementation. It is here that we should turn to more established primary health care responses to chronic conditions. These responses include the integrated management of chronic illnesses with that of chronic communicable diseases, (Coovadia and Bland, 2008) e.g. as demonstrated in Cambodia with HIV, diabetes and hypertension (Janssens et al., 2007). Responses to problems like HIV and TB has resulted in the incorporation of a regular evaluation of the program performance and achievement of outcomes. A standardised guideline for detection and treatment has been established. This approach used for the control of tuberculosis (Harries et al., 2008) can be adapted for chronic illnesses with simple systems being developed and enforced for monitoring and evaluation of outcomes of patients and of program performance.

There is concern that medical discoveries are not being translated into a measurable human benefit and although models like the Wagner CICM and WHO ICC, have attempted to provide the frameworks for delivery of evidence-based medicine to the health care team through decision support and data information systems, this is not the case. Broad clinical improvement requires that a critical mass of participating clinicians in community health services be committed

to understanding their patterns of practice and bringing these patterns into alignment with evidence-based best practices. This requires leadership, a constant flow of information and analyses, and mutual support and problem-solving. However, CICM does not pay enough attention to the broader issues of policy, implementation, the organization and equipping of the health care team. It also fails to present a clear message about process and resource development.

Some of these deficiencies were recognised by the WHO, and a modified version of the CICM was developed, namely the WHO ICCC Framework (see figure 5). The ICCC takes into consideration the broader aspects of the chronic disease management and is potentially more suitable for larger scale community implementation. The ICCC framework expands on the community and policy aspects of improving health care for CD, but also includes components at the micro (patient and family), meso (health care organization and community), and macro (policy) levels (Epping-Jordan et al., 2004). It takes into account a “systems” activity that is difficult to conduct without organizational leadership, support, and good infrastructure. The ICCC provides a road map for decision makers who want to improve their health system's capacity to manage chronic conditions in accordance with local resources and demands, although as with the CICM, it does not offer an approach to implementation.

The WHO model, like Wagner’s, recognised that the successful management of chronic conditions required a team approach. It acknowledges that this could only be achieved when patients, community partners, and ‘proactive’ health care teams are informed, motivated, prepared and working together (World Health Organization, 2002a). Proactive care refers to care that anticipates patients' needs rather than relying on a patient-initiated interaction that is often introduced because of urgent symptoms. Clear treatment plans with scheduled, regular follow-up are typical features of proactive approaches. This partnership approach is a significant change from traditional health care, in which health care providers are seen as experts, patients are viewed as passive recipients of care, and communities are largely ignored. It also recognises different levels required for improving health care by separating chronic illness management components. Like the Wagner CICM, it acknowledges that especially in developing countries, chronic conditions present mainly at the PHC level and need to be handled in these settings

(Epping-Jordan, 2005). The ICCC framework therefore encompasses both models. This model was used in this thesis, especially when evaluating the program. However, it needed adaptation, as it did not provide a method or an approach to the implementation of a chronic illness program.

To some extent these models have been incorporated into CKD early detection and prevention programs, but only one CKD program, not already described above, for American and Alaskan Indians, used the CICM to implement and run of its program (Narva, 2007, Narva, 2008). So there is not much experience of CICM outside of DM management, and very little with regard to its application in kidney disease. Most programs and their driving models recognise the need for integration, coordinated care, and the complexity of providing health care for chronic conditions in an organized way. These models are able to demonstrate that chronic illnesses cannot be 'cured' with a single initiative but that they require ongoing effort and coordination.

Fundamentals of Chronic Illness Programs

The program examples above, demonstrate that it is possible to establish outreach programs. Most programs focus on secondary prevention, attempting to either detect disease early, or then intervene by improving management of the illness and reducing subsequent complications. They demonstrate the need to have clear approach, but not all use an overriding health system model to guide their programs. This may be a weakness. They should, according to Wagner CCIM and WHO ICCC, have decision support components, an information system, and a method of evaluating their impact. Importantly, programs using these models should develop a strong focus on developing an 'informed and proactive health team' (primary care clinicians and specialists), and strong patient and community partnerships. A focus on the team delivering health care remains as important as adequate funding and a functioning health care system (Beaglehole and Dal Poz, 2003). Some of these fundamental aspects of establishing a program, using a chronic disease model are described in Table 6 (Glasgow et al., 2001). These components of a chronic illness or chronic non-communicable disease program are both practical and philosophical in approach. They are both derived from on the ground experience but should also be linked to a clear framework or model.

Table 6. Requirements to establishing a chronic disease model or program
1. The availability and understanding of population-based chronic disease management. Strong primary health care focus with the PCC Nurse being critical especially in the developing and poorly developed countries.
2. Support from government, local community organization (NGOs), health workers and patients
3. Funding or research on real-world/practice-oriented issues, systems, and organizational change strategies (to be able to translate studies to primary care settings). Securing some form of bridging assistance from local government or an NGO, whether financial or other, such as equipment, human resources or technical skills.
4. The appropriate health care policies to provide reimbursement for and the incentives to create a chronic disease model.
5. Systems-based support for the primary care physician's (or other staff) implementation of behaviour change strategies.
6. An understanding of the personal and social-environmental factors that lead to long-term sustained self-directed behaviour change and establishment of a productive interaction between health care system managers, program organizers, patients and the health practice team.
7. Adequate integrated information systems and sharing of information across provider groups or clinics. Establishment of an organized integrated program as compared with the 'usual' standard 'find it and fix it model' of care existing in most countries. Organized care has shown better outcome compared with standard care programs.
8. Adequate time to address patient-focused issues in an interactive, personally tailored manner during office visits.

Adapted from (Katz, 2005a, Glasgow et al., 2001)

Whether or not they focus on CKD as a primary element, chronic illness models all recognise and acknowledge the role of improving management of chronic illnesses like HTN, DM or TB to reduce outcomes. The goal of any model or framework is to reduce the burden of morbidity, disability and premature mortality related to chronic illnesses through a primary care strategy which has key elements. This would include identifying and addressing risk factors which can be managed and changed, screening for these common chronic illnesses and then diagnose, treat and follow-up these patients using standard protocols. The proposed models could borrow the same elements as those developed for tuberculosis and HIV control. These models would include a clear set of goals, a strategy and targets for control, a package of interventions for quality care, key operations for national implementation, and indicators to measure progress towards increasing the impact of primary care interventions on chronic

illnesses. The framework will need regular evaluation and even adaptation in different settings. Traditional methods of review focus on measuring and reporting on program effectiveness. The challenge will remain that most results often find that the evidence is mixed or conflicting, and provide little or no clue as to why the intervention worked or did not work when applied in different contexts or circumstances, when deployed by different stakeholders, or when used for different purposes (Pawson et al., 2005). While they focus predominantly on 'functional and clinical outcomes,' they have to a lesser extent focused on evaluating the primary health care team and the health system failures and challenges, and the impact of the programs on the clinician and health system. It remains critical to evaluate comprehensively the impact of the program and not only focus on the bottom line, namely clinical outcomes, but also on why these outcomes or failures are occurring. In health systems and other public services, we are dealing with complex social interventions, which act on complex social systems, like performance measures, regulation and inspection, and inter-departmental interactions. Part of the problem is one of complexity, and there are no 'magic bullets' which will always hit their target, and effective programs are crucially dependent on context and interaction. Traditional methods of review focus on measuring and reporting on program effectiveness. Results often find that the evidence is mixed or conflicting, and provide little or no clue as to why the intervention worked or did not work when applied in different contexts or circumstances, when deployed by different stakeholders, or when used for different purposes (Pawson et al., 2005).

Facility and Consult based approach to Chronic Care

The key principles of the approach to chronic illness care have been highlighted earlier but a more detailed approach is needed if one considers the 'health care team' as critical component chronic care delivery. Many of the principles have been highlighted earlier, but they need to be implemented to achieve these goals. Couper (2007) offers an excellent approach to ensure effective PHC clinicians by highlighting commitment to the patient as the fundamental principle, but also that it be shared by other health professionals.

In all seven principles are proposed, with the next being, 'continuity of care' (Couper, 2007). It is referred to as active and sustained follow up (Von Korff et al., 1997), which arises

from a clinicians commitment to the individual, that their interests are considered. The result of this type of interaction is that a personal relationship is developed with the individual. Couper (2007) argues that the knowledge of a person's illness, their medication and complications are both more efficient and cost effective. The continuity ensures that protocols and management plans are followed, and previous problems are addressed at follow up visits. The principle of collaboration has particular pertinence to this thesis review and highlights the need for links for cardiovascular and kidney care. Although this principle has many levels, it primarily includes collaboration between patient and clinician. As outlined in the CICM and ICC models this collaboration for chronic illnesses is highlighted by the need for the patient, their family and community to also be informed and involved in their care (Wagner, 2004, World Health Organization, 2002a). It is also an important focus which is not well taught to health care providers (Couper, 2007). Overall, the collaboration of care requires that the patient is informed about their illness, its treatment and possible outcomes. The aim of this collaboration, especially related to chronic illness is a focus on achieving a healthy lifestyle and also adherence to treatment. This type of collaboration is especially pertinent to chronic illnesses like HTN and DM, where home blood pressure recordings and blood glucose readings are important. This type of collaboration is especially important in the Soweto context, where patient 'support groups' remain a key factor in patient care. Collaboration for chronic illness care would include many specialities involved in kidney and cardiovascular key e.g. endocrinology, cardiology.

Further principles covered include a clinicians understanding of the socio-psychological components of their chronic illness and the patient's comprehension of their illness. Evidence exists supporting better outcomes for patients who are better informed (Holman, 2004). This includes reduced hospitalisation and costs for care (Bodenheimer et al., 2002).

The ability for a patient to adapt to 'change' is considered to be fundamental, which embodies the need to visit their PHC clinician regularly and take responsibility for their treatment (Couper, 2007). It is especially important with regard to chronic illnesses, where lifestyle and ongoing treatment is needed, allowing for extended periods of 'self care' i.e. three to six month medication repeats, and reduced clinic numbers and visits. Fundamental to the management of chronic illnesses is the integration of clinical guidelines. Unfortunately guidelines are often

written by researchers out of touch with the 'coal face' care of the PHC setting, and a balance between the individual need and clinical evidence is required. Outcomes are improved when guidelines are followed (Weingarten et al., 2002), and so the balance is about finding appropriate guideline use and their implementation. Clinical data capture includes the focus on individual interaction with the patient and the maintenance of clinical notes. The use of electronic databases, has further complicated the process, but provides an opportunity to ensure continuity of patient care, and better audit and evaluation of progress and outcomes. Variables which should be monitored require good evidence to support their use. A clear rationale needs to be considered. It is well shown that using such approaches will improve the management of chronic illnesses (Glasziou et al., 2005).

The implementation of chronic care principles is covered in the WHO Integrated Management of Adolescent and Adult Illness Program (IMAI), and has shown to be a useful tool (Organization, 2004). This approach includes the '5 As', which assists the clinician during the consultation i.e. assessing patients clinical condition, providing Advice, Agreeing to set and accept goals of management, 'assisting' the patient with the treatment plan, and 'arranging' follow up. Couper (2007) has added a practical approach by sub-categorising the 'assessment' to include another four Cs which include evaluating patients 'complaints or concerns', 'control' of the illness, 'compliance' or adherence with treatment and finally looking for any 'complications'.

Couper's paper offers clear approach for the PHC facility or family practice to manage people with chronic illnesses, and a template against which facilities can be evaluated. A strong argument is provided for its use, but this is guarded with the concern and recognition of the challenges of implementation, and especially in the government health sector.

Primary Health Care Clinician Motivation

Having a committed PHC clinician is a fundamental requirement to achieve improved management of chronic illness (Couper, 2007), and achieving the goals of a health organization require a health worker to be motivated (Franco et al., 2002, Wagner, 2004, World Health Organization, 2002a). It is for these reasons and because models for chronic illness focus on a 'motivated, informed, and active' health care team that this issue is being covered in this thesis.

Amongst the various options of managing chronic illness, the most popular and successful is usually nurse driven. Chronic disease programs often have a strong primary health care focus involving the PHC nurses (Yawn, 2000). Nurse practitioners are well equipped to provide practical education on the everyday activities of people with chronic diseases and have been successfully used to manage and coordinate care for patients with chronic illnesses (Connelly and Connelly, 1979). Appropriately trained nurses can offer the same value as doctors and provide as good outcomes with regard to patient care (Laurant et al., 2005). Nurse practitioners have the potential to reduce doctors' workload and direct healthcare costs, but achieving such reductions depends on the particular context of care and the skills of the nurse.

Health systems in developing countries often rely on nurses to deliver health care and for success; this requires informed, activated and motivated health workers. In some instances, the nurse has even replaced the doctor with chronic disease management with the same outcomes for patients, process of care, resource utilization or cost, but importantly nurses must be appropriately trained (Laurant et al., 2005, Si et al., 2008, Nutting et al., 2007, Solberg et al., 2006, Vargas et al., 2007, Tsai et al., 2005). However, for health workers to be willing to achieve the goals of any organization and deliver high quality work and efficiency, they must be motivated (Franco et al., 2002). Motivational issues impacting on care include poor attitudes to patients, arriving late at work, absenteeism and burnout (Gilson et al., 1994, Piko, 2006, Van Lerberghe et al., 2002). A functional health system relies on its clinicians to examine patients quickly and effectively and to provide the appropriate treatment. These actions rely on a clinician being both motivated and enthusiastic. Some of this motivation is self-derived (intrinsic motivation) but the enabling organization (extrinsic motivation) is also very important. The motivation to deliver high quality care has many facets, including the policy environment and management styles, resource availability and worker competence. Franco and colleagues investigated the ‘determinants’ and the ‘motivational outcomes’ affecting health workers in developing world countries. In one in-depth study evaluating of 500 employees, carried out in hospitals in Georgia and Jordan (Franco et al., 2004), health worker motivation was evaluated using three analytical approaches, that included psychometric testing, perceived contextual factors and motivational outcomes (feelings, thoughts and behaviours). Despite the countries’

socio-political differences, the study revealed similarities in the areas of self-efficacy (a worker's sense that they can do the job and that the work is under control), pride and satisfaction (related to their job environment and organization), management openness (transparent communication and attitude to change), and job properties i.e. making the job more interesting (job recognition and responsibility, integrating tasks to improve variety and reduce monotony, job rotation through different areas). Financial reward was important but was not the only factor influencing motivation. Differences between the two sites revolved around local cultural issues and highlighted the need to create programs that are both socially appropriate and developed specifically for the type of health worker, e.g. nurse or manager. The study highlighted the complex nature of health worker motivation, and the need for interventions and comprehensive programs to improve motivation. A weakness of this study was that it was conducted among predominantly hospital based health workers.

Another study utilising this type of methodology was that of Penn-Kekana and colleagues in South Africa, but here the health workers were nurses from hospital based maternal health services, (Penn-Kekana et al., 2005). Although the study focused on maternal health services, it reflected the nursing dynamics in the South African health system in general. This study revealed that many nurses expressed a lack of motivation, burn out and an intention to leave the nursing service. Reflecting on determinants of motivation, nurses were confident in their ability but were concerned with promotion opportunities, inability to support their families and work-load. More than half wished they had not become nurses. Nurses felt underpaid, overworked, underappreciated and unsupported by management. All these factors strongly impacted on their ability to provide a quality service and implement policy interventions.

Both studies concluded on the need for interventions that addressed changes to policy and the organization environment. Other studies also support better organization commitment with good support from managers and supervisors and colleagues (Cheng-I et al., 2006) . Work motivation is an important component of achieving the goals of the organization, and this is important for achieving targets with chronic disease management (Van Lerberghe et al., 2002). The value of the health worker, and specifically nurses, and the need to invest in this vital human

resource, with better planning, production, remuneration and management, is well recognised in some programs (Schneider et al., 2006, Bodenheimer et al., 2005).

Although low levels of worker motivation plague public health systems in developing countries, there has been a surprising lack of attention to the human elements of reforms required to bring out the best from health workers (Franco et al., 2002). The focus globally is more often on technology, infrastructure and health economics than on the people and the relationships required to ensure service delivery (Blaauw et al., 2003). Blaauw et al. (2008) encourage more complex, multi-disciplinary approaches for a better understanding of the motivations of health workers and health managers and improve health system performance. Worker motivation depends upon the organizational context in which the worker is situated, the organizational structure, resources, processes, and culture, and organizational feedback about performance (Franco et al., 2002). The successful functioning of health services requires relationships between health workers and their patients, managers and health workers, and external organizations e.g. NGOs. Overall public sector, or health service, performance depends on successful relationships in all of these areas.

Franco and Penn-Kekana both developed a conceptual model of health worker motivation for their research (Franco et al., 2004, Penn-Kekana et al., 2005) (see figure 25 and Appendix 8b). The model looks at the factors interacting between the health worker and the organization in which they work. It takes into account those aspects within the health organization and within the society that influence workers' motivation. It looks at workers as individuals, their psychological and internal make up driving them to deliver good care. This is the willingness of the worker to achieve the policies of the politicians and managers. This in turn is influenced by an individual's work ethic, internal forces and the external rewards which they derive from their work. These internal motivational processes can be viewed as a series of measurable inputs (determinants) that lead to certain measurable motivational outcomes or a motivated health worker. Individual determinants are influenced by personality and value systems. Factors also at play in determining an activated and motivated health worker include the way clinicians perceive their working environment. It includes how workers perceive themselves as knowledgeable and able to deliver the service, although this is also dependent on

the work environment. These can be defined as behavioural (what workers do); emotional or affective (what workers feel) and rational or cognitive (what workers think) (Franco et al., 2004). These perceived contextual factors are enabling factors for the worker to be motivated and be ready to work. These factors interact with each other and the other factors. The inputs and outcomes arising from the individual health worker must operate within the existing social, environment and organization context. Ultimately the health workers internalize these factors, and from this, produce an output to deliver the required improved functional and clinical outcomes. Health systems are social systems, and therefore health system researchers and reformers need to pay much more attention to social theory (Blaauw et al., 2003). Natural science methods of enquiry are inadequate and inappropriate for understanding social systems.

Often, reform programs have focused on a very limited number of channels (e.g. financial incentives) to influence worker behaviour, and have neglected less tangible incentives such as the work itself, achievement, and recognition. Successful initiatives in PHC have often taken cognisance of these factors and introduced performance-related incentives, i.e. financial incentives, for clinic staff to deal with issues impacting on delivery and improving quality of care (McDonald et al., 2007, Roland, 2004, McElduff et al., 2004).

The conceptual model proposed by Franco et al. (2004), which is particularly relevant to South Africa, offers an opportunity for evaluating worker motivation as part of a new program or reform. Franco recommended that researchers replicate his evaluation of workers motivation in developing countries. This includes validation of scales of motivation used for evaluation including evaluating potential interventions. In South Africa the transition from Apartheid has brought widespread economic difficulties and the declining value of salaries, coupled with rapid and poorly planned health system changes. Rather than embarking on developing a new instrument to evaluate motivation, which is often the case (Steiner and Norman, 1994), it makes sense to rather validate existing models. The Franco conceptual model has been validated both at face value and content by researchers (Franco et al., 2004, Penn-Kekana et al., 2005), and has been shown to both appropriate and to reveal reproducible informative data. The only criticism is that its domains remain fairly broad and this may result in lack of validation of individual concepts.

Health workers in South Africa are often criticised for their behaviour towards patients, as "harsh and unsympathetic" (Global Forum for Health Research, 2002).This reflects the importance of managers paying attention to factors which influence this behaviour and attempts should be made to improve working conditions. It is more often the mechanisms by which programs or services are implemented that result in their success (Travis et al., 2003). The components outlined here relate to how management looks after its health workers. It also relates to how policies are implemented and their impact on health workers environment. Managers need to recognise the impact of a policy or program on the health workers environment before implementation.

Health workers also have to understand what needs to be achieved e.g. who should be referred. When norms ,standards, and associated processes are clear, it is possible for workers to understand how they can help in reaching the goals or targets of disease management (Franco et al., 2002). When embarking on initiatives or programs within the public health sector, factors need to include the individual, the organization, and society at large. The worker is a critical component of health systems performance, and one that is largely understudied. Consequently, effective programs will depend on all these aspects taking place within a health system.

Linking Primary Health Care and Tertiary Health Care

An effective PHC system is important. However, the treatment of chronic illnesses is complex and will often require specialist support at some point in the life course (Coovadia and Bland, 2008, Tollman et al., 2008). The major constraint with chronic illnesses is the continuity of care with life-long therapy required, often with multiple drugs. The treatment and continuity of care, as outlined above, is clearly best suited for the PHC clinician, but the failure has often been to invest in vertical interventions and not focus on the interrelationship of illnesses (Magnussen et al., 2004). The late referral, and resultant detrimental morbidity, mortality and cost implications are well documented in kidney disease (Roubicek et al., 2000, Levin, 2000). The communication and collaborative efforts of the nephrologist and PHC clinician are highlighted as factors influencing timely referral (Navaneethan et al., 2008), and effective systems of education and

communication need to be enhanced. An effective health care system relies on all components being intact, and PHC systems have to be able to recognise and implement appropriate strategies for managing disease, and if disease is advanced, to refer the patient on to the next tier (see figure 2). District health systems, comprising primary health care and first referral hospitals, are the key to the delivery of basic health services in developing countries (Segall, 2003). Although management of chronic illnesses like HIV and CKD may be complex, the complexity lies in the problems and complications and can be addressed with adequate support from specialist tertiary services and a systematic approach. Monitoring and evaluation, on the other hand, is relatively simple. Primary health clinicians have the ability to provide good quality and continued care for a range of chronic diseases, as demonstrated for patients with type 2 DM (Griffin and Greenhalgh, 1998, Renders et al., 2001) and in the management of HTN (Oakeshott et al., 2003, Ornstein et al., 2004). However, not all patients are treated to the correct standards (Harris and Zwar, 2007b). Nurse-based intervention to assist with management of HTN and DM have been shown to be effective in two different clinical settings: one, a doctor driven HTN specialty and the other a doctor-nurse driven primary care setting (Norby et al., 2003). In this latter study, Norby and colleagues demonstrated that a doctor-nurse partnership model to manage HTN led to improvements in control rates and decreased complications and associated morbidity and mortality. Importantly, better outcomes were more often achieved with an organised, decision support and data base driven computerised systems (Ornstein et al., 2004), with specialist support integrating with primary health care (Gruen et al., 2002). Optimal care often involves some kind of “shared care” arrangement between generalists and specialists, as part of an ongoing relationship among the patient, PHC clinician, and specialist (Starfield et al., 2005) .

In view of the increased prevalence and broad spectrum of cardiovascular disease in developing countries like South Africa (Sliwa et al., 2008), improvements are required for primary-care screening, early detection and treatment of CVD and CKD, including prompt referral of patients at early stages of disease. However, patients should be referred back to primary care when stable, highlighting the need to integrate care. Ensuring these systems are working is important. It is often in the tertiary care sector that the latest evidence-based methods

are researched, and being able to implement these in the PHC system requires good communication between the systems. Although the intellectual capital resides in the academic institutions, the focus of these institutions and their research often does not address the needs of the health system or the disease. Systems research and primary prevention is often seen as mundane and of secondary importance. The defining features of primary care (that is, continuity, coordination, and comprehensiveness) are well suited to care of chronic illness (Rothman and Wagner, 2003). The proposed solutions to managing chronic illnesses should not consist of resting the responsibility primarily in the specialist or PHC clinician, but the effective integration of these components of healthcare. For this to be achieved a positive policy environment, appropriate health care organization, collaboration and effective clear guidelines highlighting when people move up and down a system need to be established and implemented (Wagner, 2004, World Health Organization, 2002a, Couper, 2007, Si et al., 2008, Nutting et al., 2007, Solberg et al., 2006, Vargas et al., 2007, Tsai et al., 2005).

Scaling Up Prevention and Disease Management Models

Chronic illnesses require a functioning public health system. This is not the case in sub-Saharan Africa and South Africa (McCoy et al., 2005, Sanders et al., 2005, Schneider et al., 2006). Although South Africa is distinctly better off than other sub-Saharan countries (Van Damme and Kegels, 2006), with better doctor to patient ratios and very good nursing ratios, the improvement of health systems still remains challenging.

In order to impact on the morbidity and mortality from chronic illnesses in an economically sustainable manner, tobacco control measures, salt reduction strategies, and multi-drug strategies to treat patients with high-risk cardiovascular disease and kidney disease, are all needed (Gaziano et al., 2007, Schoolwerth et al., 2006). These interventions are cost-effective interventions now needed to be scaled up to have an impact on reducing chronic conditions (Gaziano et al., 2007). We also need to determine their feasibility. Ultimately policymakers have to decide on which intervention are most cost effective to scale up to reduce the risk of chronic disease and alleviate the existing burden. Although the need for reorientation of service delivery towards chronic disease care is suggested, insufficient supply of human

resources for health and existing service delivery cultures remain major constraints to scaling up health services (Van Damme and Kegels, 2006, Schneider et al., 2006). Many studies are focusing on HIV/AIDS and ARV therapy sub-Saharan Africa studies but the challenges are similar for other chronic diseases.

The challenges for scaling up efforts and introducing new health interventions in developing countries are well described (Victora et al., 2004, Schneider et al., 2006, Gaziano et al., 2007). Constraints to the successful introduction of new interventions in the health system includes access to services, the affordability of the treatment, stigma of disease, unsatisfactory service delivery infrastructure, weak medication regulatory processes and supply systems, and the lack of good management of the required processes. Health system delivery challenges related to scale up are similar for HIV and chronic diseases and are described in the WHO report on health systems (World Health Organization, 2000a). Treatment has been made more affordable for chronic illnesses and especially HIV ARVs but, as outlined earlier, the constraints to reaching universal coverage go beyond financial issues (Victora et al., 2004, Schneider et al., 2006).

A particular problem has been the lack of investment in people and infrastructure. The inadequate supply of skilled, motivated health care workers is now the primary limitation to scaling up treatment for chronic illnesses (Kober and Van Damme, 2004, Hongoro and McPake, 2003, Liese et al., 2003, Chen et al., 2004). The problem has many dimensions and includes supply, migration of nurses and doctors, maldistribution, a skills mix imbalance, and also poor knowledge (Chen et al., 2004). In South Africa and other sub-Saharan countries, the shortage of health professionals, is recognised as important in HIV and AIDS care, but not in relation to other chronic diseases (Department of Health, 2003). The inadequate supply of health professionals is mostly in underserved areas, and posts are not being filled to support any health care initiative in the public health sector (Padarath et al., 2004). This is both a reason to develop outreach support initiatives and a reason for concern, since they risk failure without adequate staffing of public health clinics. Given the skills shortage in South Africa, the focus should be on investing in training health workers and preventing the 'brain drain' of nurses and doctors internationally and internally within South Africa, with health workers moving away from the

primary care sector to tertiary and private sectors, including NGOs (Padarath et al., 2003). Response options include increasing the numbers of doctors and nurses or adopting delivery models with less reliance on these skills. However, models utilising fewer doctors or nurses seem have attracted limited attention (Van Damme and Kegels, 2006). Health professionals have had to deal with a decline in their incomes over time (Liese et al., 2003), and if poorly paid, are unlikely to be motivated and productive (McPake et al., 1999, Van Lerberghe et al., 2002). Community members, know as health promoters are often employed to assist PHC clinicians, and an aggravating factor includes the fact that volunteers are also poorly paid and lack motivation (Schneider et al., 2006).

Additional problems include the complex service delivery challenges for chronic illness. Chronic diseases often require processes to be simplified, especially if managed in primary care sector. Although treatment is available in the early phases of disease, it is time consuming to continue close monitoring with laboratory investigations. Unfortunately failure to do so early on makes it impossible for the primary care sector to manage the complex later stages of disease e.g. dialysis and transplantation. Simple algorithms or clinical targets can be established, but at some stage, linking with a 'specialist' may be required to manage complications or difficult treatment decisions. Here the integration of the primary care worker and specialist becomes critical.

4 METHODOLOGY

Hypothesis

The establishment of a chronic disease outreach program in Soweto will assist with the early detection and management of chronic kidney disease and cardiovascular disease, including the improved and more efficient follow up of patients once detected. The chronic disease outreach program will improve management of patients with kidney and cardiovascular risk factors, as well as improve referral to a specialist centre of those patients detected to have advanced disease, and have an impact on the knowledge and motivation of primary care clinicians, predominantly the primary health care nurses, in the primary care clinics involved on the program.

Study Aims and Objectives

The study aim was to establish a chronic disease outreach program (CDOP) and evaluate its operation in an existing urban and peri-urban regional primary and specialist health care setting. The program was developed to assist the PHC clinicians (PHCNs and doctors) in the primary care clinics with the management of high risk patients, those with uncontrolled hypertension (HTN) and diabetes (DM) and HTN who were at risk for, or already had kidney and cardiovascular disease.

Specifically, the objectives were to determine if CDOP was effective in:

1. Detecting, managing and following a cohort of high risk patients in a primary and tertiary setting for two years.
2. Retarding the development of kidney and cardiovascular disease in high risk subjects by intervening if they have uncontrolled hypertension, diabetes and proteinuria or other cardiovascular risk factors e.g. obesity, hypercholesterolemia.
3. Retarding the progression of kidney and cardiovascular disease in subjects already afflicted, with the aim of fewer needing dialysis or dying with kidney failure.

4. Improving the knowledge and motivation of the clinicians working with chronic illnesses.
5. Demonstrating a chronic disease management model which aids in improved risk factor control, treatment adherence and improved outcomes.

Methodological Approach

An intervention to improve care can be measured both quantitatively e.g. determining if target blood pressures are achieved, or qualitatively e.g. determining why patients miss visits or why patients do not return for follow up visits. A study such as this would be referred to as an outcome and process evaluation study. Examples of chronic disease and CKD programs, described in chapter 2, indicate the complexity of the requirements needed in order to achieve successful patient care. Evaluating a program includes evaluating the biological, social, clinical and behavioural factors which influence its outcomes. An understanding of the health system or program being evaluated is important. It is important to break down the components of the health system. This would include the structure (resources, users and organizations), processes (actions, services provided and utilised), and outcome (changes in health, behaviour, knowledge). The health system designed for managing chronic illnesses in Soweto could be described as in Figure 17.

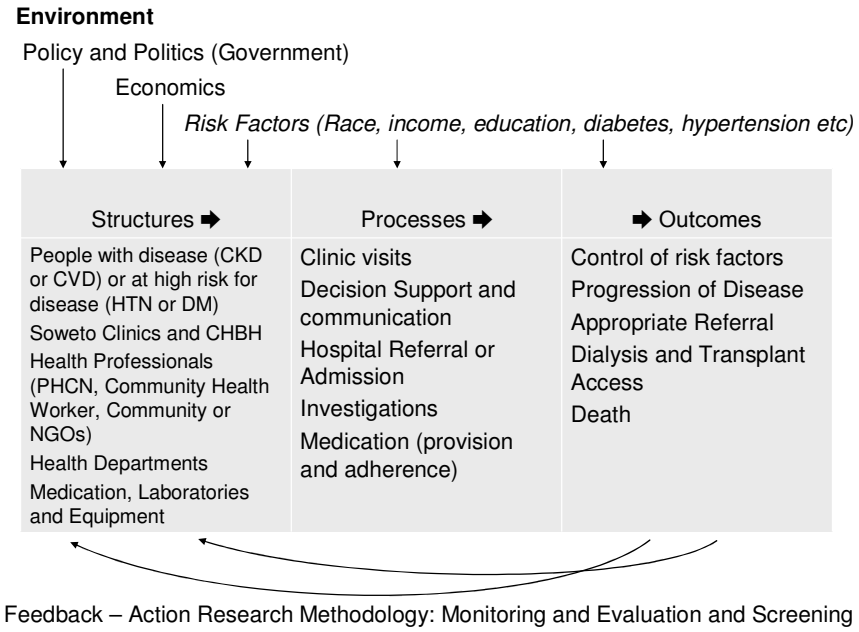


Figure 17. The Health System and Chronic Disease Care in Soweto
(Adapted from Bachmann (2007) CKD – chronic kidney disease, CVD – cardiovascular disease, HTN – hypertension, DM – diabetes, CHBH – Chris Hani Baragwanath Hospital, PHCN – primary health care nurse, NGOs – non-governmental organizations

Service quality needs to be part of the evaluation of a health system. Four key components are described and all these require different methods of evaluation (Bachmann, 2007). The quality of a program or service includes its ability to achieve what it set out to do, and its effectiveness is best evaluated using a randomised control study. However, if this is not possible then other designs could be considered. Efficiency and equity can also be measured as part of the quality.

Epidemiological Approach

No strategy for change is effective under all circumstances, but multi-faceted strategies are more expensive than simply evaluating a single intervention and outcome (Wensing and Van der Weijdent, 1998). Public health interventions are complex programs and this complexity includes the need to change behaviour in chronic diseases e.g. lifestyle modification (Kelley, 1996, McLeroy et al., 1988, Winett et al., 1989). Public health often involves the poorest and marginalised in societies, and evidence is often gathered from easily accessible subjects, which

may exclude these types of peoples. The result is that very little research based evidence exists on disadvantaged groups (Rychetnik et al., 2002, Hawe and Sheill, 1995).

Randomised controlled trails (RCT) provide the most valid approximation of effectiveness and provide strong evidence of causation. Their value is in the minimisation of selection bias and confounding variables. A RCT can be used to evaluate the effectiveness of an intervention, but despite this methodology there is still no good evidence about many types of care (Bachmann, 2007). The RCT has been used to gather information about drug effectiveness rather than about programs. Although simple to allocate people to different drugs or groups, its implementation in the 'real world' situation is far more challenging. Many evaluation mechanisms, such as randomised controlled studies, may be unable to fully evaluate complex public health interventions. Validity in quantitative approaches to research relies on rigorous adherence to methodological rules and standards, which is not possible in real life interventions. This makes it is difficult to apply these same rules to qualitative research (Angen, 2000). In instances where poor methods are used, it may be difficult to determine whether it is because the tools of evaluation failed or because the program itself failed. In many cases the evaluation of a program using clear simple quantitative methods are not sufficient. In cases where a RCT is not logistically or ethically possible, then well designed observational studies can still provide useful information.

Observational studies involving a cohort can also provide information about the effectiveness of health care. These studies can estimate the needs for health care quantify inequity and measure indicators of health quality. A cohort study can identify people and health services characteristics associated with worse outcome, determine predicative factors in health outcomes, distribution or usage (Bachmann, 2007).Qualitative evaluation may provide the link to explain why a clinical health delivery model was successful or not.

Integration of Quantitative and Qualitative Information

For evidence to be transferred elsewhere it is important not only to measure outcomes but also to provide a description of the process of the intervention, as part of this qualitative measurement. This means one has to evaluate the context of the program i.e. existing

circumstances and processes and not only clinical targets e.g. blood pressure levels. In addition, disentangling the various factors associated with outcomes is best identified utilising a range of methods, both quantitative and qualitative. This includes triangulating information from various methodologies.

The chronic disease outreach program's analysis draws on multi-method approaches involving triangulation between methodologies, data sources, time frames and levels of human interaction. The focus for this study is predominantly on the PHCNs as the 'prepared proactive team' members, the key health workers in the existing health care structure to detect early and advanced kidney and cardiovascular disease. The value of utilising multi-method evaluation here was to combine the best of quantitative and qualitative data to evaluate the program. The qualitative component of this study looked at and evaluated the processes involved in a public health intervention of this nature. The clinical component focused on the clinical outcomes over time and additional qualitative data focused on the processes and people trying to achieve these 'improved functional and clinical outcomes'.

The qualitative evaluation thus necessitated both a framework analysis approach and a grounded theory approach to evaluate all aspects of the program. It looked at how effective the intervention was and the processes of professional behaviour change. It tried to identify the barriers to changing behaviour, and what personal skills and attributes were needed by the primary health clinicians and other health care workers, to effect change

Description of intervention and evaluation

This study on which this thesis is drawn was conducted from February 2003 to February 2006. Patients were enrolled at 20 clinics and health centres (11 in Soweto and 9 other regional clinics) in the South West Gauteng region, and were followed for 2 years (Figure 18).

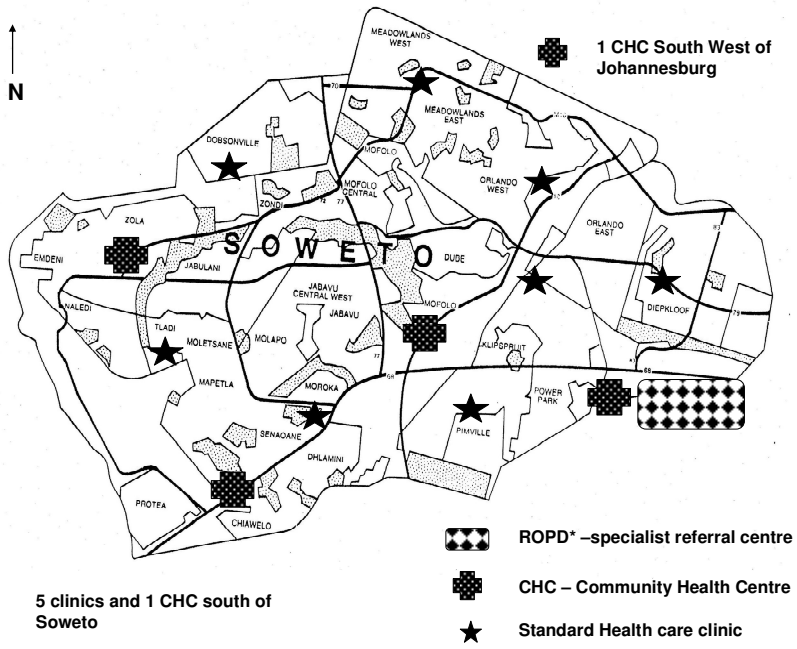


Figure 18. Chronic Disease Program Clinic Sites
Note: Eight CDOP sites were outside of the Soweto area and comprised, 2 CHC and 6 clinics; *ROPD - renal outpatient department/clinic, CDOP – chronic disease outreach program, CHBH – Chris Hani Baragwanath Hospital

All clinics were from the same health region, controlled by the province, and had registered PHCN as staff. All patients at risk of kidney disease were referred to a single specialist nephrology clinic at Chris Hani Baragwanath Hospital. All clinics were incorporated into a program modelled on the Chronic Illness Care Model (CICM) (see figure 4), which utilised PHCNs to link primary care and specialist care (Wagner et al., 2001). The evaluation of the program and health system environment was further assessed using the WHO ICCC Framework (see figure 5). The WHO models' advantage was its improved acknowledgement of the policy environment and health care organization to support chronic care (World Health Organization, 2002a). The PHCNs were provided with decision support, escalated scaling up of medication, and prompt access to specialist care. Program nurse coordinators provided this link and they were in constant contact and available to the health care team at the clinics, for clinical 'decision support' and to assist with communication to management if the need arose e.g. medication shortages. These interactions took place through telephonic communication and regular visits when collecting patients' data forms, i.e. 'Annual visit' and 'Follow Up' forms, or when providing

'feedback reports' about a patient's clinical progress and management, and during education visits or at the regular focus group meetings with PHCNs (Figure 19).

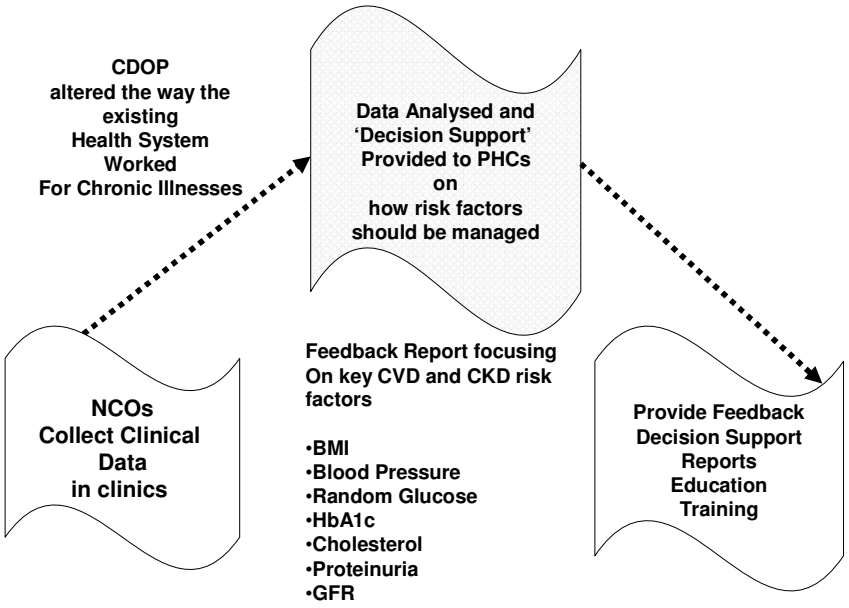


Figure 19. Feedback Report Process

Two program nurse coordinators collected patient visit forms, (generated by the PHCNs), and together with a nephrologist, they evaluated and analysed the information and provided feedback and decision support to the PHCN (see also figure 20 and figure 21).

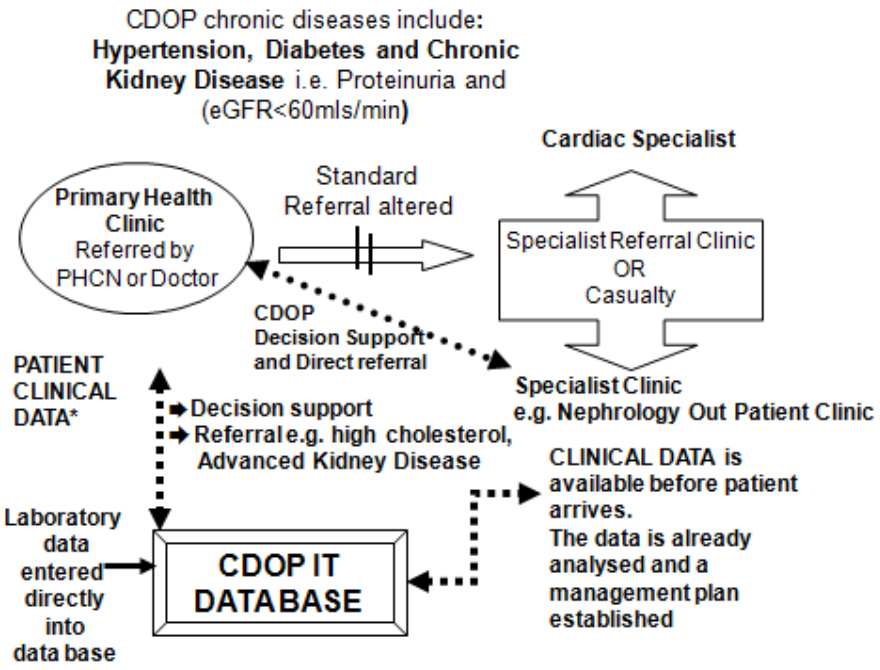


Figure 20. CDOP Health System Processes

Note: Typical referral pattern - solid open white arrow, CDOP referral pattern – dotted line, CDOP – chronic disease outreach program, eGFR – estimated glomerular filtration rate; IT- information technology

** Patient clinical data is analysed by Program Nurse Coordinators and Program doctor*

Clinical data evaluation included assessment of modifiable CVD and CKD risk factors, body mass index (BMI) and waist circumference, systolic blood pressure (SBP), diastolic blood pressure (DBP), random serum glucose, HbA1c, serum cholesterol, proteinuria and an estimated glomerular filtration rate (eGFR), using the Cockcroft-Gault (CG) (Cockcroft and Gault, 1976b) and the abbreviated Modification of Diet in Renal Disease (MDRD) formulas (Levey et al., 2000).

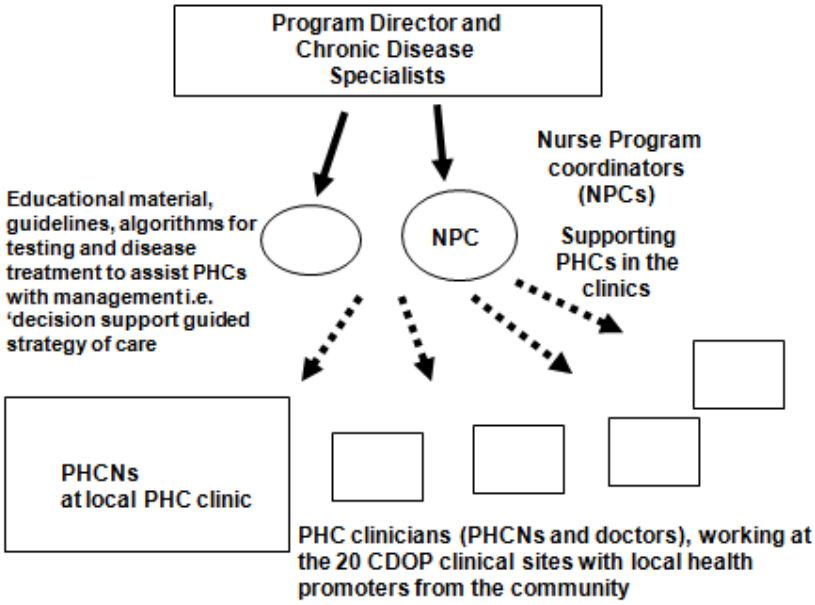


Figure 21 Chronic Disease Outreach Program Structure
NPC – nurse program coordinator, PHC – primary health care
Note: CDOP was implemented in a vertical manner with the aim of integrating screening methodology into chronic disease care practice

PHCNs in the clinic were encouraged to sequentially, enrol adult males and females, ≥18 and ≤80yrs old, who met the criteria for high risk or established CKD or CVD; women who were pregnant were excluded, as were patients not willing to participate (Appendix 1; Patient Consent). Participants included patients with uncontrolled DM with HTN (≥140/90mmHg) and/or proteinuria or uncontrolled DM (random glucose ≥8mmol/L), or with HTN and/or proteinuria. Proteinuria was measured by albumin creatinine ratio (ACR) on a spot urine sample, and was defined as microalbuminuria (ACR 2.2 - 33.9mg/mmol) or macroalbuminuria (ACR ≥ 34mg/mol), or nephrotic if ≥200mg/mmol.

PHCNs were encouraged to start early treatment with insulin if DM was uncontrolled and angiotensin converting enzyme inhibitors (ACEi) for HTN or proteinuria, but no specific treatment regimen was enforced. If uncontrolled, then PHCNs were instructed to add other classes of DM or HTN medication and increase them to the maximum acceptable levels. Care was free in the primary care clinics and ranged from zero to $8 at the specialist centre, depending on a patient's employment status or age. Only 'essential drug list' medication for HTN and DM (an ACEi,

calcium channel blocker, thiazide diuretic, beta blocker and aldomet, insulin and oral hypoglycaemic agents) were available in the clinics. CDOP authorized the initiation or scaling up of medication, where no doctor existed, and ensured medicines were up-scaled faster than was normal practice. Most clinical targets were determined by national and international society guidelines. For cholesterol management, simvastatin an HMGCoA reductase inhibitor, was the only lipid lowering medication available at the specialist clinic.

Due to resource constraints, referral occurred only if cholesterol was >7mmol/L, despite existing guidelines advising referral at $\geq$6.5mmol/L. All medications were available at the specialist centre to manage HTN and DM, including angiotensin receptor blocking agents. Indications for specialist referral included uncontrolled HTN or DM despite at least one year on program and on maximal therapy available at primary care centre, uncontrolled HTN or DM with other serious CVD risk factors, uncontrolled DM requiring insulin, with no doctor or PHCN available or able to initiate treatment, established kidney disease – eGFR <60mls/min, nephrotic range proteinuria ACR$\geq$200mg/mol, cardiac disease (heart failure or chest pain requiring an evaluation), a new stroke, or if the person required anti-lipid medication not available at the clinic. The existing health system referral process enabled patients to be referred directly to the nephrologist specialist clinic, not through the casualty/emergency room as is normal practice (Figure 20). The existing chronic disease management and referral system was altered by CDOP, attempting to ensure improved health care organization.

Components evaluated by CDOP at follow up clinic visits, feedback meetings, and from the clinical data and an exit questionnaire, included: (i) functional and clinical outcomes (ii) Health systems and (iii) PHCN knowledge and continuing education. Diary recordings were collected by the same three CDOP team members, and underwent thematic analysis using Atlas.ti software. All PHCNs working at the clinics were encouraged to participate in the exit questionnaire. This questionnaire, besides evaluating motivation, evaluated the continued medical education support for clinicians, the existing working conditions of health workers, the program itself and the environment in which clinicians worked i.e. equipment and medication. The Franco existing conceptual model was used to assess health worker motivation (Franco et al., 2002, Franco et al., 2004, Penn-Kekana et al., 2005). CDOP evaluation was triangulated

with the analysis of clinical and functional outcomes, diary recordings, and the questionnaire. All participants, patients and PHCNs signed informed consent before enrolment or completing the questionnaire, and the study was passed by the University of the Witwatersrand Ethics Committee (protocol number 03-10-17).

Nurse program coordinators were in constant contact and available to the health care team at the clinics, for clinical 'decision support' and to assist with communication to management if the need arose e.g. medication shortages. These interactions took place through telephonic communication and regular visits when collecting patients' data forms, i.e. 'Annual visit' and 'Follow Up' forms, or when providing 'feedback reports' about a patient's clinical progress and management, and during education visits or the weekly focus group meetings with PHCNs.

The program maintained an 'action based' component, although this could not be considered to be participatory action research (PAR), and nurses and doctors were asked to critique and make suggestions about the program. The program was based on the actual experiences of all participants, and the information collected was based on strict scientific method. So in fact the program included some aspects evaluating its 'efficacy' under experimental circumstances where patients were randomly enrolled into a 'controlled' study but also included determining its 'effectiveness' under conditions of a functioning health service. Information about program methodology and evolution change was documented. In practical terms this meant that the clinical enrolment and outcomes evaluation was initially to have a more traditional randomised component to its design. However, in keeping with early feedback received from nurses, the model was slightly altered, and patients were sequentially enrolled who met the inclusion criteria. This change reflects the more flexible design adopted, which met the PHCNs' needs. All changes were documented in the diary recordings, and both program changes and methodology changes were tracked over time and were recorded in the program and methodological time lines (see figures 37 and 38 in results).

The scaling up of the program was not a key focus or aim of the program. However, the experiences of implementing the program, and the information gathered from the diary recordings and questionnaire provided some insight into the potential challenges for future

scaling up of chronic disease programs in Soweto. This issue was therefore addressed in the literature review and discussion.

The key practical components of organising CDOP can be described as follows:

- PHCNs were trained by nurse program coordinators, using standard protocols, on how to enrol patients onto the program
- PHCNs on their own, or with the assistance of a nurse program coordinators, enrolled patients onto the program
- Nurse program coordinators and I were available for queries every day, providing a link between tertiary and primary facilities
- Weekly visits were undertaken by nurse program coordinators to different clinics, which included the delivery of patient the 'feedback reports' that outlined the 'decision support' for patient treatment
- A usual once weekly visit by the nurse program coordinators and myself was arranged and this included a 'focus group' meeting with nurses to discuss program and their patients
- Regular tracking took place of the patients lost to follow up on the program
- Teaching on a requested topic e.g. HTN Management, was conducted at weekly visits by the nurse program coordinators and myself
- Individual patient 'feedback reports' for PHCNs, were delivered by nurse program coordinators which assisted them with clinical management i.e. decision support
- 3-4 monthly 'feedback meetings' with all PHCNs took place at the tertiary hospital (nephrology unit) to provide a report on programs progress and challenges
- 3-4 monthly 'feedback meetings' were arranged with the Johannesburg Metropolitan Health Department (JMHD) managers who were responsible for health care delivery in the region
- Intermittent visits to some of the clinics were also arranged with the Assistant Director from JMHD responsible for chronic disease management in the Soweto region

- A review of individual patient data was undertaken during the focus group discussions at the clinics and PHCNs were advised on future treatment and educated about the protocols of management.

Enrolment Processes

Study participants were shown a 'Health Information and Education Booklet' by the PHCN or the HW, who explained the study, information about HTN, DM and its CVD and CKD complications, and investigations that would be carried out in someone with DM, HPTN or CVD and CKD (Appendix 2 - Health Education Booklet). The booklet was designed by the CDOP team, members of JMHD chronic disease directorate and patients. Every clinic was supplied with 2 booklets, and the CDOP PHCN or a health worker trained to provide education assisted nurses, and they were asked to spend at least 10-15 minutes going through the booklet with the patient. At follow up visits PHCNs and nurse program coordinators were to check that someone had gone through the booklet with them, and also when patients were referred to the specialist clinic at CHBH. Adherence problems were to be documented in the diary recordings.

The follow up process included PHCNs filling in the patient's clinical data on the 'Initial/Yearly Visits' form at enrolment and then yearly (Appendix 3) and then a 'Follow up visit' form 6 months after enrolment (Appendix 4). The 'Initial and Yearly visits' forms were filled in at enrolment in the program and then yearly thereafter. The 'Follow up visit' forms were completed every 4-6 months. A minimum of 2 visits per year were captured, and PHCNs were allowed a 2 months leeway either side of the 6 month follow up period. All forms were analysed by program coordinators, myself or by another specialist in the department. The process was outlined in figure 20-22, and the results of this analysis were delivered back to each clinic in the form of a 'Feedback Report' or a 'decision support process (Appendix 5). A feedback report comprised of a summary of the patients' demographic information and clinical information, including that which required attention by the PHCNs. These forms were intended to provide 'decision support' for PHCNs at the clinics. It helped them to decide on medication which should be used, if clinical targets were not achieved, or to advise PHCNs to refer a patient to the renal outpatient department (ROPD) for specialist attention, if a patient had advanced disease. These reports

were typed by the two nurse program coordinators. PHCNs and health workers were supplied a support manual to guide and remind them about the process and investigations (Appendix 6). This included basic information on normal tests, investigations required, and basic information about DM and HTN management. The 'Support Manual' together with the nurse program coordinators visits, focus group and 'feedback'/CME meetings, all served to reinforce CDOP protocols.

The weekly visits to a PHC clinic, included 'focus group' discussions, with the 2 nurse program coordinators, me and all nurses, doctors and health promoters. These discussions were summarised in dairies and were semi-structured, taking on a similar format each week. Discussions included feedback on program progress, a review of the program and its challenges, and clinical cases. The patients enrolled were reviewed, focusing on clinical issues around management. An educational topic related to DM, HTN, CVD or CKD was usually included at the end of the meeting. The average duration of these meetings was 1.5 to 2 hours. Discussions informed the protocol changes.

Feedback meetings, every 4-6 months, were held separately for PHCNs and for managers at JMHD. All PHCNs at the clinics participating in CDOP were invited to the renal unit at CHBH, where the meetings were held. Here, nurses were presented with patients' clinical data and its analysis. Time was set aside for discussion of the results and to discuss action that should be taken to deal with challenges which had arisen from the data and its analysis. Time was also allocated to a CME topic. These topics were canvassed during the focus group meetings or from detecting shortfalls in patient care during analysis and follow up visits. The 'feedback' meetings with JMBH management had a similar structure, but did not include a CME topic. These meetings lasted 2-3 hours. There was single meeting held with the executive management committee, comprising of all department directors at the end of phase II. All meetings were recorded by me and the nurse program coordinators.

Patient Follow up

All patients' data were captured at baseline ('Initial/Yearly Visits' form), and every 6 months thereafter ('Follow up visits' form). The nurse program coordinators collected the data forms from the clinic and the forms were brought back for entry onto the computer.

The data were analysed and from this analysis, a list of comments and management proposals were generated. Analysis took the form of determining whether clinical information was normal or abnormal, and especially to determine if risk factor targets were being achieved or were too high and required referral e.g. blood pressure was ≤120/70 if hypertensive; proteinuria ≥0.2g/mmol or ≥200g/mol. It also included evaluating the number of patients enrolled and the enrolment speed. A report comprising of both clinical targets and the 'decision support' for each patient was delivered to the clinic in the form of a Feedback Report, described earlier. This report included management advice about the patients' chronic illnesses (see Appendix 5). The entire process of CDOP enrolment, data capture and follow up process is summarised in figure 22.

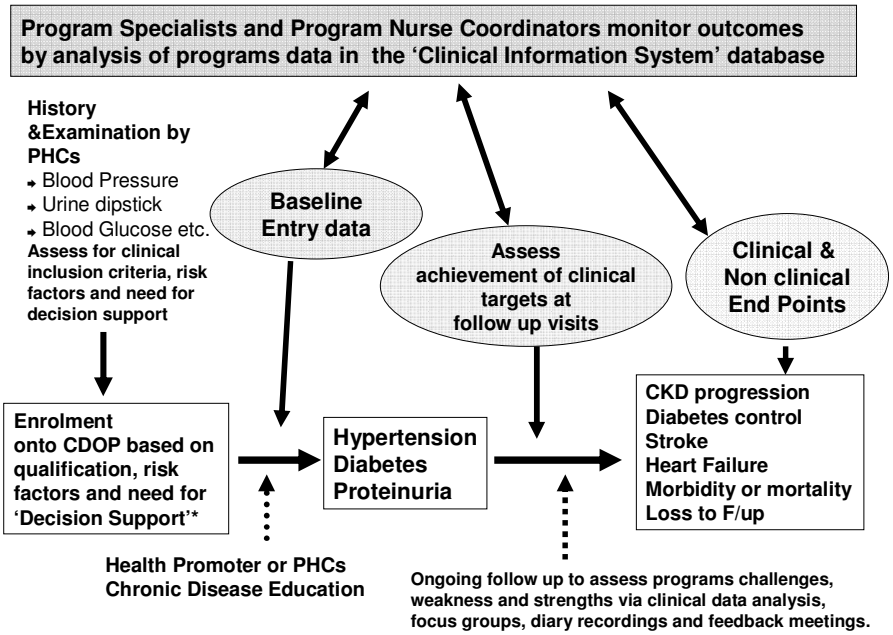


Figure 22. Enrolment and Follow up Processes
* Enrolment criteria of 'decision support' became criteria 4months after program initiation

Qualitative Data Collection

At the same time as the quantitative evaluation process (clinical outcomes, e.g. blood pressure targets and functional outcomes e.g. follow up and referral of patients), a qualitative component also took place. This took the form of informal 'focus group interviews' during clinic follow up visits, by the CDOP team, as described above. Diary recordings documenting the focus group discussions follow up visits and meetings were also reviewed, and these informed

changes to the program and determined the continuing medical education topics. All people involved in the organization of the health services i.e. PHCNs, doctors, and administrators, were invited to participate in these focus group meetings.

A decision was taken at the outset that patients would not be routinely interviewed nor would they participate in organised regular focus groups. This decision was made, due to time constraints and that CDOP only had 2 full time nurse program coordinators and one part time program director. Although patients were not interviewed, information regarding their challenges with the CDOP was documented during follow up visits, the PHCN/doctor focus groups and feedback meetings, and was recorded in my and the nurse program coordinators diaries. Interviews were unstructured, and attempted to ascertain challenges encountered by clinicians and nurse program coordinators. Interviews also covered aspects such as existing levels of knowledge and available ongoing CME (continuing medical education). A questionnaire (discussed earlier) was also used to assess these components of program delivery and patient challenges were noted in an open section of the questionnaire.

Clinical Data Measurement Validity and Reliability

Clinical data were evaluated at the time of downloading into the data base. The clinical data and questionnaire data were recorded by a single data manager throughout the study. For the clinical data, a series of queries were generated when necessary, i.e. missing data and illegible data. The data queries were followed up by nurse program coordinators when visiting clinics. Nurse program coordinators also evaluated data at the time of assessing patients' risk factors and achievement of targets and when writing up a 'feedback report' for the clinic. Individual diaries were kept by the two program nurse program coordinators and the program doctor, and then they transcribed their own diary recordings into word documents for analysis.

Treatment and Management Options

The medication made available and prescribed for patients with HTN and DM at CDOP clinics, was from a National Department of Health Essential Drug List (EDL). The medication

available at the clinic differed from that available at the specialist clinic. Medication at the specialist clinic was from the Secondary and Tertiary Hospital National Department of Health Essential Drug Lists. The use of prescribed medications was based on the normal clinical practice protocols available at clinics and hospitals. Standard EDL guidelines and Soweto Primary Health School Primary Health Care Manual were used for patients being managed at the clinics (National Department of Health, 1998a, Pein et al., 1999). These guidelines were used in conjunction with the national EDL guidelines, and the schools guidelines do not have any specialist input The Soweto Primary Health School was responsible for training most PHCNs who participated in the program (see results section), with one year training open to all professional nurses wishing to specialise as PHCNs. The PHCNs have a tremendous respect for the school and its teachers, and tend to use the schools guidelines more than EDL. These guidelines were developed recognising the limitation and challenges faced by PHCNs in the clinics, and the school continued to provide ongoing education and support by afternoon weekly continuing medical education sessions at the school. The school is based at a clinic next to CHBH. PHCNs are expected to travel, using government supplied transport and their own if transport is not available, to these meetings.

Patients enrolled on CDOP were given the same medications, but the speed of up-titration differed from the protocols used by PHCNs at the clinics, and the range of medications available at the hospital was much larger. At the specialist clinic, the adult hospital level EDL and some quaternary medications were available (National Department of Health, 1998b). This included a broader variety of DM and HTN medication and medication for the management of associated risk factors, e.g. angiotensin receptor blockers (telmisartan) and cholesterol lowering agents (simvastatin).

Although CDOP used the same medication, it used established national and international HTN, DM and renal society guidelines (Society for Endocrinology, 2003, Southern African Hypertension Society, 2003, South African Renal Society, 2004). It also used its 'decision support' system like 'feedback reports' and 'telephone support' to achieve treatment targets. Up-titration of medication was quicker than existing up-titration of medication in the clinics, which followed EDL protocols. CDOP patients' risk factors were aggressively tackled and all patients

enrolling onto program required baseline blood and urine investigations, resulting in a more aggressive approach to managing their chronic disease and associated risk factors. Risk factor targets were simplified for CDOP clinicians to assist with earlier up-titration to achieve these targets. The clinic or hospital pharmacies were responsible for the dispensing and the accountability of the medication.

Lifestyle Measures

The lifestyle measures prescribed were derived from two sources, the CDOP Education Booklet and Support Manual (see Appendices 2 and 6), which was given to each clinic, and the 'Prevention and Management of Overweight and Obesity in South Africa' guideline, developed by the National Department of Health (Department of Health, 2001). Lectures summarising the guidelines were given to PHCNs at a feedback meeting and their clinics. Lifestyle measures centred on the PHCNs measuring a person's body mass index (BMI) and waist circumference, and then advising them on appropriate lifestyle measures. People were encouraged to limit total sugar intake, salt intake, alcohol intake, reduce portion sizes and reduce intake of high sugar and fatty foods such as fried and processed foods, soft drinks and sweets. People were encouraged to eat low fat and sugar alternatives like whole wheat bread, fruit and vegetables and low sugar diet soft drinks. Physical activity and exercise were also encouraged. This was seen as part of achieving their appropriate BMI and waist circumference, by promoting loss of fat tissue and limiting the amount of muscle tissue lost during dieting. It was advised as part of the overall management of HTN and DM.

Any amount of exercise was considered beneficial, but where possible people were encouraged to do at least 30minutes, moderate intensity exercise daily. This should have been done on most days of the week but could be 10-15min at a time, accumulated to a maximum of 2.5 hrs per week. Exercise prescribed ranged from home maintenance, gardening, and house work to brisk walking and running. PHCNs and HW were encouraged to use the CDOP education booklet and government obesity guidelines which included tools for evaluation and advice regarding readiness for physical activity and weight reduction.

‘Routine’ investigations

Blood tests (full blood count and platelets, urea and electrolytes, random serum cholesterol, Haemoglobin A1c, random serum glucose) were done yearly, at the baseline and at yearly follow up visits. The urine testing for ACR (albumin creatinine ratio) or PCR (protein creatinine ratio) was taken at the in-between, six monthly ‘Follow Up’ visit. Blood and urine tests were done as indicated, unless otherwise requested by a specialist or the nurse program coordinators at a specialist’s request. All blood tests and urine investigations were routine for patients with HTN and DM, according to the essential drug list (EDL) or National Society guidelines. Blood pressure measurements, a urine dipstick and finger prick haemoglucotest (HGT), were considered part of the standard clinical examination.

‘Special’ investigations

Any patient referred for investigations to the renal outpatient department (ROPD) at Chris Hani Baragwanath Hospital may have had additional investigations at the discretion of the managing physician, and this may have included kidney ultrasound, urine microscopy, echocardiography and even kidney biopsy. These investigations were not included in the analysis at the end of the study.

Outcome Measures and CDOP Simplified Clinical Targets

The study’s outcome measures and clinical targets were again determined by national and international society guidelines. They were based on existing resources and the ability of the PHCN to monitor them.

The primary measures to be evaluated were

1. Weight reduction (measured by BMI and waist circumference measurements)
2. Blood pressure (Systolic Blood Pressure and Diastolic Blood Pressure)
3. Glucose and HbA1c (if diabetic)
4. Random Serum Cholesterol measurement

5. Proteinuria
6. GFR changes (Cockcroft-Gault and MDRD methods)

The secondary measures included

1. Referral and reasons for referral
2. Death
3. Chronic Kidney Disease stage
4. Heart failure
5. Stroke
6. Other information e.g. haemoglobin

The CDOP simplified targets were as follows (Figure 23)

1. Blood pressure ≤120/70 mmHg
2. Blood glucose ≤8mmol/L and HbA1c < 8%
3. Proteinuria < 1g/24hours (ACR PCR<0.1g/mmol) or a decline from the baseline reading.
4. Reduction in weight and cholesterol through Lifestyle Measures

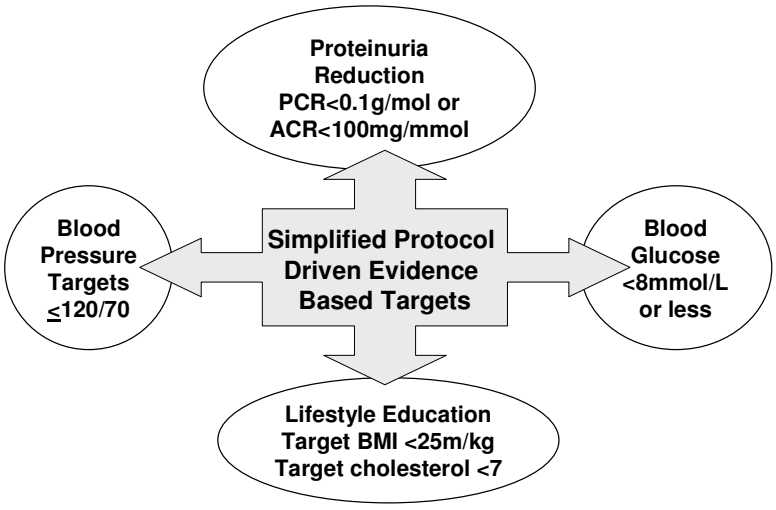


Figure 23 CDOP Simplified Treatment Target

CDOP and Health System Evaluation – Process Review

As already explained, a population intervention strategy was implemented by enrolling high risk participants with diabetes and hypertension onto an observational cohort study and to follow them for 2 years. The program included primary, secondary and tertiary prevention strategies and it was implemented in a vertical manner, with the intention that screening methods for CKD and CVD would be incorporated into clinic policy. The evaluation of CDOP comprised of quantitative and qualitative components and was based on the ability to implement a program designed around the Wagner CICM to manage chronic disease in Soweto. Achieving control of CVD and CKD risk factors and the diseases associated with these risk factors formed the cornerstone of the quantitative evaluation. It included progression of disease, appropriate referral, and the patients needing dialysis. Morbidity and mortality information about CVD and CKD was included in the clinical outcomes. The functional outcomes included the challenges of implementation and scaling up the program. The health care team comprised predominantly of the PHCNs who focused on whether the program was implemented as planned and what had changed with the 'delivery design system' in the clinic and Outreach Program as a result of CDOP. Again, focusing using the CICM the model, I evaluated whether the clinic PHCN teams were 'prepared and proactive'. This included PHCNs ability to supply healthcare and to determine their knowledge and understanding of the use of current guidelines and protocols for DM and HTN. The information gathered was used to assess how such chronic disease programs should be implemented, and what had been its successes and failures. Here the randomisation, observational cohort study and research methodologies were assessed as mechanisms to implement and scale up chronic disease programs. The qualitative components were gathered from the diary recordings and the questionnaire. Cross referencing of quantitative with the qualitative methodology allowed the investigators to focus on the processes and evaluate whether the outcomes were achieved or failed. The clinical data, diary recordings and questionnaire (including health worker motivation and knowledge) was evaluated through a process of triangulation (Lacey and Luff, 2001) . Findings gathered from both quantitative and qualitative components, were 'triangulated' to ensure a complete evaluation of the program

(Figure 24). The triangulation process was seen as critical to evaluate the complex nature of a public health program like CDOP.

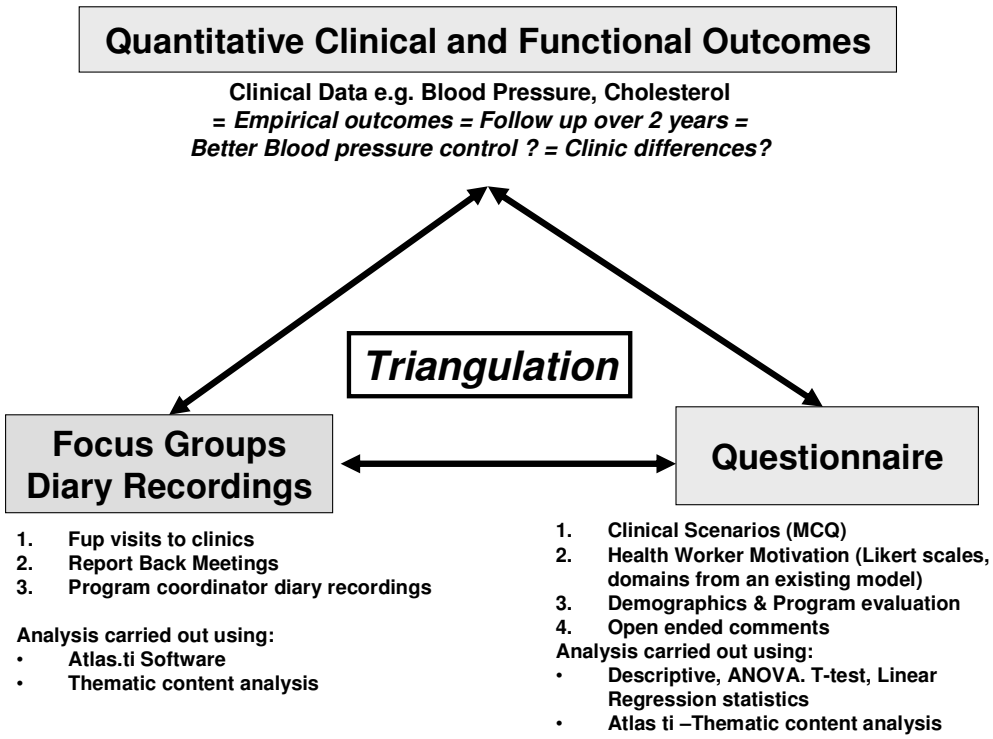


Figure 24. Triangulation of Data
Note: CDOP involved the integration of quantitative and qualitative data. The focus groups, diary recordings and questionnaire was used to evaluate health systems, CDOP integration and health worker knowledge and motivation

Methods for gathering qualitative data

Information was gathered in CDOP diaries by the nurse program coordinators and the program director/doctor. Thematic analysis was carried out from the diary recording sources of the nurse program coordinators and program doctor (author). Analysis was also taken from an open ended section in the questionnaire which was used to evaluate clinicians' knowledge and motivation.

The diaries recorded all information gathered during the general meetings and focus group meetings with clinic PHCNs, which also sometimes included the clinic doctors, administrators and on one occasion clinic patients.

The data collected in these semi-structured focus group meetings provided additional and different insights into the program. Where additional information was gleaned to be important,

this resulted in the investigation of additional information found to be relevant to the study e.g. PHCN turnover in each clinic and total number of patients seen monthly at each clinic (see results section). This additional information included the creation of a program timeline, methodology timelines, patient follow up and enrolment statistics at each clinic.

At the end of the study, an exit questionnaire was to be given to all the PHCNs and nurses working in the clinics i.e. n=162. For this questionnaire, a consent form was filled in by the participants (Appendix 7 – Nurses Consent Form).

The questionnaire (Appendix 8a) comprised four components (i) Demographic information (ii) Questions to evaluate PCCs knowledge and (iii) Questions to evaluate PCCs motivation (iv) Questions to evaluate CDOP and (v) An open ended question which was included in the thematic analysis.

Diary Recording Thematic Content Analysis

Five key diary recording sources were used. They included the CDOP clinician questionnaire which included an 'Open ended comment section'; the Report Back' meeting notes taking during the meetings with PCCs and Johannesburg Metropolitan Health Department (JMHD) management; a 1st nurse program coordinator's (NPC) diary recordings and clinic reviews; a 2nd nurse program coordinator's diary recordings and clinic reviews and the program director/doctor diary recordings. The notes in diaries were summarised at the time of the focus groups and were then transcribed into 'Word' document format to allow analysis (Appendix 9). The diaries were collected in the 'raw' format when the nurse program coordinators and or the program doctor/director visited the clinics. The reasons for visiting included CDOP training, collection of Baseline-Annual and Follow up clinical forms, when delivering 'feedback reports', during PHCN follow up training on protocols and when visiting the clinics for 'formal' focus group meetings. Notes were also taken during management planning meetings and program review meetings and the 'report back meetings' with the PHCNs and the JMHD management team.

Information relevant to the program was generally recorded into the diaries and it became clear that a 'recurring' theme of information emerged. The NCOs and PD had an

'implicit' sense of the recurring material and what parts were relevant and should remain in the Word document transcripts.

The analysis undertaken was 'thematic analysis' only and no 'discourse analysis' occurred. Recordings were coded according to 'what' was said and not 'how' it was said. The aim of this analysis was to present the PHCNs views and challenges during their running of a chronic illness care service. However, the primary focus was their views and challenges of working with the CDOP. The diaries were then all included in a process of vertical analysis, using Atlas.ti software. Thereafter horizontal analysis took place across all the diaries and text. The common features were analysed using Atlas.ti version 5.2.0 software package and codes were developed from the pieces of text. At the time of creating codes, memos were also created from the text using the Atlas.ti software.

Diary Recording Sources

1. Primary health care clinicians questionnaire – Open ended comment section
2. 'Report Back' meeting notes to PCCs and Johannesburg Metro Health Management
3. 1st Program Nurse Coordinators Diary Recordings and Clinic Reviews
4. 2nd Program Nurse Coordinators Diary Recordings and Clinic Reviews
5. Program Doctor/Director's Diary Recordings

Health Worker Knowledge and Motivation Assessment

A questionnaire was developed to evaluate the impact of the program on both knowledge and motivation. The basis of this evaluation was based on the fact that policy implementation and protocols for chronic illness management required an 'informed, prepared, and motivated' health care team (Wagner, 2004, World Health Organization, 2002a). In the case of the program and chronic illnesses in general this rested on the shoulders of the primary health care clinicians (PHCNs and doctors) in the clinics. A conceptual model previously used by the Centre for Health Policy of the University of the Witwatersrand and adapted from this work and that of Franco et al was used to develop questions for sections 3 (Franco et al., 2004, Penn-Kekana et al., 2005) (Figure 25 and Appendix 10a) .

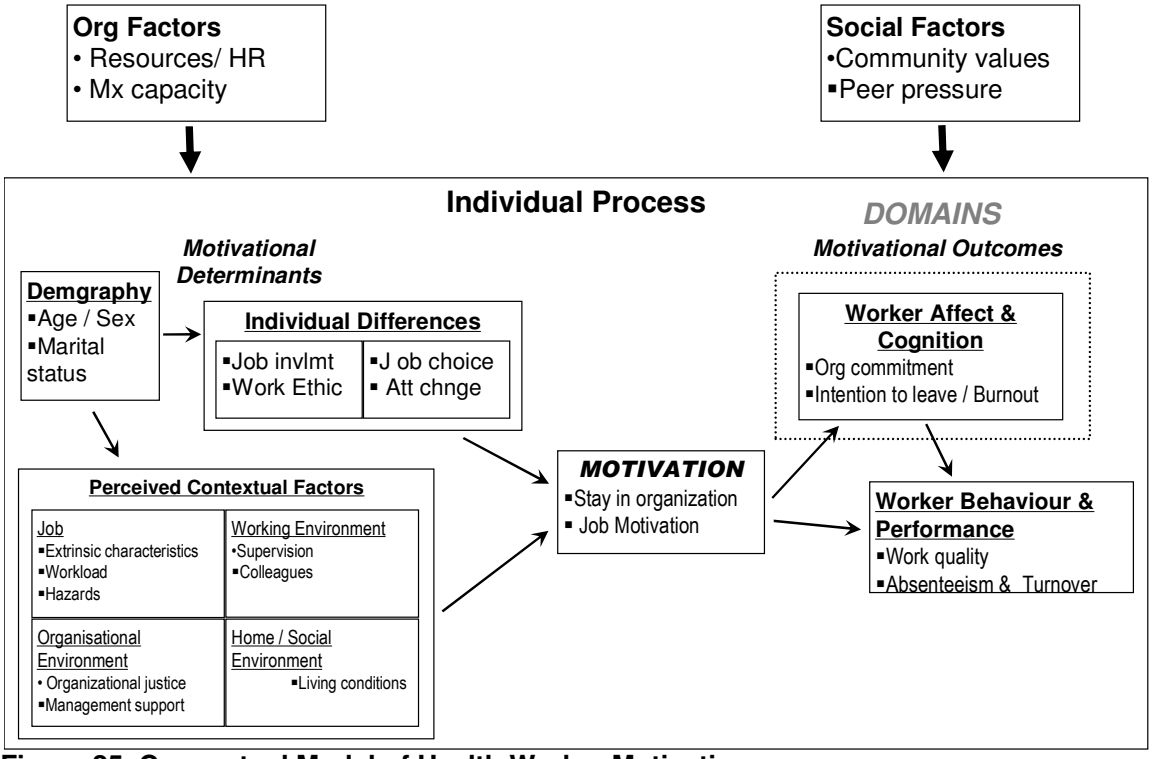


Figure 25. Conceptual Model of Health Worker Motivation

Org – organizational; HR – human resources; Mx – management; J ob job; Att chnge – attitude change
Adapted from Franco Social Science and Medicine 2004 & Penn-Kekana models 2005
Note: Full figure can be viewed in Appendix 10a

Health Worker Knowledge Assessment

PHCN knowledge was assessed by various means. Clinical data were evaluated during the course of the program and where clinical risk factor treatment targets were not being achieved, this was noted in the diary recordings .e.g. HbA1c target levels not known or guideline knowledge for blood pressure targets were not current. This type of information was also gathered during focus group meetings with PHCNs.

Section four of the questionnaire comprised of questions focusing on the outreach program itself and its value to the nurses. It included an evaluation of implementation, clinic systems, clinics medications and equipment (Appendix 8a). The questionnaire also had sections evaluating PHCN knowledge, health worker motivation, and continuing medical education and supervisor support. These are presented in the results chapter (see also Appendix 8b).

Knowledge was also assessed in part one of the questionnaire, which included four clinical scenarios, and these clinical scenarios were similar to conditions that a PHCN would see at the clinic (Appendix 8a). They were asked to read the scenario and then answer ten questions about clinical management and risk factor targets; each statement required the PHCN to take a clinical action, and nurses were required to tick or circle 'yes', or 'no' or indicate if 'not sure'. Where a PHCN indicated 'not sure', this was taken as a negative result when the answers were analysed. Each question was scored separately and an overall score was calculated. Comparisons were made between clinics and between PHCNs who participated in CDOP (CD) and those who did not participate in the program (NC). The questionnaire covered the topics of HTN, DM and HIV management, with particular reference to CKD and CVD complications. It also evaluated PHCNs knowledge of guideline targets for these diseases e.g. HbA1c, BMI and blood pressure targets.

Health Worker Motivation Assessment

A conceptual model of the outcomes and determinants of motivation was developed for this component of the study (appendix 10a and 10b, figure 25), drawing on the work of Franco and Penn-Kekana (Franco et al., 2004, Penn-Kekana et al., 2005). The chronic illness program described in this thesis offered an opportunity to further validate the model, to identify the motivational determinants that may be important for primary health care nurses, and to ascertain if these methodologies are relevant in this particular sector of public health management. In order to evaluate the chronic disease models of Wagner and the WHO, it was necessary to identify the kinds of interventions and strategies that should be built into a health care system to facilitate health worker motivation for managing chronic illnesses. More generically, the aim of using this conceptual model was to improve both clinical and functional outcomes for people with chronic diseases, to understand how workers motivation could impact on these outcomes. Worker motivation is an important determinant of worker behaviour and performance, and should be an important consideration in the design of micro- and macro-level organizational reforms and for developing specific interventions like a chronic disease outreach program.

This questionnaire was the main method for evaluating health worker knowledge and motivation.

Section 1 gathered demographic and background information about the PCCs and nurses working in the clinics. Section 2 of the questionnaire assessed health worker knowledge by using a number of 'clinical scenarios' which covered HTN and DM management, as well as level of knowledge about existing guideline treatment targets. Section 3 used a conceptual model to develop questions to assess health worker motivation, used by Pen-Kekana and originally by Franco et al (Franco et al., 2004, Penn-Kekana et al., 2005). This conceptual framework was used to define various domains of interest for motivation, outcomes of motivation and related factors influencing motivation (see Appendix 10a and 10b – figure 25). Section 3, also covered questions selected from the above studies but included additional questions developed to cover the domains of interest to evaluate PHCNs motivation but also a CDOP and clinic pharmacy and equipment resources evaluation. Section 4 evaluated PCCs and nurses' previous education and training support received for managing chronic illnesses.
The conceptual framework was used to define 22 domains of interest for the motivational survey, 1 for CDOP (Extrinsic Characteristic) and 1 for Equipment and Medication (Working Environment). Nine concerned the outcomes of motivation and 13 related to factors influencing motivation. Seventy-five questions were selected, some from existing organizational survey tools (Price, 1997, Franco et al., 2004) used by Penn-Kekana and others were developed to cover the domains of interest (Appendix 10a and 10b).

To assess motivational outcomes, self-assessment scales were employed. Work behaviour referred to general work actions, manner, and conduct that reflected diligence in work and consideration in the work environment. Respondents were required to identify how strongly they agreed or disagreed with each statement, using a 5-point Likert scale. Scales were adapted (and occasionally developed) for use in this project and around managing chronic illnesses. The questions were developed to ensure it was appropriate for the context of the study, through discussions with the local outreach team, and on the basis of information gathered during the phases of the study.

Questionnaire data were analysed using Analyse-ti and Statistica software. The internal consistency of the questions in each domain was measured calculating Cronbach's alpha scoring. The clusters of loadings were marked and those clusters determined the oblique factors for hierarchical analysis. The marked loadings had scores that were greater than >0.45 or 0.55. The internal consistency of the question for each domain, assessing the correlation between scores within this domain, was measured by calculating Cronbach's alpha score. The internal consistency scores were considered ideal if they exceeded 0.8, but were acceptable if above 0.5. Questions were also evaluated using factor analysis. This was used to evaluate whether or not the identified domains were valid and separate constructs.

For the questionnaire the variables were analyzed using the original Likert coding (ordinal analysis) and recoded as binary categorical variables (agree compared to not sure and disagree), and then also as numerical indices derived from the Factor Analysis. Chi-square testing for categorical data will be used. Factor Analysis was used to evaluate whether or not the identified domains were valid and separate constructs. Subsequent analysis explored bivariate and multivariate relationships between motivational outcomes and determinants using different coding and responses. The results obtained from these different methods were very similar. The PHCNs were surveyed at the end of the program i.e. when 2 year follow up period had been completed. PHCN participating in the program were compared with those who did not.

The 'open ended' narrative data from the last section of the questionnaire was transposed to a Word document and thematically analysed using Atlast.ti software.

Coding of Diary Recordings for Thematic Analysis

In order for the diary recordings to be analysed, codes needed to be developed to analyse the text using Analyse-it Software (see Appendix 11).

The codes or common text analysis were developed from three sources.

1. The Health Worker Motivation tool –discussed above
2. Wagner Chronic Illness Care Model (Wagner CCM)
3. Innovative Care for Chronic Conditions Framework (WHO ICCC)

From the CCM, ICCC and the Health Worker motivation models codes were generated with broad classifications. Under these codes the diary recording were analysed and quotes extracted based on these codes.

The 'memos' were classified into five categories; 1) memo 2) commentary 3) methodology 4) program evolution and 5) theory. These memos were then used to create 'timelines', various tables and evaluations. Some of the conceptual model outcomes and determinants of motivation domain definitions and questions were used for this component of the study (see below).They were concerned with outcomes of motivation and included 6 codes covering 'Worker Affect and Cognition' and six codes covering 'Worker Behaviour and Performance'. The latter 'area' was not evaluated by the questionnaire. Additional data were gathered by the nurse program coordinators from the clinic records and directly from PHCNs.

The thematic analysis evaluation did not include a comprehensive use of all previous domains coding as was used for the questionnaire (see below). The diary recordings were used to complement the questionnaire and clinical data and reinforce the triangulation process. In some instances, certain themes may not have been analysed in the questionnaire or clinical analysis e.g. Worker Behaviour and Performance and Positive Policy Environment. These two domains were only analysed from the diary recordings (see results section).

Horizontal analysis of the information was then fashioned across the diary text at two levels. Firstly, across the diaries without using scientific literature (see Results Chapter and Appendices) and secondly, referencing various experts (see Discussion Chapter).

A total of 74 different codes were generated under the nine different classifications and this resulted in quotes being extracted from the diary recording and questionnaire's open ended comments (Appendix 9). In order to determine the program's evolution and the methodological changes which occurred during follow-up, a further 200 memos were created during the analysis. The self administered questionnaire was completed by the PHCNs from the clinics (Appendix 8a and 8b) at the end of the phase II of the program. The questionnaire included an open ended question which was analysed using thematic analysis.

Statistical Analysis

Statistical analysis was conducted with Analyse-it for Microsoft Excel (Analyse-it Software, Ltd, Leeds, United Kingdom) and Statistica release 6 (StatSoft, Inc, Tulsa, OK). The thematic analysis was analysed using ATLAS.ti's version 5.2.0. The clinical data was analysed using the Shapiro-Wilk test was used to test for normality. Continuous data variables were expressed as mean ± SD if parametric and median (IQR) if non parametric. Student t-test was used when data had symmetrical distribution and both paired dependent testing was performed on patients enrolled and then at 2years after follow up.

Determination of Sample Size

The sample size was calculated based on the change in HTN and DM control and their CVD risk factors, required to achieve significant results. Patient enrolment was based on the required number for a p value <0.05. This was also based on comparisons between a treatment and control group. It was calculated that if a 10% change in control group occurred then a 20% change was required in the treatment group. This would ensure a 10% difference between the groups and then 780 people needed to be enrolled. If a 5% change in control group was required or achieved then a 25% change was required in the treatment group and the program would need to enrol 203 people. For a 5% change in control group and 15% in treatment group then need 566 people were needed. This was taken for a follow up period of 24 months. If those enrolled were evaluated against their baseline risk factors then similar differences would be required, as compared to a control group, for significance to be achieved.

The sample size for evaluating nurses' knowledge and motivation was based on ensuring an 80% response rate to the questionnaire, from the total of PHCNs working at participating clinics.

5 RESULTS

The results are presented in the following order. The functional and clinical data are presented first, and includes 'functional' outcomes in the form of enrolment process and follow up challenges, followed by the baseline clinical information of the cohort and clinical follow up data. The outcomes include those patients referred and followed in the specialist centre for two years. The results are also presented using the structure provided by the chronic disease management models, described in the earlier chapters (figures 4 and 5). The next section covers program implementation and the health care organization. It includes an evaluation of delivery system design, decision support and clinical information systems, and is followed by an evaluation of current health policy. The questionnaire focuses more specifically on the evaluation of the health care team, with a specific focus on evaluating clinician knowledge and motivation. This latter section also draws on the 'conceptual model of health worker motivation', (figure 25), to provide results on health worker motivational outcomes, motivational determinants and worker behaviour and performance. This completes the triangulation process of evaluation outlined in the chapter 4. All evaluation includes the integration of information gathered from the diary recordings, focus group meetings and questionnaire.

Functional and Clinical Outcomes

Enrolment and follow-up of Cohort

From February 2004 to February 2006, 618 'high risk' patients (61% females, 39% males) were enrolled into CDOP by the PHCNs, from an estimated pool of 38 000 HTN and DM patients at 20 clinics. The focus of CDOP was on patients with uncontrolled HTN and DM. Extrapolating from previous surveys of DM and HTN control in the Soweto clinics (Mohammed and Mthombeni, 2000), the pool of eligible HTN and DM patients for CDOP was half to two thirds of the total number of patients i.e. 19 000-26000. The mean age of those selected at baseline was 60$\pm$11years. Patients were enrolled randomly, but according to the PHCNs' judgement of whether they met the inclusion criteria, and this may have been influenced by whether the PHCN needed management support or believed the person required referral to a specialist.

They were guided by the inclusion and specialist referral criteria. The cohort of patients enrolled was followed for two years.

Of the 618 patients enrolled onto the program, 68.7% (n=425) were lost to follow within six months. The survival or attrition rate of the cohort from baseline, excluding those patients who completed follow up in the clinic, partial follow up (>18months but <24months), moved, died or were referred, is shown in figure 26.

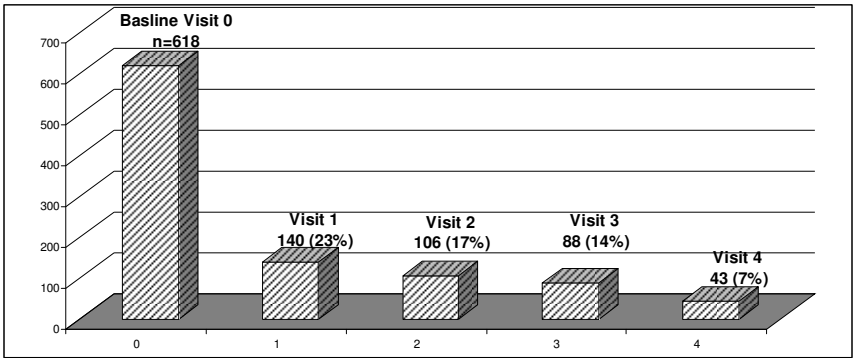


Figure 26. Cohort Survival by Follow up Visit Number in the clinic
Note: Includes patient visits over 24 months at 6 monthly intervals and excludes those referred patients and those who moved or died.
0 = baseline visit; 1st visit = 6month visit; 2nd Visit=12month visit; 3= 18 month visit; 4 = 24month visit

Those patients not followed on the program were able to be differentiated on the basis of whether they were still attending the PHC clinic but chose not to participate in CDOP, labelled 'Not followed in the clinic' group and included 213 (34.4%) patients, whereas 123 (20%) were truly lost to follow up and outcome was not known, hence labelled 'Outcome not known' group. There were 24 (4%) patients who were found to have moved to another clinic, area or province. None of these "lost" patients required specialist referral. This was determined as we had their baseline clinical data, and could determine if they had met the ''specialist referral criteria' at the time of being enrolment. The one percent (n=6) who died and those referred to another specialist clinic, obviously could not be referred to the kidney clinic. Only 27 (4.3%) patients were

lost to follow up who should have been referred. Again this is because we kept data of each visit and could evaluate at what stage a patient would have required referral. Of the 27 lost who should have been referred, 23 would have been referred at baseline and only four patients at the final visit. Sixty nine (11.1%) were actually referred and arrived at the specialist clinic (Figure 27). Of these, 47 (68%) were referred from baseline, 5 (7%) at the 6 month visit, 6 (9%) at 1 year, 4 (6%) at 18 months and 7 (10%) at final 2 year visit. In summary, evaluating the referral outcomes of patients enrolled, 82.2% (n=515) were not referred from the PHC clinic. Of the 17.8% (n=104) referred to the specialist clinic, 11% (n=69) arrived and were followed for 2 years, 4.3% (n=27) did not arrive at the referral hospital and 1% (n=6) died during the 2 years of follow-up, i.e. two-thirds arrived and were followed for two years.

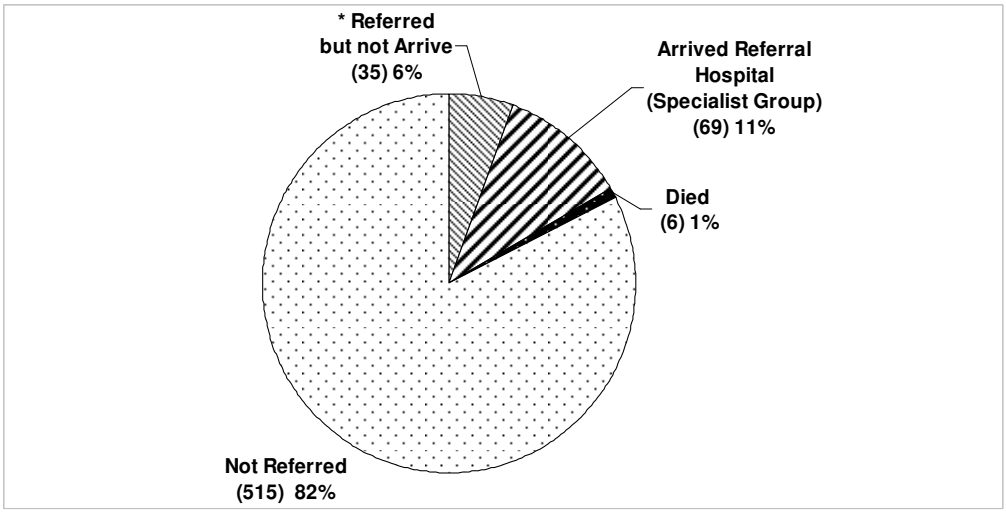


Figure 27. Referral Outcomes from Baseline CDOP Group
Note: 104 patients referred and 69 arrived at specialist clinic and 6 others referred directly to cardiac outpatient clinic i.e. 27 patients lost to follow up at specialist kidney clinic
* Referred but not arrive indicates patients who did not arrive at kidney clinic (ROPD)

Of the 35 patients who did not arrive at the renal outpatient specialist clinic, eight were referred with cardiac problems directly to the cardiac outpatient clinic and two were referred back to the renal outpatient clinic as kidney disease was the primary problem. The cardiac clinic

joined the direct referral system of CDOP during the course of the program (see program evolution figure 37 below). Considering that 72 out of 104 patients who were referred to the specialist clinics arrived at a clinic and 69 were known to be followed up at the kidney clinic (renal outpatient clinic – ROPD), the success of following patients in a specialist setting was significantly better at 69.2% and 71.2% compared with the PHC clinic at only 7.9%; n=40. Only four clinics were able to complete a full 2 year of follow up. Some PHC clinics were significantly better at following-up and referring patients compared with others (Figure 28). The reasons for this are investigated more closely from the diary recording and open ended section of the questionnaire and are described below.

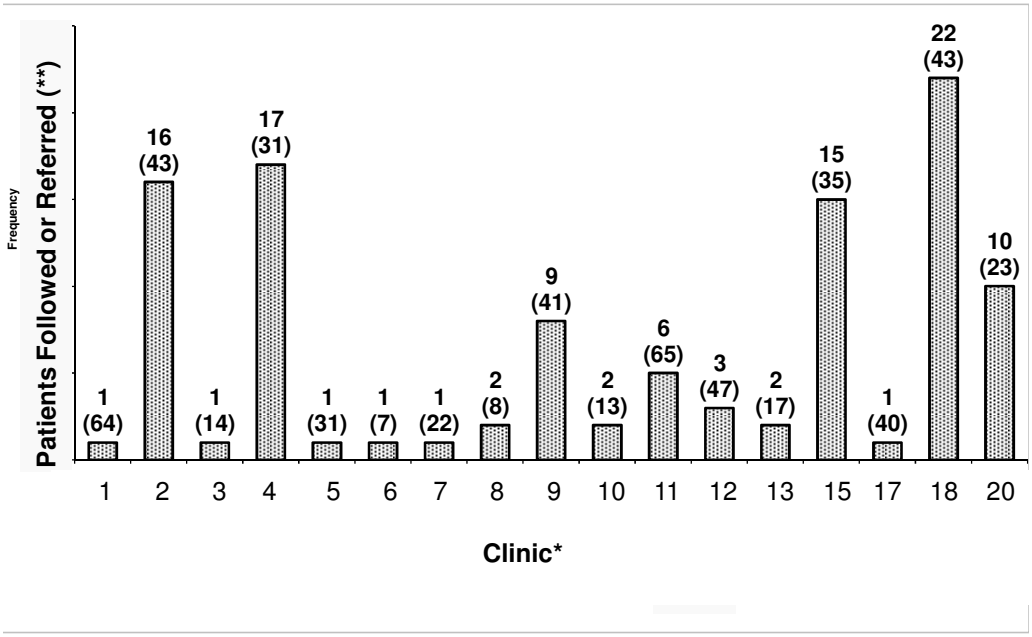


Figure 28. Referral of Patients according to PHC Clinic
** Note:* Each clinic was assigned a number in order to maintain confidentiality **** Number in brackets denotes total number of patients enrolled at this clinic

Of the 618 patients enrolled, only 23% (n=141) completed 2 years of follow up, 104 of whom were referred to a specialist and the remaining few were followed up at PHC level. Most were unable to be followed by the PHCNs in the clinics 54% (n=336) i.e. remained at clinic but lost to follow up or their outcome was never known. Only 4% (n=24) were known to have moved to another area or clinic, and 1% (n=6) were known to have died (Figure 29). We were able to

differentiate the 'Outcome not known' group from the 'Not followed in PHC clinic' group. This was done when going back to the clinics at the end of the program to assess the reason why the 'Lost to follow up group' was so large. Nurse program coordinators tracked each patient by using health promoters working in chronic disease clinics and clinic clerks. Those known to still be attending the clinic were classified as 'Not followed in clinic', and those patients whose whereabouts remain unknown were labelled 'Outcome not known'. It was felt important to see if patients had left the clinic or just left the program.

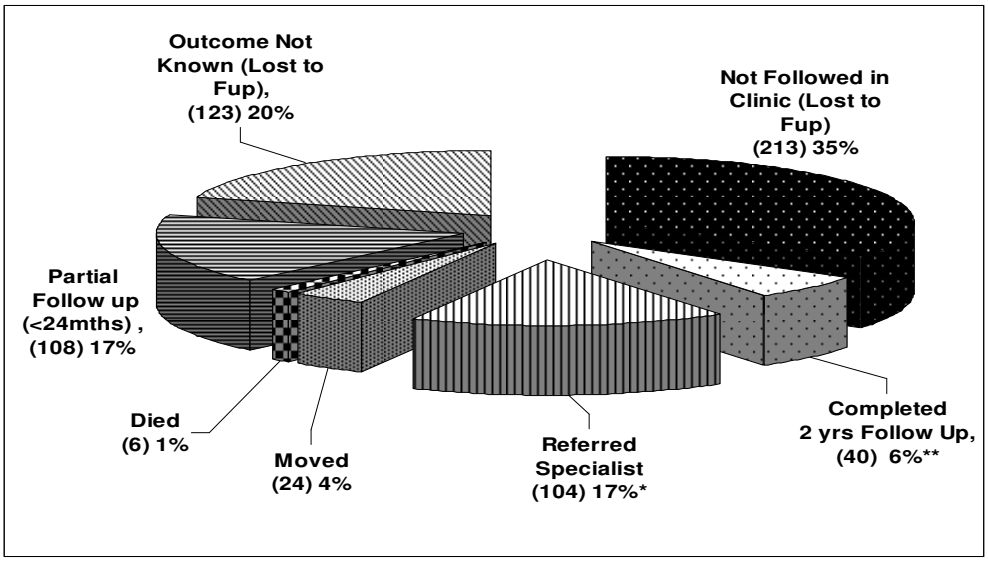


Figure 29. CDOP Patients Outcomes
* 69 patients referred to specialist completed a full 2 years of follow up, ** 6% of patients in clinic completed 2 years of follow up (Note therefore 23% of patients enrolled from baseline completed 2 years of follow up)
Note: 46 patients were supposed to be referred but were not referred as they were lost to follow up or never received a 'feedback report' indicating they should be referred to a specialist

Of the 104 patients requiring specialist referral, most were sent to the kidney clinic (15.5%; n=96), with only a few to the cardiac clinic (1.3%; n=8). Most people enrolled at baseline did not have an indication for immediate referral (82.2%; n=502). There were therefore 27 (4.3%) patients who required referral to the specialist kidney clinic but never arrived or were not contacted to go to the specialist clinic. Of the 110 patients who required referral, 70 (11.3%) met

the referral criteria at the time of baseline screening and a further 40 patients (6.5%) met the criteria during the 24 month follow up period (See Table 10 for indications).

Of the 104 (17.8%) patients who the program was able to refer to the specialist centre, 69 (71.8%) arrived at the kidney clinic and were then followed until the end of the study period. A breakdown of indications for referral is summarized in Table 7. More than half of the patients were referred with significant CKD or proteinuria, 3% required lipid lowering medication, and equal proportions were referred for insulin initiation, significant proteinuria or to the cardiac clinic.

Table 7. Indications for Referral to Specialist Centre

Reasons for referral	n	Percent
No Referral Needed	***508***	***82.2***
Stage 3 CKD*	**54**	**8.7**
Stage 4 CKD*	**3**	**0.5**
Stage 5 CKD*	**4**	**0.6**
Suspected Cardiac Disease**	**8**	**1.3**
Significant Proteinuria***	**8**	**1.3**
Diabetes needing insulin#	**8**	**1.3**
Cholesterol requiring medication$	**19**	**3.1**
Total Referred	**104**	**17.8**
Died	***6***	***1.0***

* CKD with a eGFR <60ml/min/m^2; ** Suspected Cardiac Disease – chest pain, abnormal electrocardiogram; ***Significant Proteinuria - nephrotic range proteinuria ACR>200mg/mol or PCR >0.20g/mmol; # HbA1c>10 and on maximum oral hypoglycaemic medication; $ cholesterol >7mmol/L

Six patients were known to have died, three from 'heart failure', and two from a 'stroke' and in one the cause was unknown. Of the 6 patients who died, four were known to have an eGFR<60ml/min, one had uncontrolled diabetes (random glucose 10.1mmol/L) and HTN (BP 178/85mmgHg), and one nephrotic range proteinuria (ACR 690 mg/mol). The causes of death were not confirmed but were based on a report from the clinic. An overview of the groups by

chronic disease diagnosis (DM or HTN), total number and gender distribution is summarized according to follow up from baseline to 2 years in figure 30.

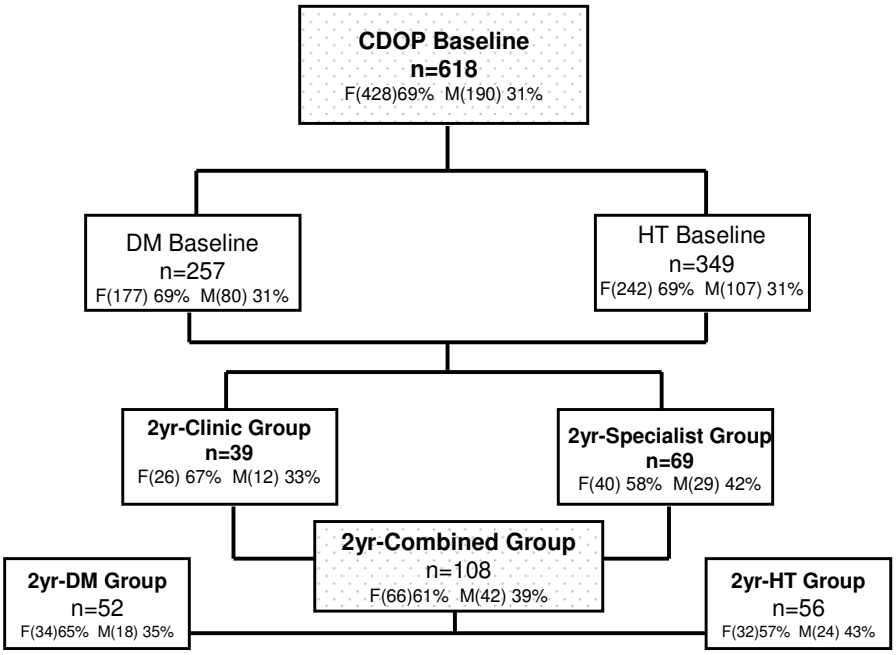


Figure 30. Overview of CDOP Baseline Enrolment and Follow up by Diabetes (DM) or Hypertension (HT) Diagnosis

Baseline and Follow-up Clinical Evaluation

Amongst those enrolled at baseline, fifty-eight percent (349) had uncontrolled HTN, and 42% (257) DM with HTN and/or proteinuria. Patients enrolled with diabetes (DM) had type 2 DM with 20.1% of these patients using insulin. Table 8 demonstrates that at baseline, those patients enrolled met the criteria of 'high risk', having uncontrolled blood pressure or diabetes and significant risk factors for CVD and CKD (see also section on screening below).

Table 8. Baseline Demographics and Risk Factors

Parameters	Men		Women		All	
	n	Mean (SD/%)	n	Mean (SD/%)	n	Mean (SD/%)
Age (yrs)**	188	62±11	422	59±11	610	60±11
Diabetics	80	31%	177	69%	257	42%
Hypertensive	107	31%	242	69%	349	58%
Smokers**	35	6.6%	22	4.2%	57	11%
Waist cm*	138	100±16	317	103 ±16	455	102±16
BMI *kg/m2 *	162	28±7	344	33 ± 8	506	32 ± 8
SBP * (mmHg)	186	153	424	153	610	153 ± 23
DBP * (mmHg)	186	93±11	424	94 ± 13	610	94 ± 12
GFR(ml/m2)	133	69± 21	311	72 ± 26	444	71 ± 25
ACR mg/mmol*	108	60±143	311	58±217	377	59±199

Note: Data are mean (SD) or proportions; ** Significant difference by gender * Indicates risk factor higher than 'normal' – see text and inclusion criteria Table 10.

Focusing on the baseline group, CDOP Baseline (n=618) (Table 12), the ratio of women was significantly higher than men (M: F; 31%, 69%). Eleven percent were smokers and a significant difference existed between genders (M: F 6.6% and 4.2%; $p<0.0001$). On evaluation of obesity and CVD risk, measuring waist circumference, women were significantly more likely to be have a waist circumference in the high risk zone ($p<0.0001$); 84.5% of women; ($\geq$88cm), and 36.2% of men ($\geq$103cm) (Figure 31). The BMI patterns were similar, where women were significantly more likely to be obese (BMI 30-39.9kg/m^2), (F: M; 44.8%: 29%) or morbidly obese (BMI >40kg/m^2), (F: M; 21.8%: 5.6%). Men were more likely to be overweight (BMI 25-29.9kg/m^2) rather than obese or morbidly obese as compared to women (F: M; 18.9%: 35.8%; $p<0.001$) (Figure 32).

The results were similar when all overweight groups were combined, with 85.5% of women and 70.4% of men overweight or obese. Women and men were more likely to be overweight, obese or morbidly obese if they had DM compared with the HTN group.

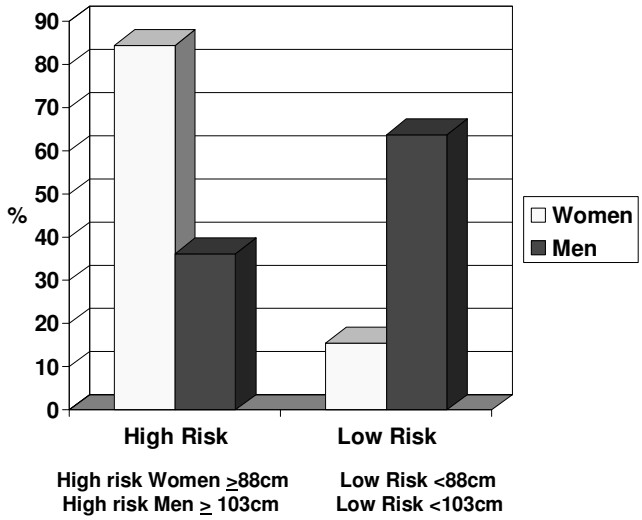


Figure 31. Waist Circumference at Baseline
Note: *Significant difference between genders p<0.001

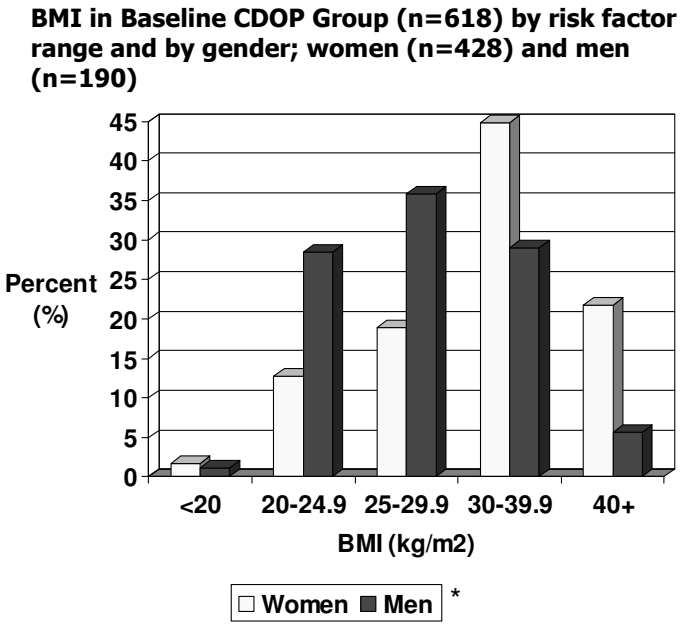


Figure 32. Body Mass Index (BMI) at Baseline
Note: *Significant difference between genders p<0.0001

In the evaluation of patients' lifestyles at baseline, 86% (n=531) admitted to doing no exercise and 3% (n=19) exercised 3 or more times per week. Seventy nine percent (n=483) of people enrolled admitted to eating 'fatty foods' more than four times per week and only three patients to eating no fatty foods at all.

At baseline, evaluating BP control, only 25.4% of patients were controlled (≤140/90mmHg) (Figure 33), and of those with diabetes, only 15.4% achieved current guideline target BP (≤130/80mmHg).

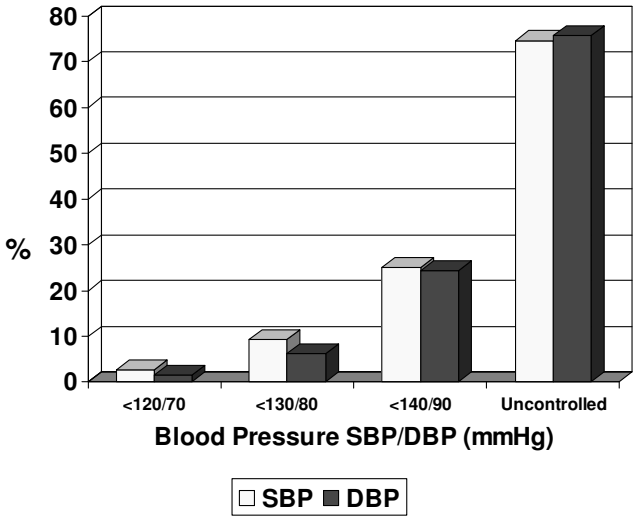


Figure 33. Blood Pressure Control at Baseline
Note: No gender differences existed

The mean serum cholesterol for all patients was 5.03 ±1.31mmol/L, and women were more likely to have higher cholesterol than men, (F: M; 5.14mmol/L: 4.77mmol/L; p <0.008), and more likely to have levels which required referral for medication i.e. ≥6.5mmol/L; (F: M; 14.9%: 7.2%), (Table 9). The mean serum cholesterol for all DM patients was 5.07 ±1.46mmol/L, and women were more likely to have higher cholesterol than men, (F: M; 5.21±1.44: 4.78±1.47; p <0.05). However again, the women with diabetes were more likely to have levels which required referral for oral anti-lipid medication i.e. ≥6.5mmol/L; (F: M; 18%:7%), compared with men. This was similar for non-diabetic (Baseline HTN group) men and women, (F: M; 5.12±1.17: 4.74±1.14; p <0.05), but total levels requiring referral were much lower in this baseline HTN group, i.e. ≥6.5mmol/L; (F: M; 11%:6%). Evaluation of the burden of kidney disease in this cohort included assessing the amount of proteinuria and an estimated GFR (eGFR) using the modified diet in renal disease formula (MDRD).

Table 9. Total Cholesterol at Baseline

Total Cholesterol	Women (n=276)	Men (n=125)	Total	
Target Range mmol/L	Percent %	Percent %	n	Percent %
<5.2	53.6	62.4	226	56.4
5.2-6.4	31.5	30.4	125	31.2
6.5-6.9	6.2	2.4	20	5
>7[$]	8.7	4.8	30	7.5
Mean (SD)	5.14 $\pm$1.31[@]	4.77 $\pm$1.29[@]	401	5.03 $\pm$1.31

$ Specialist Referral Criterion; @ t-test total serum cholesterol (mmol/L) by gender p <0.008; **Total Cholesterol (non-fasting 2hr post-prandial)

On evaluation of proteinuria in the group, overall 28.3% had an albuminuria $\geq$30mg/mol, which is a significant risk factor for CVD. The mean urine albumin-creatinine-ratio (ACR) was 59$\pm$199mg/mol, and 6.9% of the patients met the referral criterion for nephrotic range proteinuria ($\geq$0.20mg/mol), indicating both CKD and a high risk for CVD (Figure 34). A higher number of patients with DM compared with those with HTN, had albuminuria $\geq$30mg/mol; 33%. No significant gender differences existed for urine albuminuria.

Using the estimated glomerular filtration rate (eGFR), MDRD formula not corrected for the population group, i.e. appropriate ethnicity factor [6], it was found that 12% of patients with advanced stages of CKD (eGFR<60ml/min) required referral. Those patients with DM were more likely to have advanced CKD or low eGFR (<60mls/min), compared with the baseline HTN group (30% vs. 17%; p=NS) (Figure 35). Twelve percent of patients (n= 53) had advanced CKD requiring referral i.e. GFR <60mls/min, and 1.6% (n=10) patients had ESRD (i.e. eGFR<15mls/min) requiring dialysis. Only 70% of patients had a baseline eGFR calculated,

[6] This was not possible as the research to determine an ethnicity factor for black South Africans had not yet been completed at the time of initiating and evaluating this study. This study was only recently published using some of the information from this study. The reference for this study is H.E. van Deventer, J. George, J. Paiker, P. Becker, I. Katz. Estimating Glomerular Filtration Rate in Black South Africans by use of the Modification of Diet in Renal Disease (MDRD) and Cockcroft-Gault equations. Clinical Chemistry. 2008;54;7:1197-1202.

because the availability of serum creatinine levels enabled calculation. This possibly underestimated the true burden of kidney disease in this group.

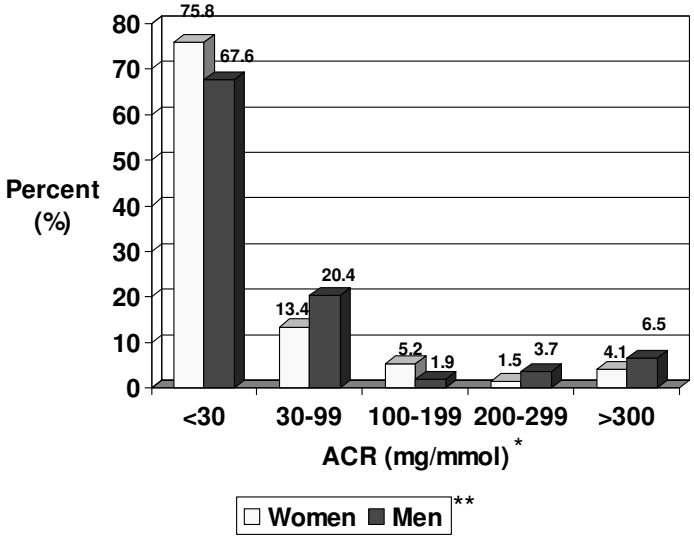


Figure 34. Spot Urine Albumin Creatinine Ratio at Baseline
*ACR – albumin creatinine ratio; ** No gender difference between ACR level; Baseline CDOP Group (n=618) for Women (n=428) and Men (n=190)

Finally evaluating baseline diabetes control and medication use, eight patients (1.3%) were referred for insulin as no doctor or PHCN was able to prescribe insulin at the clinic. All of these patients met the criteria for specialist referral due to uncontrolled DM or HTN or significant risk factors. The level of DM control was poor overall, with only 31% of patients having optimal control i.e., HbA1c <7%., with a mean HbA1c of 9$\pm$3% (Table 10). Only 20.1% of DM patients were on insulin and only 39% were on an angiotensin converting enzyme inhibitor (ACEi). The use of ACEi amongst HTN patients was much higher (84.2%) than in people with diabetes (Table 11).

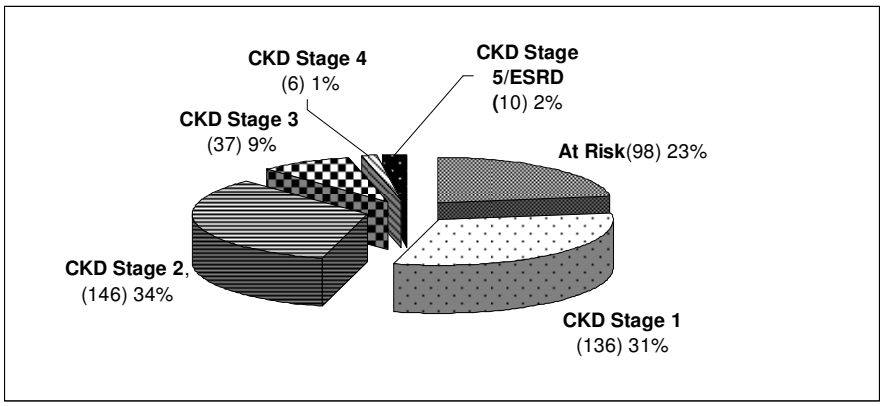


Figure 35. CKD Staging at Baseline
* CKD – chronic kidney disease; Note – staging calculated using an estimated glomerular filtration rate with the modified diet in renal disease (MDRD) formula and not corrected for ethnicity

Table 10. HbA1c level Amongst the Baseline Diabetes Group

Diabetes Control for HbA1c	n	HbA1c %	Percent %
Optimal	45	<7	31
Acceptable	20	7 to 8	14
Additional Action	81	>8	55
Mean (Std Dev)	146	9 ±3	

In general, there was a low use of HTN medication other than hydrochlorothiazide (HCTZ) and ACEi. The use of this combination in diabetes occurred in <50% of patients. It should be noted that not all classes of HTN medication are available in the clinics. HTN medications not available in PHC clinics but at hospital level include alpha blockers, angiotensin receptor blocker (ARB) and minoxidil. Other classes of medication unavailable in most clinics were anti-lipid medication, i.e. simvastatin – HMGCoA enzyme inhibitor. Less than one percent of patients were on anti-lipid medication at baseline, despite elevated cholesterol levels. An anti-lipid agent was only available at one of the twenty clinics.

Table 11. Medication Prescription at Baseline

Medication	Diabetics		Hypertensive	
	N	257	N	349
HCTZ	120	47%	310	89%
Furosemide	4	2%	38	11%
ACEi	100	39%	294	84%
CCB	27	11%	38	11%
N-CCB	12	5%	44	13%
Beta Blocker	6	2%	58	17%
Aldomet	11	4%	69	20%
Gliclazide	98	70.5%	-	-
Metformin	86	61.9%	-	-
Insulin	28	20.1%	-	-

HCTZ – hydrochlorothiazide; ACEi – angiotensin converting enzyme inhibitor; CCB – calcium channel blocker; N-CCB – non-dihydropyridine calcium channel blocker.

Specialist Referral Group Clinical Data

As noted above, two-thirds (n=104, 17%) of the patients required referral, at baseline and during follow-up, but only 69 (11%) were those followed at the specialist renal outpatient clinic and this group of 'Specialist Referral' patients was followed for a full 2 years (see figure 27 and 29). The remaining 40 (6%) patients, who completed 2 years of follow up, were from the PHC clinics and did not require referral (Figure 33 and 34). The data at baseline and at 2 years, for the specialist referred group only, is summarized in Table **12** as the 'Two-year-specialist group at baseline and 2 years'. The Two-year clinic group (n=108) was not considered for analysis as there were statistically significant differences in ages between the Two-year-clinic group (n=39) and Two-year-specialist group (n=69) (67.2yrs vs. 61.4yrs; $p<0.01$). There were also differences in the chronic disease distribution between the groups. The clinic group had a greater HTN to DM patient ratio at 2 years (27:12) compared with the specialist group which comprised of more people with diabetes (29:40) ($p<0.01$), indicating that a greater number of patients with diabetes required referral and were referred to a specialist. The Two-year-clinic group could have been a self selected group, as the reasons for their completing follow up, compared with those who were lost to follow up is unknown. Therefore analysis of follow up could only be carried out for the specialist group, as these patients were not self selected (see paragraph above).

Table 12. Risk Factors in the Two-year-Specialist Group at Baseline and 2years

Parameters	Baseline (n=69)		2 years (n=69)		p
Age	69	61 ±10	69	62 ± 9	-
Gender	29	Males 42%	40	Females 58%	-
Diabetes	40	58%	40	58%	-
Hypertension	29	42%	29	42%	-
BMI (men)	11	28±4	11	28 ± 5	NS
BMI (women)	35	35±5	22	35±5	NS
Cholesterol*	51	5.8 ±1.6	51	5.3 ± 1.4	0.0005
Glucose (mmol/L)**	15	10.1 ± 5	15	8.8 ± 4	NS
HbA1c (%)**	23	9.5 ± 3	23	7.6 ± 2	<0.01
SBP	66	155 ± 22	66	142 ± 22	0.0002
DBP *	66	92 ± 12	66	80 ± 13	<0.0001
ACR, mg/mmol *	47	149 ± 287	-	-	-
Urine protein ≥3+*	62	13	60	14	NS
GFR (MDRD)***	38	56	55	50	NS

Note: Data are Mean (SD) or proportions; * Significant difference p<0.05; Student t-test used for continuous variables and Pearson Chi-squared for categorical variables; @CVD – cardiovascular; #CKD – chronic kidney disease;** Evaluated for diabetes patients only: *** Median; MDRD – mls/min

Participating in the program for 2 years showed no benefit in reducing the patients' body mass indices (BMI) i.e. men remained on average overweight and women remained obese. There was however a significant difference achieved with risk factor control in the specialist group with respect to the serum cholesterol levels, diabetes control measured by blood HbA1c levels and systolic and diastolic blood pressure (see Table 12). The 'specialist clinic' was unable to collect adequate data to analyse differences in proteinuria by albumin-creatinine ratio, but on urine dipsticks there was no difference from baseline. There was also no significant decline in glomerular filtration rate from baseline in this group of patients. Regression analysis of baseline variables which affected GFR at 2 years included male gender ($p<0.05$), serum cholesterol ($p<0.01$) and serum haemoglobin ($p< 0.01$). Systolic and diastolic blood pressure, body mass index and HbA1c were not significant factors affecting GFR decline.

There were significant changes in medication prescription over the 2 year period and this is summarised in Table 13. There was a high use of ACEi in this group at baseline and at 2 years, and significantly more calcium channel blockers (CCB), minoxidil alpha-blockers and angiotensin receptor blockers (ARB) used for hypertension compared with at the clinics. More

furosemide was used instead of hydrochlorothiazide and more statins were prescribed in the specialist clinic. There was also more insulin used in the patients with diabetes, compared with those at baseline in the PHC sector.

Table 13. Changes in Medication use over 2-year Follow-up

Medications	% Baseline	% After 2-years
HCTZ	84	61
Furosemide	8.3	35.2
ACEi	75.0	71.3
CCB	19	54
N-CCB	14.8	9.3
Beta-blocker	8	34
Methyldopa	15.7	1.9
Minoxidil**	0.0	5.6
Alpha-blocker**	0	36.1
ARB**	0	11.1
Statin**	2	16
Gliclazide or Glycomin $	71	50
Metformin$	62	50
Insulin$	20	35

HCTZ – hydrochlorothiazide, ACEi – angiotensin converting enzyme inhibitor, CCB- calcium channel blocker, N-CCB – non-hydropyridine calcium channel blocker, ARB – angiotensin receptor blocker
* Denotes drug not available at primary health care clinic; ** Denotes drug with limited availability in one PHC clinic $ Includes only patients with diabetes (n-257) and percentages calculated using a lower denominator.

Success of CDOP and PHCN Screening

Enrolment depended on patients meeting the inclusion criteria but also if the PHCN chose to enrol the patient for decision support or if they thought the patient needed referral. In order to assess if the PHCNs accurately 'diagnosed' those patients at 'high risk' for CVD and CKD, and appropriately referred the patients to the hospital, their 'screening' ability or the 'criterion-related' validity was measured. The 'measuring instrument' in this case was the PHCN in the clinic and this was evaluated against the patients' clinic data at baseline and at the time of referral. The aim was to determine how many patients were correctly enrolled and referred. The validity of their 'diagnostic' ability was evaluated in terms of sensitivity, specificity and predictive values.

Appropriate screening and enrolment onto the program by the PHCNs was based on whether the patients met the inclusion criteria of uncontrolled HTN (BP≥140/90mmHg), uncontrolled DM (random glucose >11mmol/L or HbA1c>8) and uncontrolled HTN, DM and proteinuria (trace protein on dipsticks or ACR>2.2g/mmol) or proteinuria alone.

Unfortunately nurses did not collect the data for all patients they screened or they considered enrolling, and therefore the sensitivity and specificity or predictive value for PHCNs for appropriate program enrolment could not be calculated. Correct enrolment was therefore measured by comparing the numbers enrolled and who had met the inclusion criteria, against those enrolled who did not. The results are shown in figure 36. From this information, the PHCNs showed a 90.4% success in enrolling the correct and appropriate patients for the program.

The data were available for assessing appropriate or correct specialist referral and appropriate referral was considered if patients met the 'specialist referral criteria' (Table 10). For analysis, this was taken as a GFR<60mls/min, proteinuria >200 g/mol, uncontrolled blood pressure ≥140/90mmHg after visit 2 (1 year) of the program, glucose or haemoglucotest ≥11mmol/L and uncontrolled blood pressure and HbA1c ≥8% after visit 2 (1 year), a serum cholesterol ≥7mmol/L or HbA1c ≥10% alone at any time.

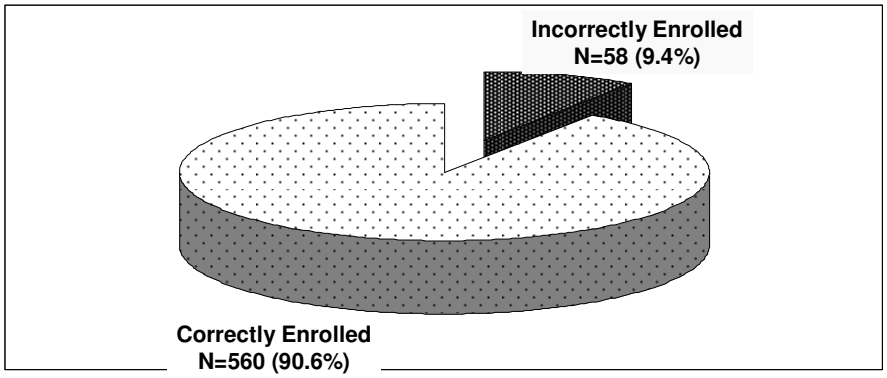


Figure 36. Evaluation of 'Correct' Enrolment onto Outreach Program
Note: Correct enrolment was measured against patients meeting the inclusion criteria for the outreach program

The 'measuring instrument' in this case was the ability of the 'Outreach Program' to detect those who needed referral. The validity of the program's 'diagnostic' ability was evaluated in terms of sensitivity, specificity and predictive values. This was evaluated against those patients who were actually referred by the PHCNs and CDOP and who arrived at the specialist clinic (graduated). The aims were to determine the program and nurses ability to correctly refer all patients who required referral and to determine if all those requiring referral arrived at the specialist. The sensitivity and specificity of referral decisions by PHCNs are outlined in Table 14 and 15.

Table 14. Sensitivity and Specificity of Referral Decisions

Were referred by PHCN or CDOP	Required referral		
	Yes	**No**	**Total**
Yes	104 (true +ve)	0	104
No	6*	508 (true –ve)	514
Total	110**	508	618

Note:* This refers to patients who required referral and were referred but did not arrive ** Patients being referred to cardiac clinic or who died were included in analysis

The sensitivity according to those patients meeting the criteria for referral and who actually were referred was 95% (Sensitivity = % = 104/110 = 94.5%), and specificity for those who didn't need

referral and were not referred was 100% (Specificity = % = 508/508= 100%). The positive predictive value for the program's ability to refer patients appropriately was overwhelmingly positive at 100%, with a negative predictive value of 98.8% i.e. 508/514.

Table 15. Sensitivity and Specificity of Referral Process

Arrived at Specialist Clinic	Required referral			
		Yes	No	Total
	Yes	83 (true +ve)	0	83
	No	27	508 (true –ve)	535
	Total	110	508	618

Note: Patients being referred to cardiac clinic or who died were included in analysis

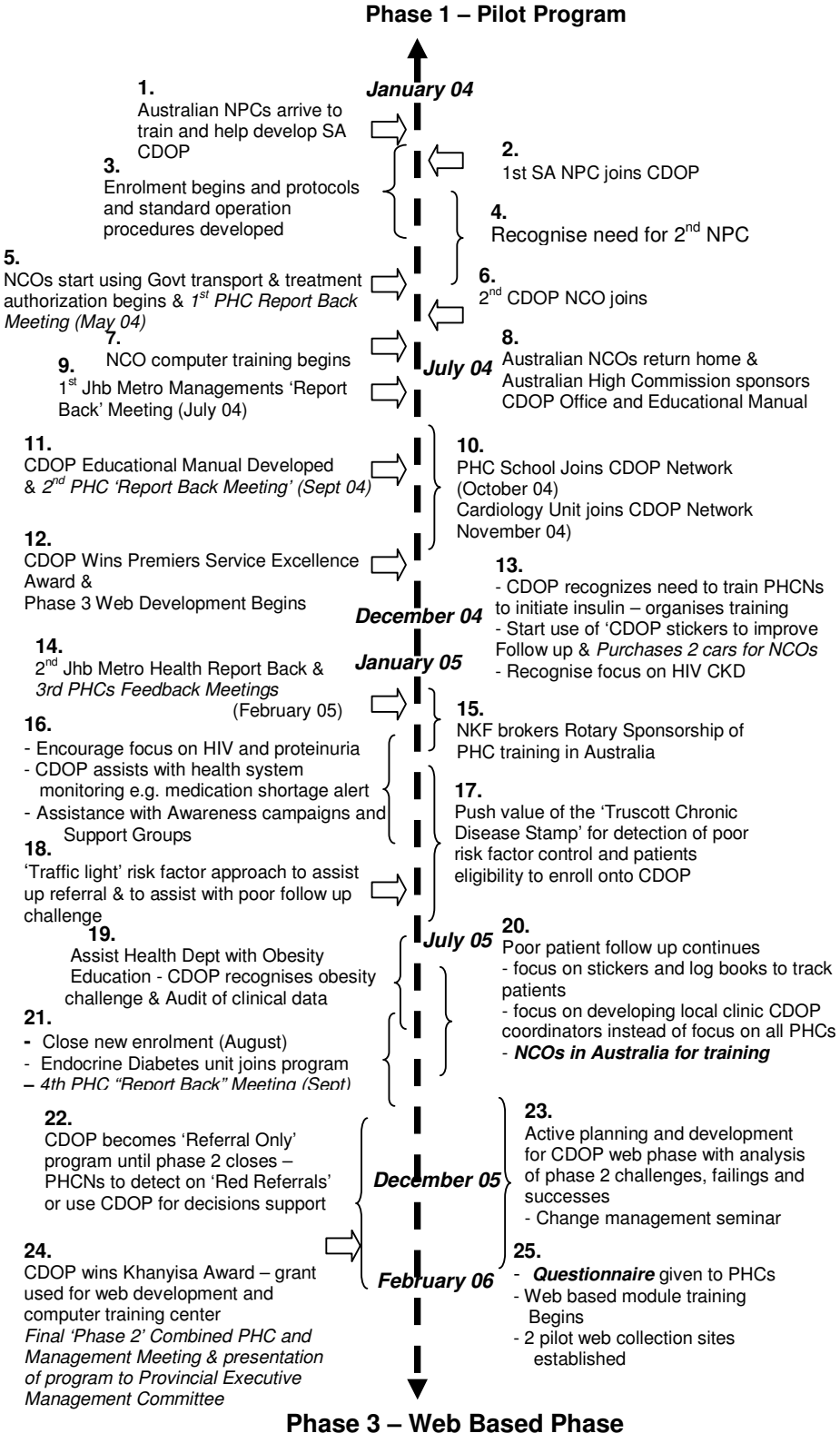
The specificity for referring the most appropriate patients was high, as all those referred did qualify for referral i.e. Specificity = 508/508 = 100%.

Summary of Clinical and Functional Outcomes

In summary, the follow up in the PHC clinics was extremely poor after baseline enrolment, although some clinics performed better than others. However, once patients were referred to the specialist clinic, the ability to follow these patients was much better, and led to improved control of some risk factors for CVD and CKD i.e. cholesterol, HbA1c, systolic and diastolic blood pressure. Decline in kidney function, measured by GFR and proteinuria, was minimal in this specialist clinic group followed over 2 years. However, very little impact was seen with weight control. The PHC nurses were successful at enrolling patients who could be considered 'high risk' for CVD and CKD, and the program systems were able to detect those patients who required specialist referral with advanced disease or who required medications unavailable at the clinics. However, not all patients had the required laboratory investigations at baseline. Although the rates of measurement of the risk factors were more than 70% for all measurements, this was not the case for kidney function measurements GFR and ACR where rates of measurement were, 61% and 62% respectively. This could indicate an underestimation of those patients with advanced disease who required referral, and indicates another limitation of the program.

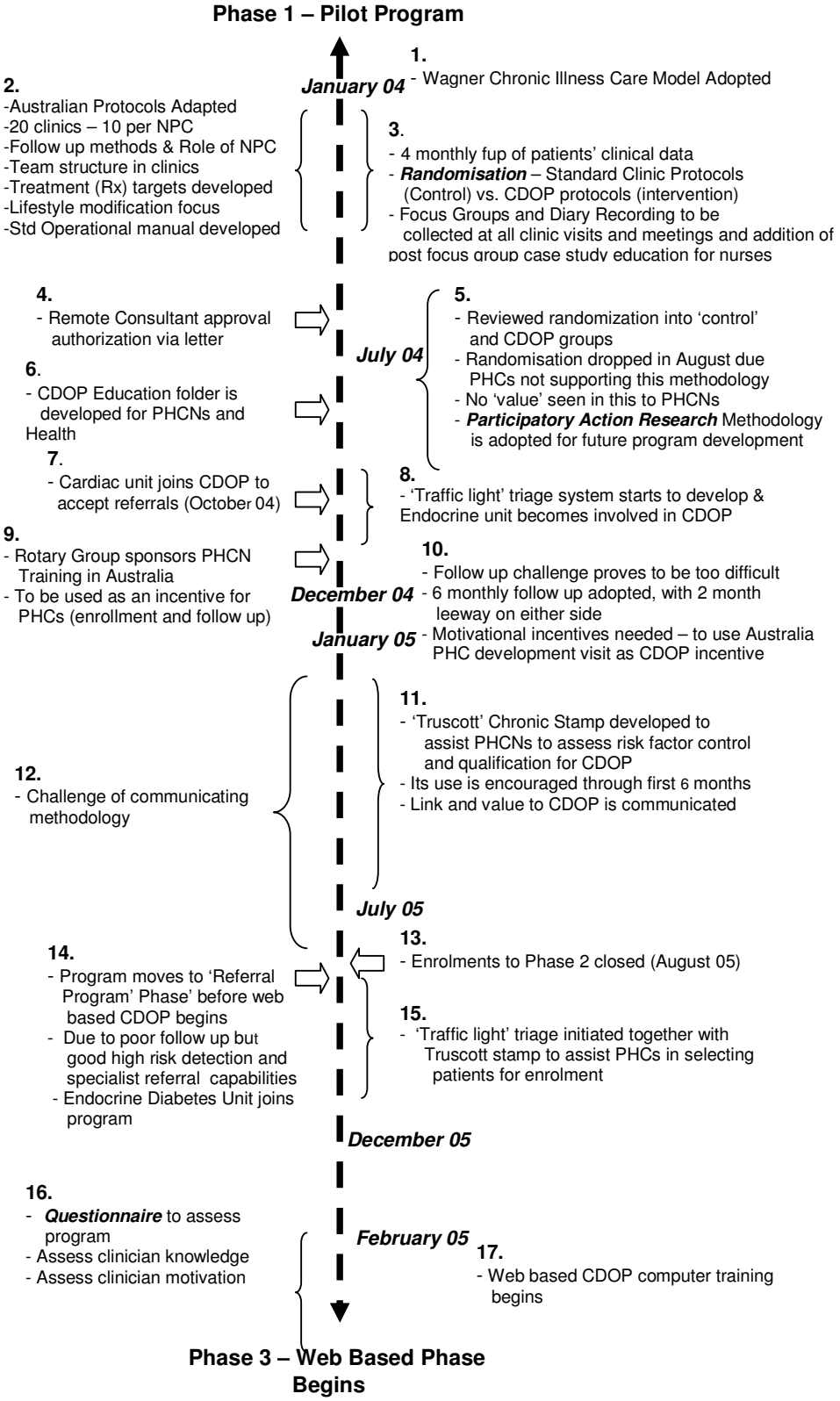
Program Implementation and Health Systems Evaluation

Figure 37. Program Evolution Timeline



Note: Program Evolution timeline was developed from the diary recordings
NPC – Nurse Program Coordinator, * CDOP – Chronic Disease Outreach Program; PHCN – Primary Health Care Nurse; HIV CKD – HIV chronic kidney disease

Figure 38. Program Methodological Timeline



Note: Methodology timeline was developed from the diary recordings
NPC – Nurse Program Coordinator, * CDOP – Chronic Disease Outreach Program; PHCN – Primary Health Care Nurse;

The program's implementation and existing clinic systems were evaluated using the results from the clinical and functional outcomes data, described above. This evaluation was strengthened with triangulation of results obtained during group meetings and program planning meetings in the CDOP, nurse program coordinators' and program doctor/director's diary recordings, and the questionnaire. The diary recordings, questions and comments from nurses in the questionnaire resulted in information which explained reasons for CDOP's successes and failings, and its ability to integrate into the existing clinic systems (Figures 37 and 38). During 50 focus group meetings, which took place at the 20 clinic sites, the discussion was recorded in diaries. The focus group meetings were primarily conducted with the primary health care nurses (PHCNs), but on some occasions were also attended by the clinic doctor. Focus groups were conducted using a similar structure, comprising of a review of the program to date, nurses' challenges running the program, and then at least one case review of a patient participating on the program at that clinic. Discussions were also recorded during 5 'Feedback Meetings' with all the 20 PHC clinic nurses at the specialist referral hospital, and a further three meetings with the Johannesburg metropolitan regional health department management team. In addition, discussions of a meeting to discuss future funding and plans for the program with the Gauteng Health Department Executive committee, comprising all department directors, and regional directors, were diarised. Finally, diary recordings were also kept at 23 program management/planning meetings, which included meetings with specialist departments involved in the program, i.e. primary health care nursing school, cardiac and diabetes/endocrine departments. Recordings were also made of all phone calls to the CDOP office at the specialist hospital and when nurse program coordinators visited clinics. Organization

The evaluation of the program, where possible, has been presented using the main headings from these models. The results have focused on and relate to health system context factors, the chronic disease outreach program (CDOP) and to clinic factors.

Thematic content analysis with Atlas.ti was carried using 9 overriding classifications and their codes which were developed from the above models (Table 16 and 17).

Table 16. Thematic Analysis Classifications

Classification
1. Motivational Outcomes - Worker Affect & Cognition
2. Motivational Outcomes - Worker Behaviour & Performance
3. Perceived Contextual Factors – Health Worker Motivation
4. CDOP Evaluation – Extrinsic Characteristics – Health Worker Motivation
5. Wagner CICM Model*- Health System -Delivery System Design / Decision Support / Clinical Information Systems
6. Wagner CICM & WHO ICCC** Models - Prepared Motivated Proactive Health Care Team
7. Wagner CICM & WHO ICCC Models - Patient Prepared, Informed and Activated
8. WHO ICCC - Health Care Organization
9. WHO ICC - Positive Policy Environment

* WHO - World Health Organization Innovative Care for Chronic Conditions Framework (ICCC)
** Wagner – Wagner Chronic Illness Care Model (CICM)

Table 17. Example of Thematic Analysis Classification and Coding
CDOP Evaluation – Perceived Contextual Factors - Extrinsic Characteristics

Codes (11): number of quotes in each code follows in the brackets
CDOP - 'Research' vs. Audit & Pay for Research Issue (11)**
CDOP - Added Value - Better Quality Treatment- Better use Resources (68)
CDOP - Doctor - Not Involved with CDOP (17)
CDOP - Failed to Train or Orientate or Involve all HCW (18)
CDOP - Management does not 'fully' support CDOP (17)
CDOP - Provided Expertise, Organization or Equipment (14)
CDOP - Staff Education, Development & Training (48)
CDOP - Staff shortages & Work load impacting on Enrolment (59-2)
CDOP - Turnover of Staff affects Enrolment/ Delivery of Program / Fup (14)
CDOP - Value and Credibility Questioned (42)
CDOP -Too Time Consuming to Enrol and Capture Data of Patients (24)

Note: This table is referred to in the section evaluating the program. **Indicates number of quotes from this code

Program Evolution and Methodology Timelines

The development of the program is documented in figures 37 and 38 above. Figure 37 is a timeline which documents the programs evolutionary changes and both figures outline the major events as they evolved over the 2 years of the program.

In figure 38, the factual occurrences are documented and the timelines reflect the changes adopted during the program. The figures document the changes which occurred as a result of the need to provide a 'real life' service for clinicians, and which would be acceptable to them and add value to their job. It documents the major program developments, including when the program nurse coordinators started and were trained. This included all PHCN training and education changes. Also outlined are the times of major report back meetings, new developments including when the program began and closed enrolments, and when phase 3, the web based phase, began. In the centre of this figure is a timeline dating these occurrences. Figure 38 documents the methodological changes that occurred during the study. Here the models adopted and the timing of protocol developments and major changes in program methodology are documented. These changes are measured against a central timeline outlining the month when a change occurred. The challenges which resulted in methodology changes are also documented in figure 38. Some inevitable crossover of facts exists between these two timelines.

The significant positive and negative evolutionary changes which influenced the program, and the methodology changes, are summarised in these figures, but some important issues need highlighting. Major methodological changes included moving from randomisation of patients to PHCN enrolment based on the patient meeting inclusion criteria and the nurse requiring decision support. From the diary recordings, it was noted that PHCNs wanted to offer the program to any patient agreeing to participate and on whom they required advice (decision support). The PHCNs wanted the program to add value to their service and did not support and could not implement randomisation of patients onto the outreach program. Some PHCNs believed the random enrolment would compromise their patients. Considering that the programs overriding aim was to mimic a 'real life situation', this meant that it was necessary that nurse clinicians were able to influence the enrolment approach but not inclusion criteria. Therefore, the initial approach to enrol every 4^{th} or 8^{th} person at the clinic failed and PHCNs failed to see the value of this approach. As a result of the early implementation of the review process or PAR methodology, the enrolment process was changed in keeping with clinicians' needs. The PAR process also drove other changes and initiatives. Any patient with whom a PHCN required

assistance with management or decision support, or who had serious risk factors, was enrolled onto the study as long as they met the program's inclusion criteria. It was felt this move was in keeping with the Wagner model of establishing improved health systems and an effective 'prepared and proactive team'. A 'standard treatment' arm was also started initially but abandoned a few months after program initiation. Patients were therefore enrolled as a 'high risk' clinical cohort into a single management stream after 6 months. PHCNs were uncomfortable with a standard treatment arm as they felt all patients should have equal access to 'better care' and they were concerned about missing serious complications or simply wanted advice.

Additional health system changes consisted of the development of a 'traffic light' triage and decision support system and the initiation of a chronic disease stamp (Figure 39), by the PHC School, through its interaction with CDOP. The 'traffic light' triage system focused on those patients who were controlled, those at high risk and those who required referral. The stamp was used to simplify patient notes and integrate essential chronic disease risk factors and treatment targets.

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

Figure 39. Chronic Disease Stamp
*PF – peak flow meter; BP – Blood Pressure; No - number

Changes in health delivery systems included remote treatment authorization from the specialist hospital for certain medication and especially for direct referral to specialist clinic. CDOP was also utilised to detect any medication and equipment shortages in the clinics, and to report this to management. CDOP was therefore used as a method of monitoring problems in the clinics and to improve efficiency by providing a quick link between nurses in the clinics and management at the central Johannesburg head office. The problem of patient follow-up in the clinics was recognised as a major limitation of the program and numerous attempts were made to try and correct this weakness. This incorporated the development of stickers to track patients

when they returned for follow up, and to prevent cohort patients from becoming lost into the general clinic population. After enrolment was closed, to allow the appropriate follow up period, the program became a 'referral only' program for patients meeting specialist referral criteria (see Table 10). This removed the need for follow up and nurses were encouraged to keep track of 'orange' high risk patients only who were potentially for referral at a later date. Follow up challenges influenced the web based clinical information system developed at the end of the study and these developments are not included in this project.

HIV patients were not included in the program, although they are at risk of CKD. What is also acknowledged in the timelines was the need to develop a more comprehensive network, which should include primary health care specialists, cardiac disease and diabetes experts. This was necessary in order to strengthen CDOP capacity and its ability to integrate all diseases affected by the risk factors and chronic illnesses being targeted. Although CKD was targeted, when previously it had not been, the aim was not to create a kidney specific program. The need was to create a 'prepared, proactive and motivated' health care team to manage all chronic illnesses, including CKD. For this reason, insulin initiation training, obesity education, case study education sessions with focus groups and computer training, were included as part of the CDOP 'package'. Other motivational developments included sponsorship for elective training in chronic disease management with the Australian Outreach Program nurses, official training in computer and organizational skills, and 'change management' workshops for the nurses.

The progress of the program was regularly presented to both the nurses participating on the program, managers at the Johannesburg Metropolitan Health Department, responsible for the region, and to senior executives in provincial management. These meetings offered an opportunity to review and re-design the program in keeping with the adopted participatory action methodology.

These and other issues describing the program and health system factors documented in the diary recording and questionnaire are described in greater detail below.

Evaluation of the Chronic Disease Outreach Program

Eighty nine percent (89%) of PHCNs' on direct questioning found the program made a significant difference to their work. It had assisted them with decision support, patient management (91%) and with patient referral to a specialist (84%). The presence of Chronic Disease Outreach Program also emerged as an 'extrinsic' motivational determinant. Seventy six percent (76%) of nurses felt CDOP had 'added value' to their job, 21% were unsure and only 3% said it had no value (Appendix 8a and 8b). However, there were many factors that impacted on CDOP uptake and success, including its ability to be integrated in the clinic's chronic illness management system. These are summarised in the thematic analysis codes from the diary recordings evaluating CDOP in Figure 40 and Table 22. The program provided expertise in the form of specialised chronic disease nurse program coordinators and specialist visits, including providing protocols for managing chronic illness. The program also provided ongoing training and development in various forms, such as updated guidelines, equipment e.g. glucose monitoring machines, tape measures, patient educational manuals (Appendix 2) and a link between the Johannesburg Metro (provincial) Health management structures and the clinicians on the ground.

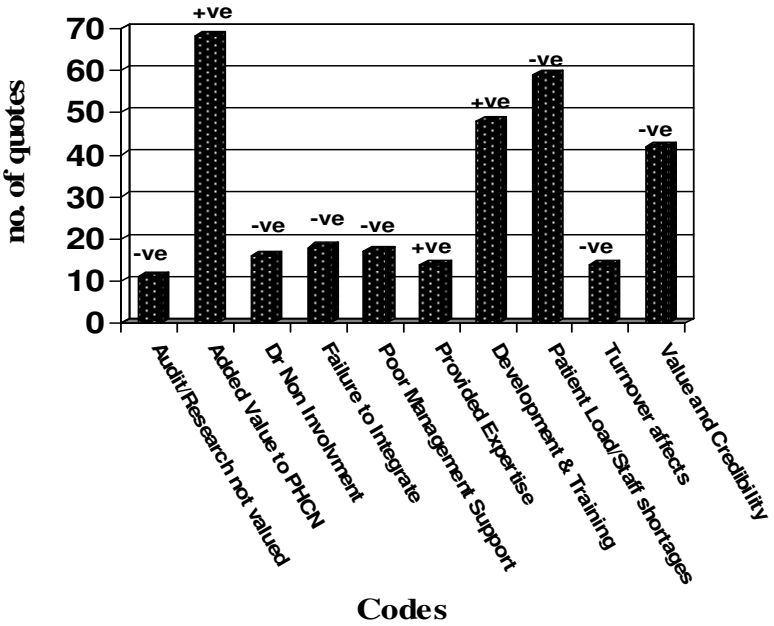


Figure 40. Diary Recordings Evaluation of CDOP
-ve – denotes diary recording noted this as a negative factor on CDOP ; +ve – denotes diary recording noted this as a positive factor in favour of CDOP; Codes – denotes thematic code used for evaluation and for collecting quotes from diary recordings.

At first enrolment was hampered by PHCNs being unsure of the program's credibility and they were unsure of the value it would add to their practice. The credibility and value related to the program being implemented vertically from the renal department, albeit with the support of the Johannesburg Metropolitan Health Department. The program was not trusted by the PHCNs, as they were used to changes in clinical guidelines being instituted from their PHC School instructors during 'in-service training', and this was whom they trusted. This was partly solved by involving their instructors from the Soweto Primary Health Care School, but this improved over time through their personal experience and from the value gained from being involved with the program. The PHCNs could initially also see no value in the program as an audit or monitoring tool of their clinical practice and the health system.

> A challenge to enrolling was the lack of motivation from the clinicians and the belief that CDOP is an audit and research program (PHCN, clinic 7).

Nurses had previously been paid for research enrolment and this affected how they viewed the outreach program:

> If the CDOP uses patients, then if it can assist us nurses in getting paid when conducting the research (PHCN, clinic 9).

The nurses did acknowledge that CDOP had improved quality of care for patients, added value to patient management and their work and improved the use of existing resources, such as noting better control of patients on the program, easier referral and consultation with a specialist and improved use of laboratory investigations all members of the clinic team. Managers in the clinics, at the regional head office and in the provincial government all expressed support and this was documented in the diary recordings during 'feedback report meetings'. At the presentation to the Gauteng Health Department executive committee (see

point 24 on figure 37), there was unanimous support for the program to be supported financially and be assisted with development in its current region and then to other regions.

> CDOP has helped so much with the chronic patient (PHCN, clinic 20).
> It (CDOP) provides effective nursing management and allows early referrals to the relevant department (PHCN, clinic 1).

On direct questioning, time constraints were not considered a factor affecting enrolment and follow up. However, from the diary recordings and again from the questionnaire under domains 'CDOP as an extrinsic characteristic', 60% of PHCNs acknowledged that if enrolment was quicker, they would have enrolled more patients (Appendix 8a and 8b).

> The CDOP program is a good tool to use for the sake of treating patients, provided that the clinicians are given enough time to spend with the patient in order to get the patients consent and then provide the best treatment (PHCN, clinic 8)
> (PHCNs) complained of no time to enrol patients and to do follow up checks (PHCN, clinic 15).

In the motivational survey, PHCNs either agreed (59%) or were unsure (81%) if the program was too time consuming or had impacted on their ability to enrol more patients. Unfortunately doctors in the clinics failed to endorse the program, seeing it as a nurses program. This influenced uptake and integration. In addition, doctors and nurses were suspicious of the program and there was poor support from local clinic management to integrate the program. The poor integration was a result of a breakdown of communication between 'head office' and 'clinic managers'. The 'senior' head office managers were unable to provide the necessary support to implement this integration. This would have required visiting the in-service education meetings, made a personal effort to be seen supporting CDOP and sent clear directives through the assistant directors to the clinic coordinators and nurses. All these issues affected CDOP's ability to integrate into the clinic service as 'a standard' method for chronic care.

> Local clinic doctor seemed to appreciate program, but reluctant to commit involvement ….program not able to work without general support and integration into clinic by management… and (CDOP) is seen as 'special program (PHCNs, clinic 14).

Many nurses and managers during report back meetings expressed the value for integrating a CDOP system into the clinic and, especially, including it for managing HIV. In the questionnaire, again evaluating CDOP as an 'extrinsic' motivational factor, 90% felt positive about the CDOP system and would like it as the 'standard' method for specialist referral. A further 88% of PHCNs indicated they would appreciate having more nurse program coordinators linking them to a specialist centre for easier referral (Appendix 8a and 8b).

> The CDOP program is very interesting and supports us…. I wish this could be the standardized practice in our province to manage chronic diseases (PHCN, clinic 1)
> This (CDOP) should also include the HIV treatment side (PHCN, clinic 9).

However, three related factors had a major negative impact on the ability to enrol patients, integrate the program, change the 'delivery system design' and carry out follow up effectively. These were the work load, staff shortages and nursing staff turnover in the clinics. The latter fact was well recognised by the PHCNs and was a recurrent issue discussed at CDOPs focus groups and planning meetings. As the program progressed, it had become clear that PHCNs were being trained by the CDOP nurse program coordinators to run the program in their clinic, and then were resigning. Reasons for resignation included dissatisfaction with working conditions and not receiving a 'scarce skills grant', known as the "occupation specific dispensation" policy, poor pay compared to local clinics and better opportunities working for NGOs or in the private health sector. For these reasons, clinic staff turnover was evaluated by the nurse program coordinators at the end of the program (Table 18).

Table 18. Primary Health Care Nurse Turnover

Clinics No	PHCNs Start*	Resigned& Retired#	PHCNs End$	% Lost
15	12	7	5	58
9	13	3	10	23
10	13	2	11	15
18	12	3	9	25
20	16	7	9	44
5	5	3	2	60
14	3	0	3	0
17	12	7	5	58
19	3	0	3	0
2	12	4	8	33
1	12	9	8	75
3	7	1	6	14
4	12	7	7	58
12	12	2	12	17
13	6	4	5	67
11	11	2	11	18
6	5	1	4	20
7	7	1	6	14
8	6	0	6	0
16	7	3	5	43
Total	***186***	***66***	***135***	***51*****
Average/clinic	***9***	***3***	***7***	***32***

*PHCNs Start – primary health care nurses at clinic at start of program; # Resigned & Retired – numbers of PHCNs who resigned or retired during program; $ PHCN End – PHCN at clinic at the end of the program; *% percent lost over the two years of the program; ** Total nurses lost over 2 years

Continuous staff turnover impacted not only on staff morale but also on commitment to the program. It also affected our ability to train PHCNs in the detection of patients with high risk

CVD and CKD and the outreach program functioning i.e. enrolment and referral, this was documented in the diary recordings:

> High turnover of PHCNs was affecting program. Every time one PHCN showed interest she would leave and nurse program coordinators would have to train a new person" (CDOP Planning Meeting, diary recording)
>
> Introduction and retraining of CDOP to the clinics again since there are new members who joined the PHCN staff; it becomes difficult for the old staff to explain to us about CDOP (PHCN, clinic11)
>
> At the facility where I work it was started (CDOP) but due to people resigning it just died a natural death (PHCN, clinic 1).

The staff reduction ratio was 27.4%, and there was a total loss of 51 PHCN staff members over 2 years, (i.e. Total PHCNs pre-program – Total PHCN post program divided by Total PHCNs pre-program)

Many clinicians complained that the patient load affected their ability to enrol onto the program and this was aggravated by the constant staff shortages and high turnover. Fewer staff members meant nurses had less time to enrol patients and see them at follow up.

> The problem with our clinic is that nurses are unable to adopt programs that are valuable because of staff shortage (PHCN, clinic 13)
>
> The problem is that it (CDOP) cannot be adequately practiced as the clinic has a very high number of patients and the nurse clinician is still expected to see the same number of patients and enrol them and see them again later (PHCN, clinic 8).

Documentation of the challenge resulting from staff turnover is well described from these three excerpts and they explain some of the reasons for loss of follow up.

The enthusiastic health promoter has since retired and patients come to the clinic and do not know where to go (PHCN, clinic 4)

The local authority established new clinics in the new houses and informal settlement around this clinic and a lot of patients started attending these clinics (PHCN, clinic 6)

High turnover problem - one nurse left for TB coordination, three joined the local authority, one left for the HIV research centre (Program NCO, diary recording).

Factors documented from the diaries around staff turnover included nurses resigning to private health care, moving to local city council clinics, or to NGOs or moving overseas, and the inability to constantly retrain staff about enrolment and following up patients on the program. Considering that the program was established to provide a mechanism to improve patient care and referral, evaluating the program in the questionnaire to assess its value for the PHCN was an important component of the overall evaluation. Despite the challenges outlined above, Figure 41 still demonstrated the positive value the program had on PHCNs, especially for those choosing to remain involved in the program, and with regard to management decisions and specialist referral.

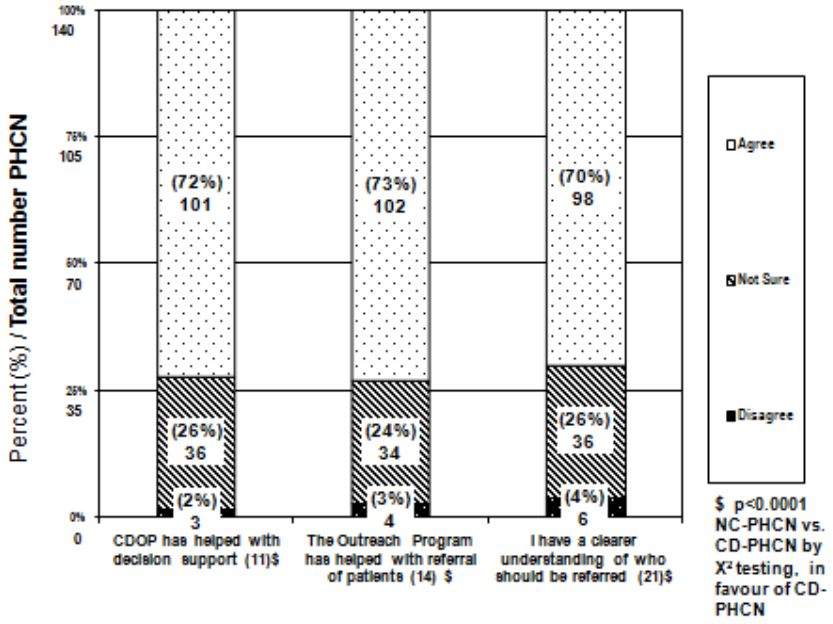


Figure 41. Health Worker Survey - CDOP Evaluation

Note: Answers to questions from Health Worker Motivation Conceptual model – Domain Perceived Contextual Factors -Motivation Determinants - CDOP Questions – Extrinsic Characteristics

NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

Evaluation of Health Care Organization and Policies

This section focuses on the investigation of factors impacting on implementation relating to the existing health care policies and organization of the primary health sector, and its interaction with the tertiary health care service in Soweto. The factors explaining the outreach programs success and failings against these issues are outlined in this section.

Health Care Organization and CDOP

As outlined above, a major concern for the CDOP organisers was the loss of follow up of patients on the program. Some of the issues are covered in the section above, but those factors pertaining to health system issues and policies are discussed in this section. These include challenges such as PHC nurses not being available for the CDOP patients at their follow up visits. Reasons included issues such as being assigned to work in areas in the clinic other than the 'chronic' clinic e.g. tuberculosis, family planning or STI (sexually transmitted infection) clinics. This demonstrates a lack of integration of CDOP by managers, but also relates to problems within the clinic systems where competing demands impacted on delivery. Nurse clinicians regularly documented that they were sent to relieve or work at other clinics as part of their 'normal duties', or because other clinics had staff shortages. PHCNs had to rotate within their own clinic between different sections. Sections such as the tuberculosis clinic or 'acute problem' clinic are seen as separate entities, and here nurses do not move around once allocated for the day or month. This included the 'chronic section' responsible for HTN and DM patients which was part of the program. The nurses and clinic did not function as a single team, like a 'family practice' should work, with all nurses being responsible to see any patient who arrived at the clinic on a particular day. The clinic rather functioned as individual and separate clinics, with almost separate staff for each clinic e.g. TB clinic or HTN clinic

> Friday 28-01-05 Reported at (clinic 1) to find clinician doing CDOP gone to help at (clinic 20) (NCO diary recording during follow up visit to clinic 1).

> The clinicians who had enrolled patients also had to change and rotate e.g.: look after T B patients, work in casualty. The change caused the patients to be lost when coming to the clinic for follow up (NCO diary recording during follow up visit to clinic 3).

Follow up challenges included patients being frustrated with lack of continuity of care in the clinic, especially with CDOP. Patients chose not to participate in CDOP any longer, although they continued to come to clinic. This issue was demonstrated in the 'clinical and functional outcomes' section in figure 29, as those patients 'not followed in the clinic and lost to follow up'.

> When the motivated clinician was off duty, patients would have no one to look after them, making them to be discouraged (NCO diary recording during follow up visit to clinic 16).

There was also regular documentation in diaries about PHCNs who were ill or on leave, and who were not replaced or accounted for by managers. Staff shortages meant that commonly no other nurse was able or prepared to see the CDOP patients.

> The patients would have no one to look after them when the (program clinic coordinator) was not at work i.e. on leave or off duty (NCO diary recording at follow up visit clinic 11).

NCO and PHCNs highlighted the problem that clinic managers accept many 'special programs' in the clinics, and this issue further impacted on their ability to effectively track patients on the outreach program. This issue was validated in the motivational questionnaire domains evaluating clinicians working and organizational environment in figure 42. The questionnaire returns confirmed that the organizational environment was chaotic, and nurses felt isolated from management, overworked and were impotent in decisions that impacted on their work environment. This is further confirmed by the diary recording extracted during thematic

analysis around the domains of organizational environment and working environment (Figure 25)

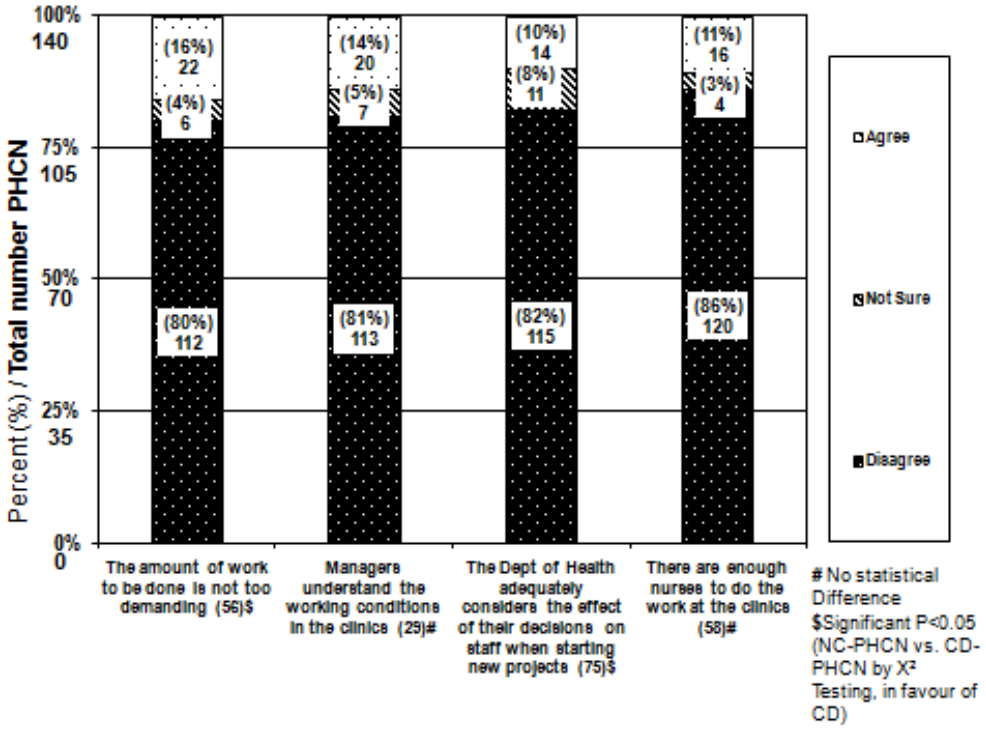


Figure 42. Policy Factors impacting on Staff Motivation
Note: Questions from the motivational survey section 'motivational determinants', perceived contextual factors – 'Job', 'Organizational Environment' and 'Work Environment'
NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

> The organization around the program is very poor… (there is) no team work, (it) seems each (PHCN is) doing their own thing. Also the original nurses involved in program have left (PHCN, clinic 1)
>
> Found only three PHCNs during visit to check patients overdue for four monthly follow up…
>
> Challenges were patients do come for follow up but the nurse is unable to follow them up as she is allocated to other departments e.g. STI and HIV clinic (NCO diary recording at follow up visit clinic 11)
>
> Follow up is not so good (and this is) due to PHCNs having to rotate to other parts (of the clinic) e.g. STI, TB etc… (there is) also problems tracking results - delay in NHLS results (coming back) and (nurses) miss patients (Focus Group, clinic 4)

The last quote highlighted the need for team work and integration of responsibility, and noted that lack of the efficient collection of results and delays impacted on patient enrolment and follow up. The reliance on the 'National Health Laboratory Service', as the preferred provider for laboratory and pathological investigations was another policy and organizational problem documented during focus groups and clinic visits.

> CDOP is done in our clinic I suggest that every PHC nurse to be given a chance so that we all know about it and what to do to the patient and everybody is involved (PHCN, clinic 20)
>
> CDOP should be for all nurses not just PHCNs, this may improve team work (PHCN, clinic 13)
>
> Currently we are experiencing problems with the NHLS otherwise the results are not reflected to make it possible for us to enrol patients on CDOP; they are late or never arrive at all (PHNC, clinic 1).

Some patients were not identified when they returned for visits. This was another reason for patients 'not being followed in the clinic and lost to follow up', prompting nurses to suggest:

> (CDOP managers must make) use of stickers to identify CDOP patients for clinic staff to know the patients (PHCN, clinic 13)
>
> Patients disappeared into the clinic. Many do not want to wait. Also (here is) no real system and no way of identifying CDOP patients (PHCN clinic 16).

The program had no mechanism initially for tracking these patients and responded, in keeping with the action research methodology, to attempt to mark CDOP patient files with stickers. The aim was to improve follow up as there was no means of identifying CDOP patient when they returned to the clinic, especially if the CDOP PHCN was not there. These problems impacting on follow up were also highlighted and confirmed from the thematic analysis coding of

the diary recordings, as shown in Figure 43. The issues outlined above are complicated and multiple factors are implicated in the functioning of the clinics and the CDOP.

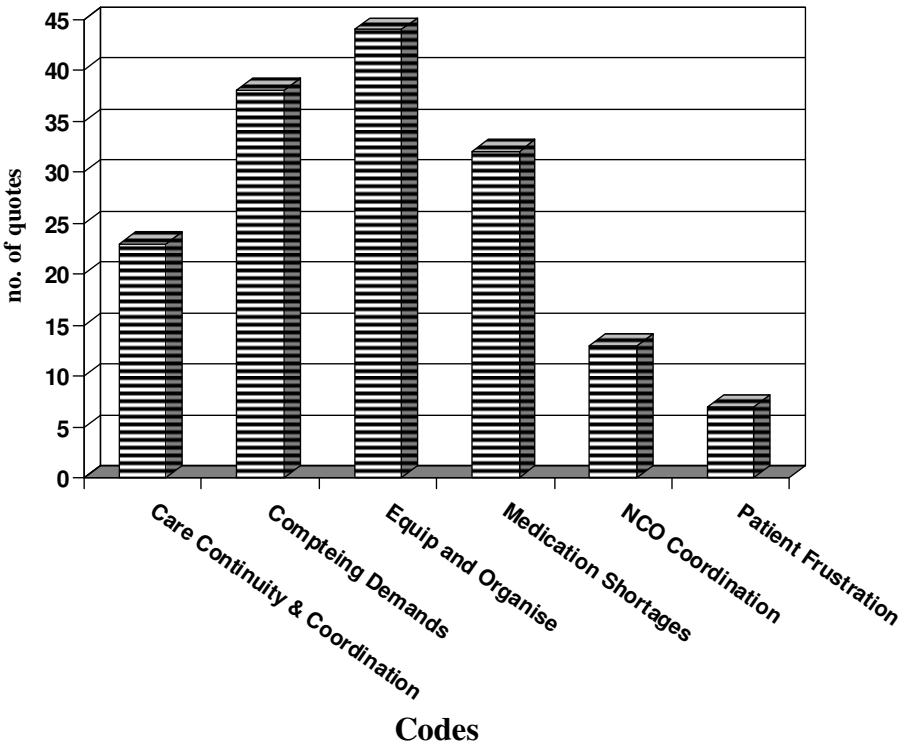


Figure 43. Health Care Organization Issues
Note: Figure outlines the quotes coded in the thematic analysis as being related to health care organization i.e. WHO Health Care Organization code

Other issues of health care organization which effected patient enrolment and follow up included claims by nurses that patients were 'migrants' coming from distant areas or patients had moved to other areas or to a different clinic. The comments that migrant issue was perceived as larger by PHCNs and may have reflected prejudice rather than the truth This issue appeared to be a relatively small factor, affecting only 24 patients (4%), and has been documented earlier (see figure 29). However, diary recordings indicate that this issue was larger than suggested in the clinical and functional outcome evaluation.

> The people in this clinic are highly rural, sometimes they would go to Limpopo for more than 6 months, nurses would then lose follow up times, (NCO, diary recording during training visit at clinic 1).
>
> Some (patients) said they do not reside here but came to visit, others said they would have problems with their employers about visiting the clinic monthly as they are domestic workers (NCO, diary recording during training visit at clinic 8)

There were also delays in follow up forms arriving at central data collection point for capture and analysis. This would have caused delays in notifying patients who required referral to specialist clinic. The delays in 'feedback forms' also related to the fact that they were being typed by only two nurse program coordinators, who had other program administrative responsibilities. The issue of delayed results from the national laboratory (NHLS) would have been a compounding factor too. These challenges highlighted the call for more nurse program coordinators to support the program and clinic nurses.

> Also delays in (laboratory) results getting to PHCs. Noted delays also with forms often means patient gets lost if do not get feedback report at (the patients) next clinic visit. Not achieving a two week turnaround time. Nurse program coordinators have too much work - typing feedbacks and doing follow up tracking (CDOP Planning meeting notes)
>
> Complained about (blood and urine) laboratory results not received on time - often wait two weeks for delivery as cannot phone for result (no clinic phone), by this time have lost patient and cannot find them (Focus Group, Clinic 11).

Included in the evaluation was the 'organizational environment', a code derived from the health worker motivation model. Factors associated with the clinic organization were assessed under these codes in the diary recording. The aims were to ascertain whether the program and clinic environment supported the program and provided an enabling environment.

I would like that the program be cascaded (spread) to other health workers even if they are not directly involved in managing patients (PHCN, clinic 11)

No team work, admin clerks were not involved and did not help with data collection especially the demographic information, this made it difficult for PHCNs to do it alone (CDOP Planning Meeting).

The success of CDOP also depended on a well functioning clinic, with management support at both the local clinic level and 'senior' regional and provincial levels (Figure 44). The lack of implementation or ability to scale up the program was limited by management support. Poor functioning systems included the lack of provision of adequate supply of appropriate medication and equipment. This was evaluated in the thematic diary recordings and the questionnaire (Figure 45).

Management seems completely unaware of the problems and challenges in the clinics (CDOP Feedback Meeting, program director diary recording)

Pharmacists are needed at the clinics and drugs for decreasing cholesterol should be made available (PHCN, clinic 7)

I wish our clinics could be better equipped with modern equipment and computers and medication made more available at all times for patient (PHCN, clinic 10)

Another big problem was no pharmacist at the clinic … often short of drugs (such as) perindopril (ACE inhibitor)… No glucophage for past 3 months (NCO diary recording follow up visit clinic 17)

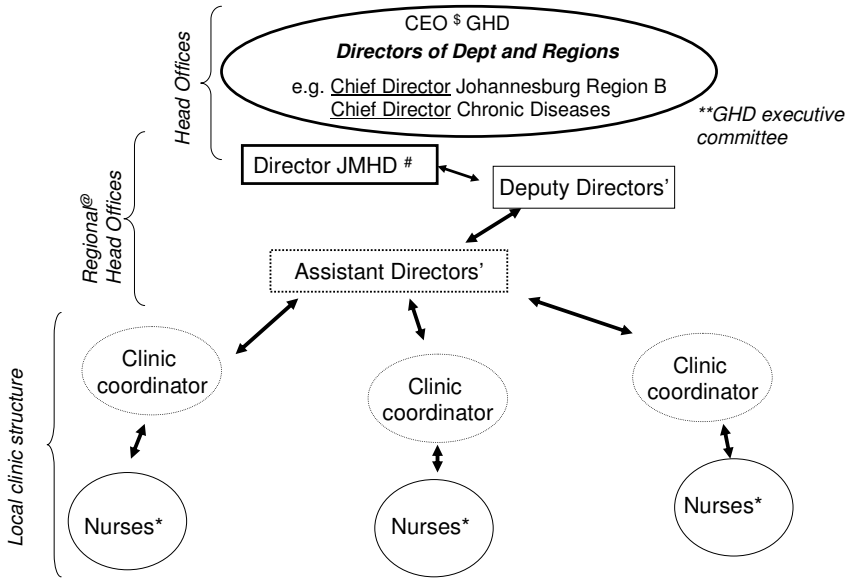


Figure 44. Gauteng Health Department Management Structure
$- CEO – Chief Executive Officer; ** GHD – Gauteng Health Department; #JMHD – Johannesburg Metropolitan Health Department * Nurse – includes nurse assistants, staff nurses professional nurses, and PHCNs; @ - There are few Regional Head Offices in the Gauteng Province
Note: has been simplified

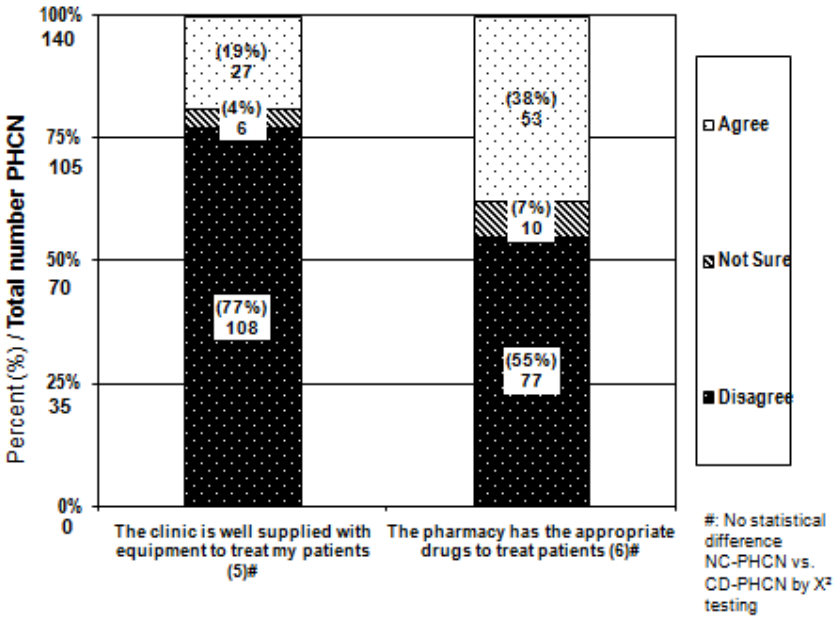


Figure 45. Questionnaire Working Environment Evaluation
Note: These answers are from the 'motivational determinants' evaluated in the health worker motivation questionnaire under 'perceived contextual factors – organizational environment and working environment' impacting on health worker motivation (see figure 25)
NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

> These include shortages of medication - regularly run out of some medications and patients do not come back to collect them at a later date (Focus Group, clinic 4).
>
> Challenges are drug shortages…. No urine dipsticks…. No strips for haemoglucotest (glucose recording) machines (Focus Group, clinic 12).

The above diary excerpts and question answers in figure 45, confirm the fact that PHCN felt isolated from their 'senior' management and frustrated with medication and equipment shortages. Follow up challenges can be summarized as CDOP nurses not being available to follow up the cohort patients for numerous reasons which included: nurses working in another area of the clinic or being ill, and no other PHCN prepared to see program patients. Other challenges included PHCNs being sent to relieve or work at other clinics as indicated above. The resultant problems included patients who were frustrated with delays and left without being seen, were 'migrants' and returned home, or moved to another area in Soweto. The CDOP 'high risk' patients were not 'flagged' or referred, and delays in follow up forms arriving at the central data collection point for capture and analysis further impacted on organization of the program. Loss to follow up may also have been affected by delays in 'feedback forms' being typed by nurse program coordinators and delays of results arriving from the laboratory in time when the patient returned for their next clinic visit (see figure 46). Finally there was a lack of communication between 'senior' regional management and PHCN clinicians, with nurses being frustrated and concerned with their working environment.

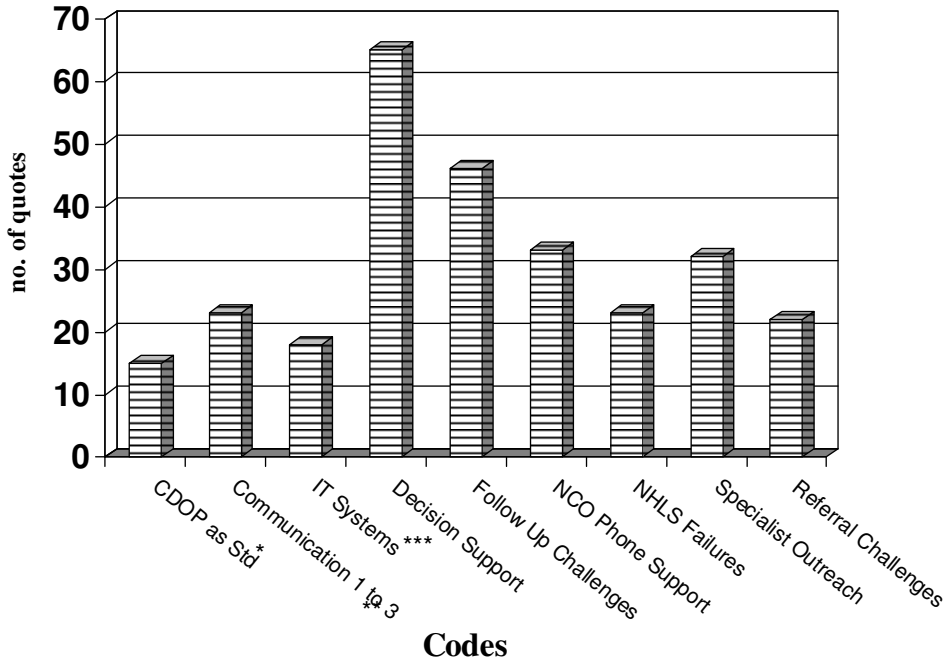


Figure 46. Thematic Analysis of Health System
*CDOP – Chronic Disease Outreach program as standard method of managing chronic care; **Communication 1 to 3 – communication primary to tertiary health care, *** IT Systems – Information Technology Systems; NCO – Nurse Program Coordinator; NHLS – National Health Laboratory Service
Note: See texts for additional explanation of each code

Thematic analysis involved using the Wagner model themes to guide the program and health system evaluation. A good example of a positive initiative arising from the program was the development of a 'chronic disease stamp' to assist nurses. However, its difficulty with implementation is also highlighted by the fact that nurses ran out of ink to use the stamp.

> Discussed the 'chronic stamp' that PHC school had designed…. the stamp was to reduce workload of PHCN and…. reflect all the patients' problems in one place (CDOP Planning Meeting)
>
> We have difficulty using stamp because there is no ink for it at all clinics or clinics run out of ink (CDOP Planning meeting, diary recording).

Evaluation of the 'delivery system design' included the evaluation of primary care to specialist care communication and specialist or program support. It also incorporated the referral challenges which nurses faced. All of these themes related to the issue of 'decision support'. PHCNs noted the importance of being able to communicate with specialists for support, and pointed out the value of having CDOP nurse program coordinators to act as a liaison between primary care and specialist care. Communication improved as PHCNs and NCO could communicate more easily, e.g. by direct phone calls to CDOP NCO office, and they received feedback about patients who were referred.

> We need to be able to communicate with specialists easily in case of problems we encounter with regard to patients (PHCN, clinic 20)
>
> CDOP trained nurses it will allow us to communicate with the CDOP (NCO) sisters more easily (PHCN, clinic 15)
>
> They (PHCNs) see value in the program for they get decision and support, feedback on how are they doing, easy consultation and access to doctors at tertiary hospital level (Focus Group, clinic 18)

Thirty two quotes (see figure 46) were documented in the diaries which indicated improved ability to refer patients to a specialist and the value of specialist outreach to the PHC clinic. Nurses indicated that CDOP improved referral to a specialist through 'decision support' systems:

> CDOP will also help with completely treating and managing chronic patients directly and without having them lost somewhere in the system before reaching the right people in the hospital (PHNC, clinic 15)
>
> Blood pressure has been controlled with decision support and due to fast up-scaling of medication through CDOP (Focus Group, clinic 4)
>
> Did appreciate having CDOP for referral and many patients appreciated this aspect of CDOP. Referring was easy and patients appreciated going directly to specialist clinic.

> This helped with enrolment and PHCs often focused on pts who they thought would need a specialist opinion (Focus Group clinic 17)

Many clinicians indicated that a CDOP method of organizing the health system should be adopted as a 'standard' method of managing and referring patients reflecting not only the value of the program discussed earlier but the improvement to ‘delivery system design’.

> (CDOP) must be done by all PHC sisters in the clinics, so as to have a clear understanding of all patients and how to refer them appropriately (PHCN, clinic 10)

Over 65 quotes commentated on the value of ‘decision support’ that was provided or improved through the program (see figure 46). This included the ‘patient feedback reports’ delivered by CDOP nurse program coordinators (Appendix 5), and included nurses receiving letters of authority from CDOP allowing medication prescriptions for HTN medication and insulin. In fact, some PHCNs documented their skills development in chronic illnesses management, which was valued by other nurses at their clinics.

> If we are not sure then we have the opportunity to discuss the patients’ conditions with the CDOP nurse coordinators and doctor. This will avoid unnecessary referrals and patients being sent from pillar to post and therefore unnecessary travel (PHCN, clinic 15).
> Sister phoned worried about abnormal blood results of CDOP patient. GFR calculated and found to be low and the patient was referred to ROPD (NCO Diary recording, phone call)
> I now know when to refer patients to hospital for management and when to manage patients at the primary care level (PHCN, clinic 13)
> (CDOP) letters of authority and new protocols delivered to the clinicians and the (clinic program) coordinator (NCO diary recording).

Follow up challenges could also be considered under 'delivery system design', although already described in the section above. On a positive note, the nurse program coordinators proved to be a valuable resource for providing quick efficient 'decision support', via phone calls from the nurses in the clinics (see figure 46).

> Received two phone calls one from …..... clinic PHCN enquiring about a patient…. a second call was from (clinic) PHCN (who) was having a patient that reacted from Adalat (nifedipine – calcium channel blocker) and needed support and management from the specialist (NCO diary recording).

The use or failure of clinical information systems to support both PHCNs and the program was assessed. This theme code indicated the need for an information system, when a clinician found CDOP's data information evaluations and system to be valuable.

> The feedback recommendations from CDOP take too much time….. Also to have the documents sent to CDOP takes time... this can be resolved with computers and better equipment e.g. fax….but I would like to thank the CDOP team for accepting my patients without hesitation or refusal and managing them well (PHCN, clinic 8).
> PHCs also complained about delay in NHLS bloods coming to clinic or not at clinics when wanting to enrol … nurses discussed computer process of direct deposit of results into CDOP (data base) (Focus Group, clinic 8).

Thematic analysis diary of recordings of 'delivery system design', 'decision support' and 'information systems' are summarised in figure 46 above.

Health System Policy Factors

A positive policy environment, as outlined by the WHO, remains a key determinant of the success of a chronic illness management model (see figure 5). Policy factors are not acknowledged in the Wagner model, but in keeping with the WHO ICCC they were considered a

very important component impacting on the outreach program. These policy factors impacting on CDOP were evaluated during the thematic analysis and the appropriate codes were created and quotes from diaries were counted (figure 47 and Table 19**)**. A positive policy environment impacts on the willingness of health workers to be motivated to deliver health care and especially to volunteer for a 'special program' like CDOP.

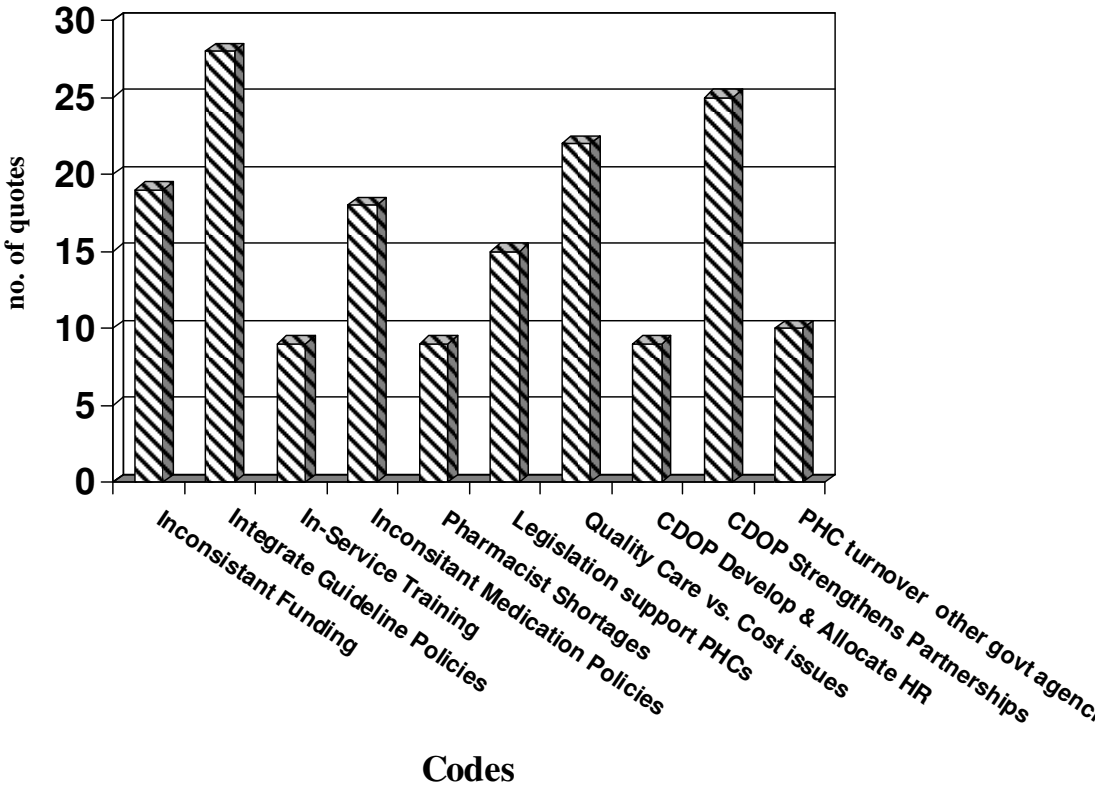


Figure 47. Positive Policy Environment Evaluation

Table 19. WHO ICCC Framework - Positive Policy Environment

Codes (10):

1. Funding Inconsistent - WHO - PPE (9 quotes)
2. Guideline and Training Uniformity - Integrate Policies - WHO - PPE (27 quotes)
3. In-Service - Clinic vs. Centralised - HW Education/Knowledge - PPE WHO (9 quotes)
4. Medication - Inconsistent Policies e.g. EDL/ACE/Insulin - Integrate Policies - PPE (18 quotes)
5. Pharmacist shortage- Develop & Allocate Human Resources - WHO - PPE (8 quotes)
6. PHCs - Need Support through Legislation for Clinicians - Support Legislative Frameworks - PPE (15 quotes)
7. Quality Care vs. Cost Efficiency - Promote consistent financing - WHO - PPE (22 quotes)
8. Resources - CDOP Develop and Allocate Human Resources - WHO - PPE (9 quotes)
9. Strengthening of Partnerships - Chronic Illness Network - WHO - PPE (24 quotes)
10. Turnover - Local Authority clinics - Consistent financing - WHO - PPE (10-quotes)

Evaluating the program nurses' environment, and assessing the promotion of consistent funding revealed discrepancies in salaries between provincial and local government nurses, and even between different programs. A recent initiative of a 'scarce skills payment' for specialist nurses, known as the occupation specific dispensation (OSD), did not include primary health care trained nurses, but only hospital based nurses e.g. maternity, ICU nurses. This amounted to 'inconsistent funding' for the primary clinics' nurses compared to hospital based nurses and with regard to the supply of medication. For example, anti-lipid medication was available only in certain clinics and at the specialist referral hospital.

> Clinic X Time: 09h00 - Found 2 PHCNs (and) clinic full**.** Other PHCNs on go slow strike for scarce skills allowance (NCO, diary recording at follow up visit)
> Also discussed up and down referral and that patients are referred for high cholesterol only - to investigate cholesterol testing and medication being more available and on CDOP request - seemed like only Clinic L allowed to do cholesterol testing or does it routinely (Focus Group, clinic 7 and Feedback Meeting Johannesburg Metro Health Dept managers)
> Problems again with doing 'routine' blood tests e.g. HbA1c. More concern from management about money than quality of service (Focus Group, clinic 12)
> High turnover-one nurse left for TB coordination, three joined the local authority, one left for the HIV research centre (Focus Group, clinic 4).

Assessing 'policy integration' and the integration of disease management guidelines and training policies revealed a number of discrepancies (28 quotes). It was noted that PHCNs' used multiple different guidelines, and most often used guidelines from their Soweto PHC School, and regularly consulted the National 'Essential Drug List' manual, and very rarely or almost never consulted guidelines issued by specialist societies .e.g. endocrine or nephrology. There was no simplification of treatment targets and policy was not unified or standardised.

> Some nurses can start insulin others not……. not sure whether PHCs get to read new guidelines…. seem to use guideline originally learned (most follow PHC school guidelines), some EDL - none look at specialist society guidelines (Focus Group, clinic 20)
>
> The clinicians' in-service training should run chronic disease management in-services so as to ensure uniformity in treatments (PHCN, clinic 15)
>
> Nurses complained of no support and no authority to give medication or even increase dose of perindopril from 4mg to 8mg without doctor (Focus Group, clinic 19)

The 'development and allocation of human resources' was evaluated in the questionnaire, but thematic analysis from diary recordings revealed problems with the allocation of human resources and the establishment of referral processes. Nurse clinicians complained about the challenge of seeing patients, then dispensing medication and doing other administrative tasks. This was a result of no pharmacists being available in most clinics.

> The local authority (health service) established new clinics in the new houses and informal settlement around this clinic and a lot of patients started attending this clinic (NCO diary recording follow up visit)
>
> Another big problem for patients being lost was that Helen Joseph and Leratong Hospitals are often the closer hospital for their patients and Bara is too far away and therefore did not want to go there (Focus Group, clinic 3)
>
> PHCs complained they also have to dispense drugs besides just seeing patient (Focus Group, clinic 1)
>
> (PHCNs) have difficulties attending continuing medical education training at (CDOP) clinic because transport not always supplied and cannot leave clinic due to patients waiting for treatment (Diary Recording NCO follow up clinic visit)

A 'supportive legislative environment' was one of the policies evaluated, and was necessary to empower nurses to implement and run the program. This issue became a problem

when nurses were supposed to act on decision support advice from CDOP 'feedback reports'. PHCNs were not empowered to prescribe the appropriate medication or make management decisions. Some PHCNs could not prescribe insulin or couldn't make dose changes. Nurses were not allowed to refer patients without approval from a doctor in some clinics. Existing legislation did not allow 'lower level' health workers, such as PHCNs, to dispense medication unless they had been on a dispensing course. This proved completely impractical, as most nurses could not attend training and many PHCNs continued to examine and dispense medication themselves. This dual role lengthened patient consultations. They were not allowed to initiate or increase dosing of some anti-HTN medication e.g. calcium channel blocker and ACE inhibitors. It was for this reason that a letter of authorisation allowing PHCNs' to initiate and increase certain common medications was developed by CDOP, as long as the patient was enrolled on the program.

> Nurses complained of no support and no authority to give medication or even increase dose of perindopril to 8mg without doctor, but clinic has no doctor (Focus Group, clinic 6)
>
> There was concern about the initiation of insulin by the clinicians and some guidance was given about the initiation of insulin, but clinicians are a bit scared to initiate without the authority of a doctor or CDOP. It was noted some PHCNs do initiate insulin at other clinics (Focus Group, clinic 19)
>
> (Nurses had) limitations to prescribing drugs…. Need a letter (of authorization from CDOP) to prescribe, even though CCB (calcium channel blockers) are part of established protocols i.e. nifedipine XL – PHCNs unable to increase from 30mg to higher dose (Diary recordings, Johannesburg Metro Health Feedback meeting)

On a positive note, there was much documentation that CDOP provided both 'the development and allocation of human resources' for PHCNs in the clinics and it 'strengthened partnerships'.

(CDOP) told nurses about the growth of program. Cardiology department coming on board and the computer training program for nurses is due to start in March 2005 (Focus Group, clinic 15)

(CDOP) was to try and include diabetes clinic (doctor) in the program (CDOP Planning Meeting diary recording)

Also resolved to involve PHC School as much as possible as this will add credibility to CDOP and get nurses to see (program) is not only for research (CDOP Planning meeting)

Visited clinic with National Kidney Foundation and Rotary Club (who are thinking of sponsoring visits for nurse clinician training in Australia) (NCO diary recording, clinic 18)

Evaluating the Prepared, Motivated and Proactive Health Team

A 'prepared, motivated and proactive' health care team is one of the two key factors considered critical for chronic illness management (Wagner, 2004, World Health Organization, 2002a) (see figure 4 and 5). In this study, the predominant research focus was on the health care team i.e. the nurses and doctors, although some aspects of the patient care and their involvement and attitude to their care was evaluated. However, this was evaluated through the PHCN perspective. It was the Primary Health Care Nurses who were responsible for the delivery of CDOP and they were the group evaluated using thematic analysis, diary recordings and health worker motivation. The nurses' existing knowledge was assessed by using three clinical scenario questions and one risk factor and knowledge question. Section 4 also evaluated the continuing medical education and clinical support environment of the PHCNs (Appendix 8a). The motivation component, (Franco et al., 2002, Penn-Kekana et al., 2005), was also included in this section (Figure 25). Results from the various assessment tools are presented below not necessarily in the order that they were assessed. The models, i.e. chronic disease and health worker motivation models provided the structure for this assessment.

The questionnaire was completed by 140 PHCNs in the clinics, a 75% participation rate from baseline PHCNs (n=186). Table 20 describes the demographic characteristics of the

professional nurses sampled from the clinics. The mean age was 47 years, with some variation, and the majority of these nurses (88%) were trained at the same school i.e. Primary Health Care School in Soweto, Lillian Ngoyi Community Health Centre

In view of the fact that 55% of nurses claimed to have participated in CDOP (CD) and 45% not to have participated in the program, some parts of the analysis consisted of comparisons between those nurses who voluntarily participated in the program and these primary health care nurses are divided into the CDOP PHCNs (CD-PHCN) and non-CDOP PHCNs (NC-PHCN) groups. CD nurses were those who voluntarily participated in the program and NC-PHCN nurses were those who chose not to participate.

Table 20. Questionnaire - PHCN Demographic Information

Questionnaire Demographics	n	%
Nurses	140	
Facilities involved	20	
CDOP PHCNs (***CD-PHCN)	75	55%
Non-CDOP PHCNs (**NC-PHCN)	63	45%
Gender – Females	139	99%
Males	1	1%
Working in 'chronic disease' clinics	125	89%
Trained as PHCs	133	95%
Trained at Central Wits PHC School*	123	88%
	Mean	SD
Mean Age	47.4	±7.25
Years working in clinic	9.84	±6.27
Years Qualified	7.3	±5.7

* Central Wits primary health care school is situated at Lillian Ngoyi community health care centre and was one of the sites involved in the outreach program

**NC-PHCN – non-CDOP primary health care nurses group; ***CD-PHCN – CDOP primary health care nurse group

Clinical Scenarios and Health Worker Knowledge

Four different clinical scenarios were given to the nurses to complete during the self-administrated questionnaire (Appendix 8a). The clinical scenarios covered clinical problems including patients with uncontrolled HTN, uncontrolled DM and proteinuria, and included a case study of a patient with HIV and proteinuria. An analysis of the health worker questionnaire revealed better knowledge and management scores for these clinical scenarios amongst CD-

PHCNs compared with NC-PHCNs (25±7pts (CD) vs. 22±5pts (NC); ANOVA; p<0.0034). A comparison of the means, differences and variance for the total score for the clinical scenario questions between CDOP (CD-PHCN) and Non-CDOP (NC-PHCN) Primary Health Care Nurses is shown in Table 21. A comparison of the means/difference for the total score for the clinical scenario questions a-d between CDOP (CD) and Non-CDOP (NC) PHCNs, using independent t-testing was equivalent to ANOVA, p = 0.0034; 25±5.4 vs. 22±7.1.

Table 21. Clinical Scenario Scores CDOP (CD-PHCN) vs. Non-CDOP PHCNs (NC-PHCN)

Total Questions a-d by CDOP participation	**n**	**Mean**	**SD**	**SE**	
(Non-CDOP – NC-PHCN) 0	63	22.1	7.103	0.89	
(CDOP –CD-PHCN) 1	75	25.3	5.415	0.63	
Source of variation	**SSq**	**DF**	**MSq**	**F**	**p**
CDOP participation	346.7	1	346.7	8.90	**0.003**
Within cells	5297.7	136	38.9		
Total	5644.5	137			

Note: One-way Analysis of variance (ANOVA) between CDOP (CD) and Non-CDOP PHCNs comparing the means and difference for the Total Score for Clinical Scenarios.
NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

In all the questions a-d, evaluated individually, the CD-PHCNs scored better, but this was only statistically significant for the HTN and DM clinical scenarios, i.e. questions a and c; p<0.002 (see Table 22, see Appendix 8b).

Table 22. Clinical Scenario Example – Question C

An elderly woman of 64yrs presents to the clinic with a blood pressure of 160/76 and proteinuria+++ and glucosuria. Her HGT is 9.9mmol/L and HbA1c is 10 and ACR 150mg/mmol . She has been at the clinic for the last 8 years. She is on Gliclazide 160mg bd, Metformin 850mg bd, Nifedipine XL 60mg daily and HCTZ 12.5mg daily. What would be your assessment and management? Please read each statement and indicate whether you would take the action. Tick or circle Yes, or No or indicate if you are Not sure.

Clinical scenario scores showed no correlation with enrolment or follow up in the clinics. Regression analysis looking at factors which may have impacted on the clinical score, such as age of the nurse, years qualified, the facility or years of experience, were not found to be significant. In the analysis of the direct questions in section 4, PHCNs were asked who they would ask for advice if they needed help with patient who had HTN or DM. The nurses expressed a higher likelihood of consulting a colleague, and many preferred asking a PHCN who had participated with CDOP and managed these patients, compared with a doctor or contacting their referral hospital (see question 14, section 4 – Appendix 8a and 8b).

Health Worker Knowledge and Continuing Medical Education

The questions which addressed issues of PHCN knowledge, and continuing medical education (CME) and clinical support, found that 95% of nurses had participated in a learning activity over the past month. Most (41%) had participated in in-service training provided by the PHC School, 30% had been on a 'training course', 4% were registered for a higher degree/diploma or said they undertook 'self-study'. CDOP provided CME to 16% of PHCNs via clinical case teaching during focus groups and from education provided by the CDOP nurse program coordinators. Most PHCNs used the National Essential Drug Listing (EDL) HTN guideline (67%), 65% also used their own PHC School guideline and only 9% the South African Hypertension Society guideline for managing patients with high blood pressure. Eight percent said they used the guidelines provided by the CDOP team. The nurses were then asked when had they learned their latest guideline and from who had they learned it. The ranges were broad for both chronic diseases, but most (49%) indicated they had learned their HTN guideline within

the last 3 years. However, when asked what the 'ideal' blood pressure or glucose target for HTN and DM, the findings were quite different (Figure 48 and Figure 49).

Eighty seven percent (87%) of nurses were much more likely to know a target which would be considered 'controlled' for HTN management i.e. <140/90mmHg compared with only 60% of nurses knowing the glucose target for diabetes management i.e. glucose ≤8mmol/L. On evaluating the last guideline learned for diabetes control, 51% had read the last published DM guidelines.

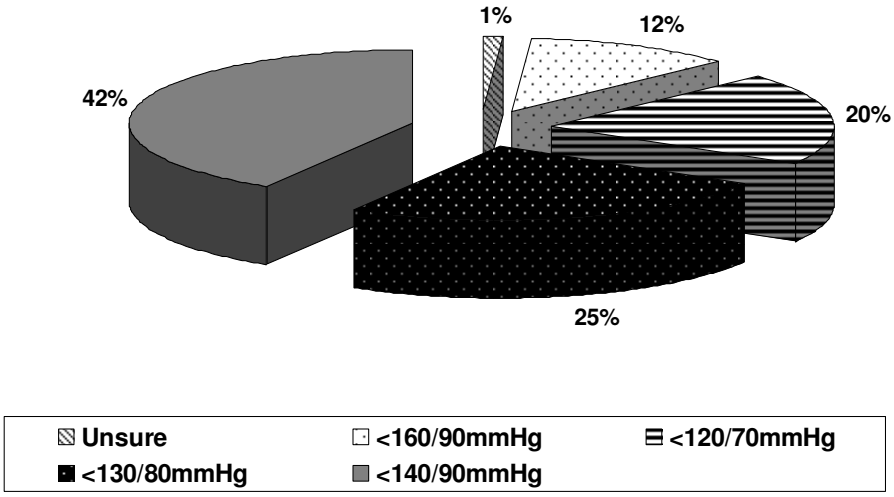


Figure 48. 'Ideal' Blood Pressure targets of PHCNs
Note: 'Ideal' target is that blood pressure at which the PHCN would consider a patient to have a controlled blood pressure

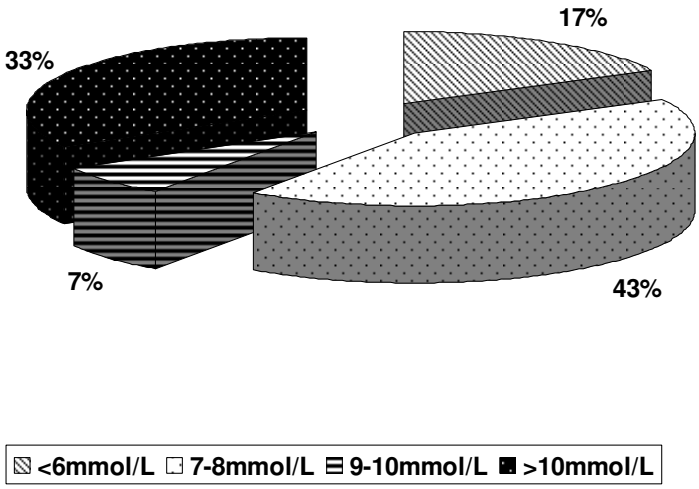


Figure 49.The 'Ideal' Glucose Targets of the PHCNs
Note: Glucose rather than HbA1c was used as a target because nurses did not use HbA1c for diabetes control in the clinics. HbA1c was used for the first time by most nurses when participating on CDOP and therefore could not be used as a comparison.

A quarter of the PHCNs last read a DM guideline more than 5 years ago. The majority of PHCNs (67%) relied on the EDL guideline and 60% on the PHC School to provide the latest diabetes management education. A further 41% relied on in-service training to up-date their knowledge, 30% from training courses and only 1% were self taught. A further 10% said they relied on CDOP for this education. From a clinical scenario question, it was found that CDOP PHCNs (CD) were more likely to know about an HbA1c test and how it was used, and the appropriate targets for glucose control, compared to NC PHCNs (Chi-square; $p<0.05$). In general a target glucose level of <8mmol/L was used by nurses as a clinical target for glucose control.

A code in the thematic analysis evaluating 'organizational justice' revealed nurse frustrated with some aspects of 'In-Service Education' and training opportunities. PHCNs expressed an inability to attend CME due to staff shortages, patient load and transport problems. There were some complaints that management did not prioritise staff development. Some of these issues are discussed further in the 'Health Worker Motivation' section below.

Need to focus more on looking after staff (PHCNs) and developing them as individuals" and "nurses felt ignored and often feel as if management does not care, and managers promised they would support nurses and try to get access to computer lab (Diary Recording, Management Report Back Meeting).

Analysis of Primary Health Care Nurse Motivation

Health worker (HW) motivation was evaluated from the diary recordings, open ended response section of the questionnaire and the questionnaire motivational survey. The conceptual framework defined 22 domains of interest for the motivational survey and some of the more relevant results are described below. Seventy-five questions were selected from existing organization tools (Price, 1997) and the Penn-Kekana study, or developed to cover the domains of interest (Appendix 8a and 8b or 10a and 10b, Figure 25). The results presented in this section are from the 75 motivational determinate and outcome questions that were included in the self-administered questionnaire, which was completed by the nurses working in the clinics participating on the program being evaluated. A complete list of questions distributed according to their domains, including the number of that question, is listed in Appendix 8b.

Motivational Outcomes

There were 9 domains concerned with the outcomes of motivation, worker affect and cognition, but the latter two evaluating 'worker behaviour and performance' were evaluated from the diary recordings only. Eighteen questions appeared to represent the domains interrogating the theme of 'Worker Affect and Cognition'. The picture portrayed was one of great difficulties faced by nurses, including a large patient workload and a management structure not understanding their predicament. This had impacted on nurses' morale. From a positive perspective, PHCNs remain ready to support their institution and deliver on its goals, as evidenced by the responses to selected questions evaluating nurses' motivation i.e. ready to be 'activated and motivated' (Figure 50).

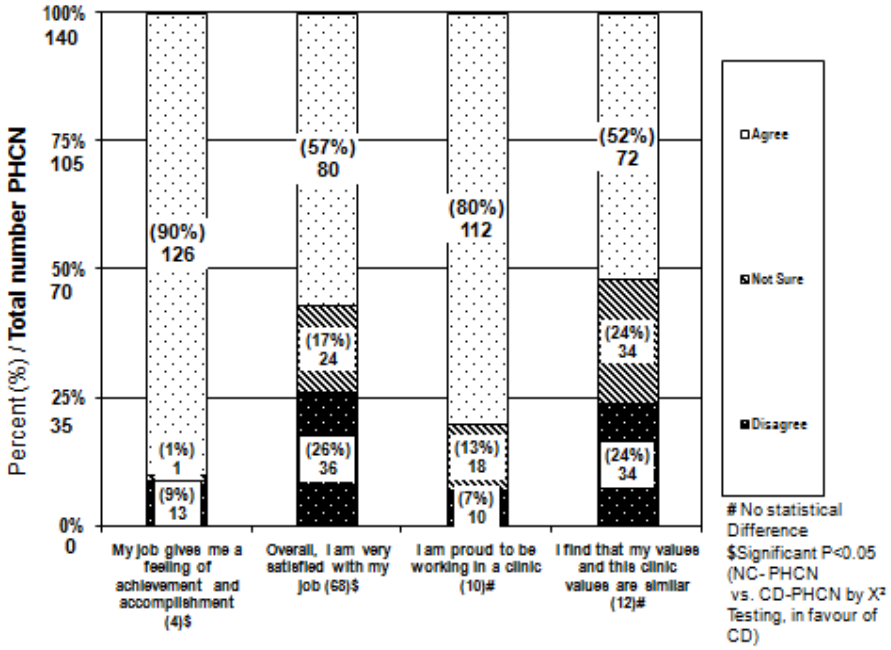


Figure 50. Selected Motivational Responses of nurses in CDOP Clinics
NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

Motivational Outcomes – Worker Affect and Cognition Domain loaded to Factor 1 (Varimax normalized) - Marked loadings are >0.45. None of these questions were excluded after Cronbach alpha correction

Figure 50 shows that 90% of nurses felt their job gave them a feeling of achievement and accomplishment and 57% were still very satisfied with their job. A further 80% agreed that "I am proud to be working in a clinic", and just over half still felt they shared similar values with the clinic or health department. There were significant differences in some of these questions between the CD and NC PHCN, with the latter group less likely to be satisfied or proud to be working in the clinic. However, when evaluating nurses "intention to leave", this did suggest problems with PHCN morale. Over fifty percent of nurses were potentially considering leaving their job, with 31% considering working overseas in the future and 32% were still unsure. More than half the PHCNs supported the possibility of leaving their clinic in the future (Figure 51).

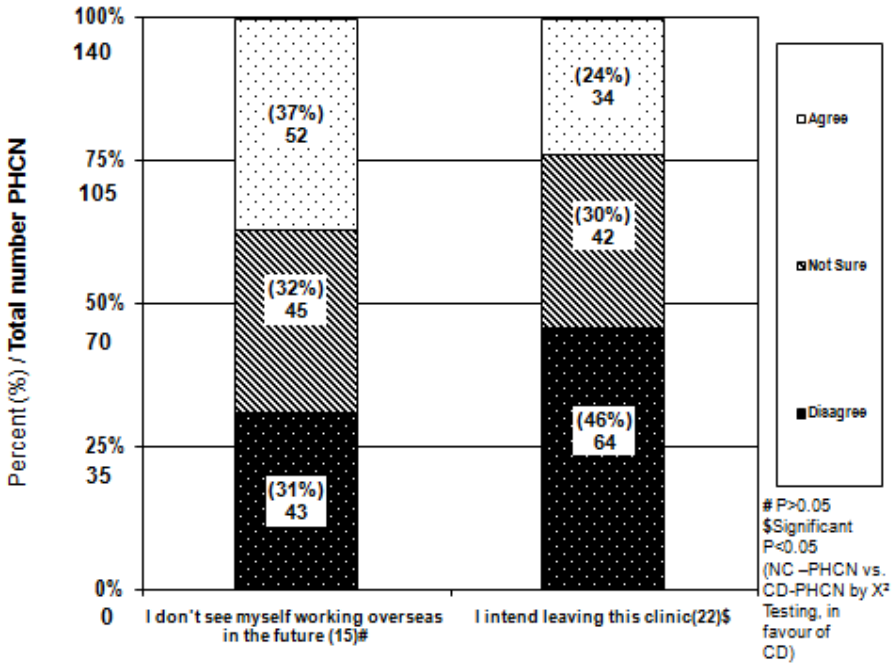


Figure 51. Evaluation of PHCNs Intention to Leave their Job
Worker Affect and Cognition Questions loading on Factor 3 according to factor analysis (Varimax normalized) - Marked loadings are >0.45.
NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

This correlated with the evidence which showed a significant staff and nurse turnover in the clinics which impacted on the ability to implement CDOP, as described earlier (Table 22). It also has serious implication for any programs planning to tackle chronic illnesses like DM, HTN and HIV in Soweto in the future. These indicators of low motivation were of concern, especially as nurses appeared to be suffering from burnt out (Figure 52).

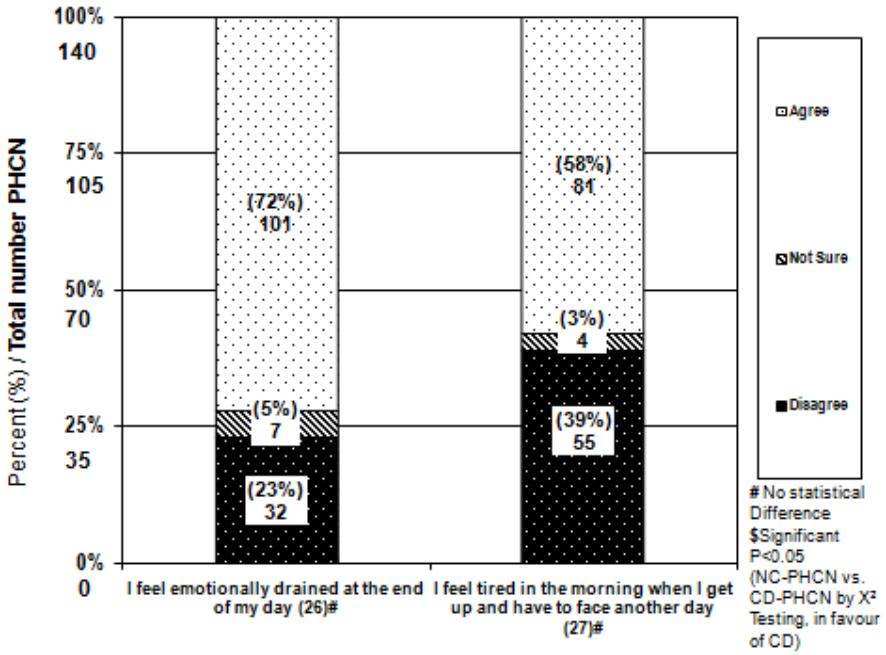


Figure 52. Evaluation of Burnout amongst PHCNs
Note: These questions evaluating burn out were all loaded on Factor 6 with Factor Analysis
NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

The thematic analysis of the domains from diary recording supported the findings outlined above, as seen from figure 53.

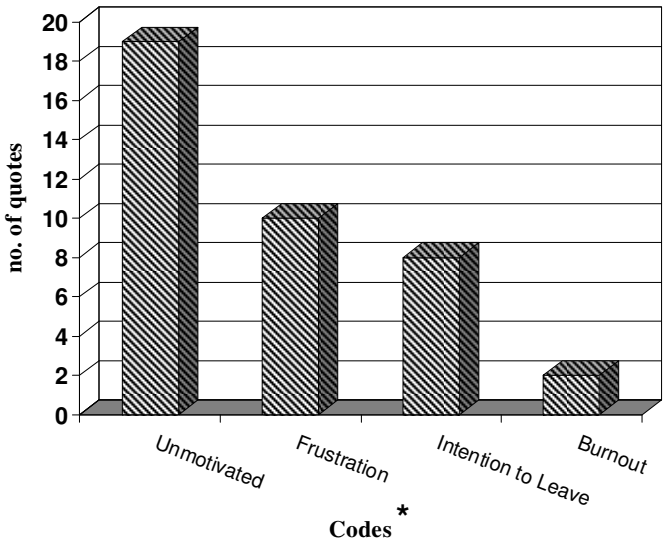


Figure 53. Diary Recordings Worker Affect and Cognition
*Thematic codes comprising of quotes extracted from the diary recordings evaluating motivational outcomes of health worker motivation i.e. primary health care nurses and other nurses

These thematic codes in figure 53 documented when a health worker expressed being unmotivated or showed low morale. It also documented the frustration felt by clinicians, or when clinicians expressed a desire to leave the PHC service.

> PHCs not very motivated, also do not seem to be that interested in patients with chronic diseases…. and (CDOP is) seen as a bit of a hassle, not seeing any value (in program) (Focus Group, clinic 1).
>
> The clinic staff are generally dissatisfied about the running of the services, and most are suffering from burn-out. There is nothing to boost their morale (Focus Group, clinic 6)
>
> Working conditions need to be improved as well as better remuneration (pay)….There are staff shortages and many leave to go overseas and this could be stopped by the motivation of better money (pay)….Nurses and doctors should be recognised for their hard work and good work that they are doing for their communities (PHCN, clinic 10).

The thematic codes specifically covered the attitude of clinicians to patients, although this was better covered in the questionnaire. In the questionnaire, nurses overwhelmingly expressed a positive attitude to patients and indicated their willingness to carry out tasks and do more than was asked of them. Eighty three percent of nurses felt that they "do more than what my job requires" and 67% believed that they "still care for patients like they used to". This probably reflects what was described earlier as a positive willingness, to deliver of the goals of the health organization, or nurses were ready to be 'activated and motivated'.

Individual Motivational Determinants

The individual characteristic domains, evaluated as part of the motivational determinants, again showed a nursing team willing and ready to be 'activated and motivated' (Figure 54), although only 55% of nurses could see themselves continuing to work as a nurse in the future. There were no differences between CD and NC nurses. These questions covered the domains of 'work ethic', 'job involvement', 'locus of control', 'job choice' and 'attitude to change'

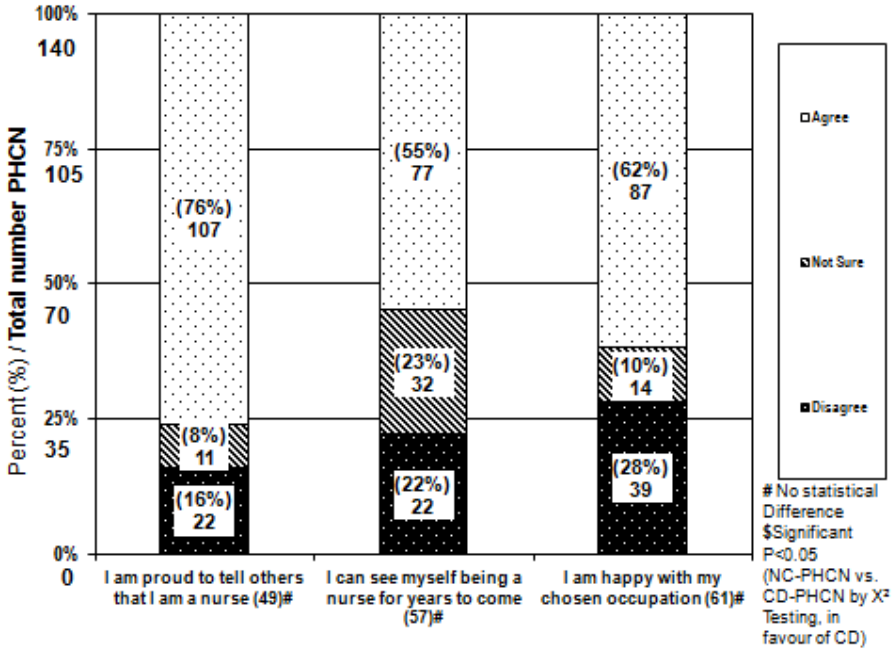


Figure 54. Motivational Determinants – Individual Characteristics
Note: All these questions were loaded on factor 1 and cover the domains evaluating 'work ethic', 'job involvement', 'locus of control', 'job choice' and 'attitude to change'
NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

In general all nurses, both NC and CD, believed they were hard working and "doing their job made them feel worthwhile". They were also confident that they were hard working and their work was of high quality. These domains were however contradicted in domains assessing 'worker behaviour and performance'. As expressed earlier in the diary recordings, 85% of nurses overwhelming felt that their job did not offer "adequate pay compared with similar jobs". Interestingly there was a significant difference in the answer between NC and CD, with CD nurses being happier with their pay; $p<0.05$ by chi-square analysis. Although 65% of PHCNs felt either "in control of things which affect my work" or unsure, more than 70% felt "there had been too many changes in their clinic in the past few years". This reflecting their being frustrated and out of control with decisions being made by senior management (Johannesburg Metro Regional Health Department), discussed earlier.

Worker Behaviour and Performance

These domains were evaluated from the diary recordings as there were no questions covering these in the health worker motivational survey (Figure 55). This was also assessed in the clinical scenarios and direct questions evaluating knowledge (see sections 'clinical scenarios and health worker knowledge') and 'health worker knowledge and continuing medical education'..

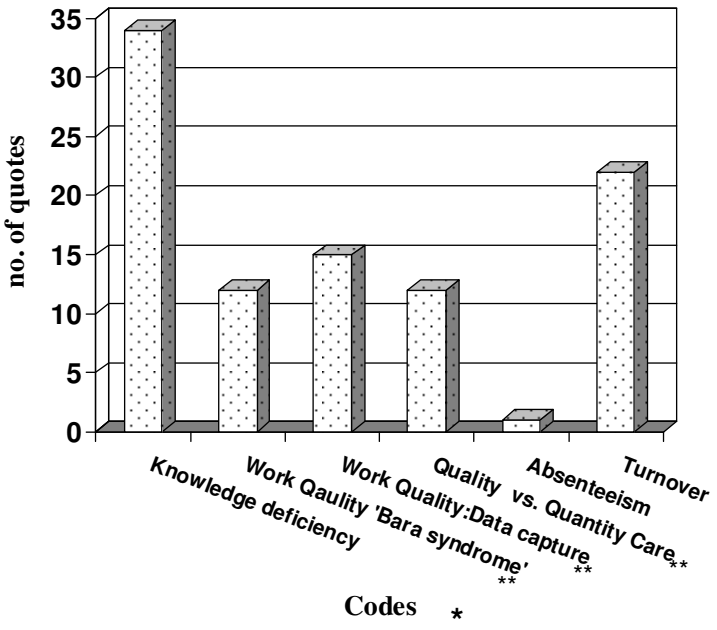


Figure 55. Worker Behaviour and Performance
*Thematic codes of quotes coded from the diary recordings evaluating motivational outcomes of health worker motivation; ** See text for explanation of 'Bara Syndrome', 'work quality – data capture' and 'quality vs. quantity care

These codes investigated knowledge deficiency but also failure in the guideline to provide this knowledge. It included evaluating clinicians' existing knowledge and information relating to the latest protocols for chronic disease management of HTN and diabetes and their confidence to carry out tasks and make decisions. It also relates the PHCs' knowledge of what is 'high risk' and why such people should be enrolled into the program and follow up well. This issue was evaluated from the clinical data by doing sensitivity and specificity testing (see Tables 19 and 20).

An example of knowledge deficiency pertaining specifically to screening for proteinuria is documented in this recording by one of the PHCNs.

> Routine urinalysis in chronic patients is a problem as patients urine is not tested regularly making it difficult to identify problems like proteinuria, blood (haematuria) etc. The only time when urine is tested is when a patient presents with symptoms like BOM (burning on micturition), and it is only then that urinalysis is done (PHCN, clinic 11).

A major concern related to both confidence and knowledge deficiency was that of nurses not initiating insulin, a problem already documented earlier. This also reflected the almost complete absence of nurses to evaluate diabetes control by using HbA1c measurements. It also reflects the complete absence of CKD evaluation as part of chronic disease management.

> Concern about initiation of Insulin by the clinicians discussed and short guidance re initiation of Insulin given, clinicians a bit scared to initiate (Focus Group, clinic 19)
> Discussed nurse training and education around the existing CDOP and specialist society protocols … need to also educate about HbA1c… unbelievably this is left out and nurses are not expected to do this test to follow diabetics - major problem related to poor control…the challenge of calculating GFR was also discussed … need to teach concept (CDOP Planning Meeting, diary recording).

Issues of work quality were covered by a few codes, one referred to as ‘Bara syndrome’. This code reflected the loss of work quality by clinicians when overwhelmed with service responsibilities, who failed to deliver any form of a reasonable quality service, and was named after the tertiary referral hospital thought to be suffering from a similar problem.

> It appears that they (nurses) are overwhelmed with the potential screening problems. One nurse mentioned that since testing albumin-creatinine-ratios (ACR), they are finding

that too many patients have proteinuria. PHCNs just cannot cope! (Focus Group, clinic 15)

There is too much overloading of the (clinics) and then one cannot expect good results (PHCN, clinic 14)

Work quality may have reflected on both training and the motivation to carry out tasks. However the desire not to carry out any audit of work and the difficulties that nurses' experience in capturing data both reflects and causes poor motivation. One of the most critical problems documented with achieving good quality was the failure of clinicians to spend quality time with patients. This arises from managements' failure to emphasize not placing an emphasis on quality and nurses being pressurised by numbers of patients they must examine each day.

Also discussed problems of missing data and that they must write information - seems to be poor attitude to collecting information…tried to discuss value of audit (Focus Group, clinic 8).

At the end of the day you give quantity care and not quality care (PHCN, clinic 10)

(We) need to attend to these chronic patients with more patience, instead of us pushing the queues that are too long. (PHCN, clinic 6)

Worker absenteeism and the high turnover, discussed earlier (Table 23), reflect a major factor impacting on ability to implement CDOP but also on underlying PHCN motivation. This as discussed above impacted on the implementation of the program. Absenteeism was discussed rarely by clinic nurses, probably because we did not ask about this problem and nurses did not want to discuss it, whereas turnover was seen as an issue which could be discussed openly by the nurse clinicians.

Challenges to enrolling and follow-up - too few PHCs, often sick or absent from work, too many patients, other clinic demands - is a big CHC (Focus Group, clinic 1)

Motivational Determinants

Nine domains were concerned with the outcomes of motivation and thirteen related to factors influencing motivation

Health Working Motivation - Perceived Contextual Factors

The diary recordings and questionnaires had codes and domains covering the motivational determinants impacting on health worker motivation (Table 23). Here, the 'perceived contextual factors' impacting on health worker motivation and specifically their 'working environment' were evaluated (see figure 25 for overview).

Table 23. Perceived Contextual Factors of Health Worker Motivation

Codes (12): (number of quotes)
1. Work Load too much - PCF - Job - Workload (34)*
2. Staff Shortages - PCF - Job - Stress (35-2)
3. PHC Training Opportunities and Staff Development - PCF - Organizational Justice (12)
4. PHCs - Value and Skills not Recognised - PCF - Organizational Justice (29)
5. Management - Supportive - PCF - Management Support -Organization Environment (8)
6. Management - No Consultation - PCF- Policy Change - Organizational Environment (6)
7. Team Work & Share Skills Lacking - PCF - Organizational Citizenship (45)
8. Management Ineffective - PCF - Supervision & Support- Working Environment (8)
9. Management Lacks Understanding of Working Conditions - PCF - Support & Supervision - Working Environment (15)
10. Doctors not Part of Clinic Team PCF - Work Environment - Colleague (5)
11. Working Conditions - Need Improvement -Work Environment (7)
12. Living Conditions - PCF - Home & Social Environment (17)

Note: *Indicates the number of quotes extracted from the diary recordings

The results discussed here are those domains pertaining to the organizational and working environment impacting on PHCNs motivation. They include the 'perceived contextual factors' domains; organizational justice, management support, the policy environment, organizational citizenship, supervision and support, including support from PHCN colleagues and doctors. Some of these challenges have been discussed earlier. The diary records' were used to reflect the health care system functioning and how it related to CDOP implementation. In this section, the context is that of worker motivation and is reflected by evaluating a working environment short of equipment and medication have specific impact on health worker motivation. There were 29 quotes highlighted in the diary records indicating how 'organizational justice' had impacted on health worker motivation. Nurses felt that their value and skills in the organization were not

recognised. There were numerous comments by clinician nurses, that they felt other workers and managers with whom they worked, perceived them to be '2nd class citizens' in the health organization. This was evidenced by their exclusion from the 'occupation specific dispensation' grant, which included a monthly bonus payment to 'specialised nurses' with scarce skills.

> (We) are not remunerated well or appreciated by management and yet (we) are the backbone of PHC service delivery with skills and competence compared to doctors working in the clinics (PHCN, clinic 1).
> (CDOP) needs to develop more authority for PHCs…. These issues are linked to nurses being seen as 2nd class citizens despite that they are doing most of the work and being at coalface of our health service (CDOP Planning Meeting notes).

Many nurses complained that 'management', referring the management hierarchy outside the PHC clinic, were not providing opportunities for development and training:

> (PHCNs) complained of no career growth and feeling of stagnation…. PHCNs felt that their working conditions were poor and they received no recognition (Focus Group, clinic 4).

This quote above was contrary to the findings in the motivational survey where 70% of nurses felt they had sufficient opportunities for training and development, but only 29% believed the 'clinic' cared for their well-being. This was also despite the fact most nurses indicated that they had good support from their immediate supervisors in the clinics. However, some clinicians expressed frustration with the management, outside of their local clinic structure, and this was captured in the diary recordings. In general, the references to management refer to managers outside of the PHC clinic at Johannesburg Metro Health Department, or Gauteng Health Department and are reflected in the diary recordings below as 'top management'. This was a way that PHCNs' generalised about managers, as opposed to the people with whom they worked in their clinic.

> Management do not know anything about the programs we are involved in….. they can hardly solve some problems at clinic level. (PHC, clinic 6)
> Management seem(s) completely unaware of the problems and challenges (Management Feedback Meeting, diary recording)

This problem was also reflected in a thematic code evaluating the organizational environment, which investigated 'management showing lack of understanding of work conditions'.

> There is a great feeling of isolation for each clinic and lack of real support from management… (We) never really have visits from 'top' management (Focus Group, clinic 5).

This issue of management not understanding the working environment of clinicians was commonly expressed in the diary recordings and the questionnaire (see figure 42). The thematic code from the diary recordings reflected nurses' frustration and its impact on their motivation.

> One feels useless when you have to examine patients and then treat them without having the medications to give to patients (PHCN, clinic 10).
> "I am sick and tired of telling patients that we do not have a single pain killer and cough mixture ….. yet patients are coming to the clinic because of pain! How do we help a patient in this case? (PHCN, clinic 12)

These expressions of frustrations really highlight the plight of clinicians. The reasons for the shortages of medication were not documented in the diary recordings. The problem of medication shortages could have been related to financial problems of administration not paying for medication, problems with procurement of medication or problems with supply to the stores

at clinics, or it may have been all of these issues. The lack of understanding between clinicians and management is further highlighted by this excerpt from a diary recording.

> Management was complaining that nurses did not want to work rather than there being an issue being overworked due to their workload despite (CDOP) explaining the issues of patient numbers, workload, poor systems, lack of medication and adequate equipment (Management Feedback Meeting, Diary Recording).

The evidence supporting one existing problem is reflected in this statement, which also had an effect on staff turnover, documented earlier (see Table 23).

> PHCNs also complained of a lack of career structure and a feeling of stagnation…. PHCs felt that their working conditions were poor and they received no recognition….. We then discussed nurses leaving and they told us one nurse was leaving for local clinic due to better salary and conditions compared with government clinics (Focus Group, clinic 4).

PHCNs did express the positive feeling that their co-workers willingly shared their expertise and skills with them, and although this feeling of organization citizenship, reflected by good team work and was expressed as being positive in the questionnaire (Figure 56), problems were detected in the diary recordings, seen below. The negative aspects of team work related to the poor integration of programs when adopted by management.

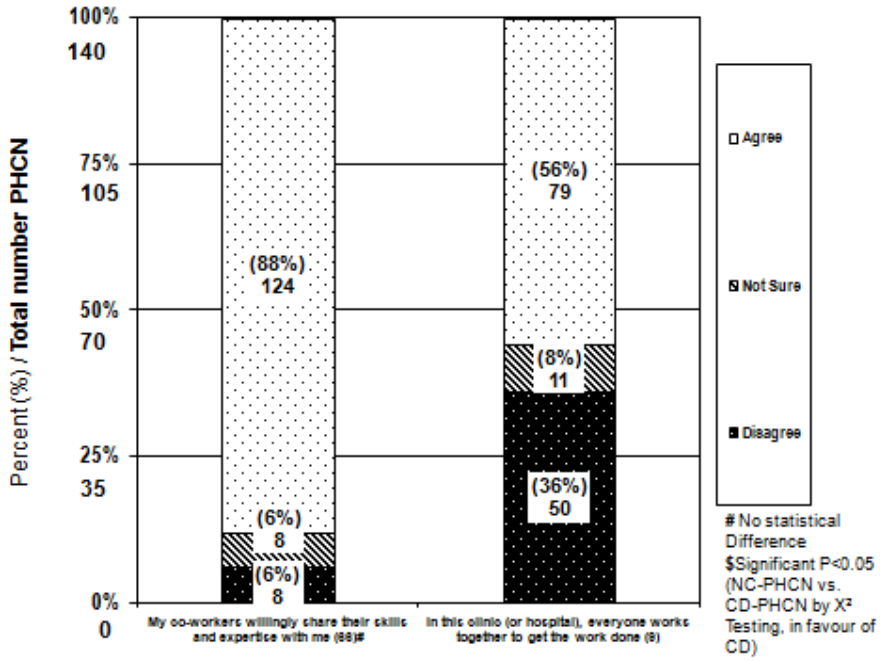


Figure 56. Organizational Citizenship

Note: These questions did not load on the same factor suggesting that this area of questioning lacked depth

NC-PHCN – non-CDOP primary health care nurses group; CD-PHCN – CDOP primary health care nurse group

> Clinic not enrolling very well…. Seems to be no real commitment to CDOP and no team work at all in this clinic…. All (PHCNs) do their own thing (Focus Group, clinic 3)
>
> CDOP is done in our clinic I suggest that every PHC nurse to be given a chance so that we all know about it and what to do to the patient (everybody to be involved) (PHCN, clinic 20).

PHCNs, however highlighted the challenges of implementing programs, discussed earlier, where policy and programs supported by management were implemented without consultation. This may have impacted on cooperation, both team work and team spirit, i.e. shared workplace values, and the clinic staff expressed the need to be consulted about decisions affecting their work environment. This included starting special programs such as CDOP.

There is too much overloading of the CHCs and then one cannot expect good results. (PHCN, clinic 5)

They should improve good communication from our managers and not just dictate what must be done (PHCN, clinic 10).

A major disappointment of the program was the documented non-participation of doctors and their isolation, by their own volition, from the rest of the primary health care team. Some of the diary recordings suggested this was partly arrogance, whist other recordings suggested that doctors were nervous about their own knowledge and may therefore not have wanted to be involved, in case they were shown up by nurses. Nurses were found to be very good at following protocols, whereas doctors showed a reluctance to be 'tied down'. What remains clear is that doctors did not participate as part of the team, in most clinics, and especially with CDOP.

A nurse complained that doctors do not appreciate their work and so they are de-motivated and want to leave the service to better places where their service will be appreciated (Focus Group, clinic 16).

Doctors and nurses do not seem to work as a team. Seem to work in different streams (Focus Group, clinic 3).

Finally an evaluation of 'living conditions' and 'working conditions' as part of the motivational determinants impacting on the nurses, this statement from a nurse highlights the degree of frustration which existed at the time of this evaluation.

There is no way that I can even talk about the pathetic salary which we poor "supposed to be nurse clinicians" are getting! Our salaries are really appalling! Nurses should be paid what they deserve as they are actually the ones who are running the clinics, without doctors (PHCN, clinic 12).

> The Department of Health should consider the influx of patients in our clinic. We see large numbers and we are not coping. They should improve working conditions for nurses and improve salaries to a living wage - not hand to mouth (PHCN, clinic 5).

Comparison of Health Workers Motivation

The health worker motivational survey included many of the components of the health system in the motivational determinants, and 'perceived contextual factors', as well as factors directly impacting on the health care team i.e. motivational outcomes. All the domains were scored together and a comparison between CDOP PHCNs (CD) and non-CDOP PHCNs (NC) was made using independent t-test and Analysis of Variance (ANOVA). Although the comparison was not statistically significant, CD nurses had higher motivational scores overall for all domains evaluated by t-test (CD 92 ± 42 vs. NC 84 ± 40; p=NS). When converting the score for each domain to reflect a 'positive' motivation affect before analysis, both groups of nurses had a similar score (CD 15 ± 9 vs. NC 15 ± 9; p=NS). When comparing other motivational questions, CD PHCNs proved to be 'more satisfied with their job' than the non-CDOP PHCNs (NC); $p<0.05$. Motivational scores were also compared between clinics having better follow up and those which did not, but this was not significant. Scores were also given to each clinic for their organization, and included an in depth evaluation of all factors which may have influenced enrolment, follow up and patient care. Although there were significant differences in the scores between clinics, this did not necessarily correlate with better enrolment, follow up or management (Table 24).

Table 24. CDOP Clinic Organization Score

Clinic	Drs	Twork	Tot PHCs	CDOP clins	FupS	RefS	EquipS	MedS	Mx SupS	OrgzS	Total Os
1	0	2	12	2	2	1	2	2	1	2	12
2	0	2	3	3	2	2	2	2	2	2	14
3	8	2	10	2	2	1	2	2	1	2	12
4	0	2	11	0	2	1	2	2	2	2	13
5	0	2	3	3	2	1	2	2	1	1	11
6	0	3	12	2	1	1	2	2	1	2	12
7	0	2	5	1	2	1	2	2	1	2	12
8	0	1	10	10	1	1	2	2	1	1	9
9	0	1	3	3	2	2	1	2	1	2	11
10	1	2	9	3	1	1	2	2	1	2	11
11	3	2	8	2	2	1	2	2	2	2	13
12	3	-2	6	1	-2	-2	2	2	-1	0	-3
13	2	2	7	12	2	1	1	-2	2	1	7
14	0	0	4	0	-2	0	1	1	0	-1	-1
15	2	1	6	1	-2	2	2	2	1	0	6
16	2	1	6	1	2	1	1	1	2	1	9
17	1	0	11	1	-1	-1	1	-1	2	0	0
18	2	1	12	1	2	1	1	2	1	2	10
19	0	2	5	1	2	1	2	2	1	2	12
20	0	2	5	1	2	1	2	2	1	2	12

Drs - number of doctors in the clinic; Twork - score for team work +2 = Very good / +1 Good / 0 = Average / -1 = poor / -2 very poor; TotPHCs - total PHCNs at clinic; CDOPclins - number of PHCNs who did CDOP work out of total of PHCNs; FupS - follow up score +2 = Very good / +1 Good / 0 = Average / -1 = poor / -2 very poor; RefS - Referral score +2 = Very good / +1 Good / 0 = Average / -1 = poor / -2 very poor; EquipS - state of equipment and upkeep score +2 = Very good / +1 Good / 0 = Average / -1 = poor / -2 very poor; MedS - State of medicine supplies and stocks score +2 = Very good / +1 Good / 0 = Average / -1 = poor / -2 very poor; MxSupS - Management Support score +2 = Very good / +1 Good / 0 = Average / -1 = poor / -2 very poor; OrgzS - Organization Score around CDOP score +2 = Very good / +1 Good / 0 = Average / -1 = poor / -2 very poor; TotalOs = Total organization score adding up all scores

The motivational scores were evaluated against the clinical scenario scores, in order to determine if more motivated nurses were also more knowledgeable, and whilst there was a trend between higher motivation and better scores this was not significant.

The one domain which did show significantly better scores by CD vs. NC nurses, was for the questions evaluating the Outreach Program. Here, the CD PHCNs who had worked on the program, scored much better (Figure 57). The questions of this domain are shown in Table 25.

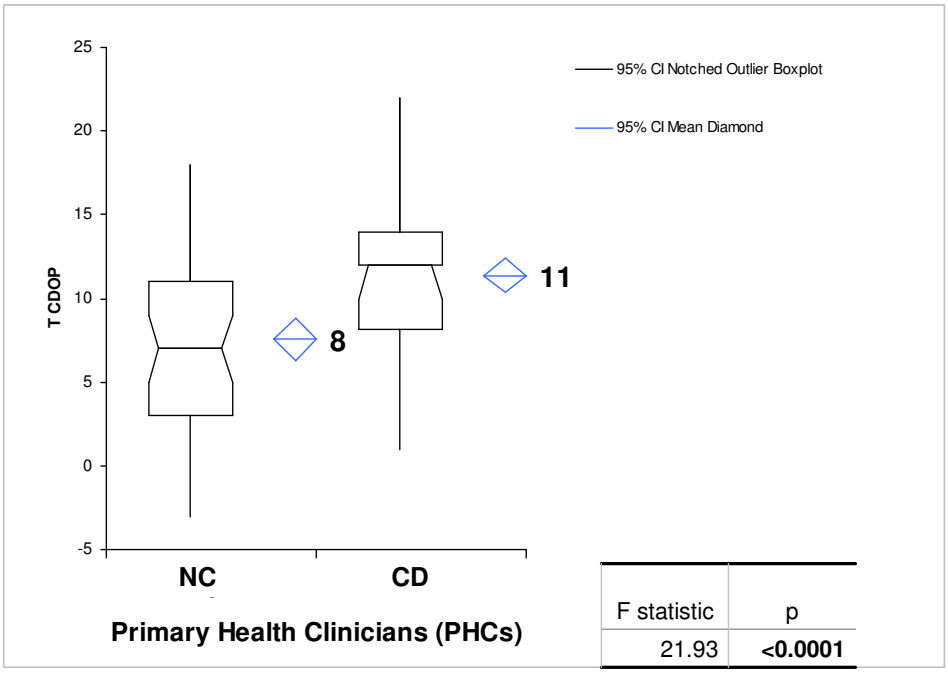


Figure 57. Comparison of Motivational Determinant Domain for Outreach Program
NC – Non CDOP PHCNs; CD – CDOP PHCNs compared using independent t-testing for Motivational Determinant domains – Perceived Contextual Factors – Extrinsic Characteristics – Outreach Program

Table 25. Motivational Determinants Domain Questions for Outreach Program

An Outreach Program (CDOPPP) has helped me with decision support regarding patient clinical care? (11)
An Outreach program (PPP) has helped me with referring patients to the hospital (14)
I feel that I have a clearer understanding of who should be referred to hospital due to my involvement with CDOPPP (21)
The CDOPPP was NOT too time consuming for me to enrol patients in it? (35)
CDOPPP had added value for me in my job as a PHCN (41)
I find getting involved in programs like PPP worthwhile (43)
I would like to have more nurse coordinators helping with managing chronic conditions (48)
I would participate in CDOPPP even if it was not quicker to enrol patients (55)
There should be more many special programs, like PPP in our clinics? (59)
CDOPPP made a difference to patient care (70)
I would like to see PPP became a standard way of managing and referring patients in the primary care clinics (74)

Note: Includes the question and its number in the questionnaire for domains perceived contextual factors, extrinsic characteristics 'outreach program"

Patient Factors impacting on Outreach Program

A patient informed about their disease, and now activated to take control and participate in their care, together with the community are factors important for managing people with chronic illnesses. This component of the Wagner CICM and WHO ICCC models was not evaluated extensively, due to time constraints and in the interest of focusing in greater depth on the primary health care worker. It should therefore be noted that patients were not involved or integrated into the evaluation and that any patient factors mentioned reflect the opinions of the PHCN only and not of the patients themselves. Failure to evaluate the patient issues in greater depth does not reflect the importance which I place on this component of the chronic illness management models. It was simply as a result of lack of time and to ensure a better and more comprehensive evaluation of one component of the model. The evaluation of patient factors should be viewed in the context of a large dropout rate. This probably reflects the poor overall education and motivation which was provided by both the clinic and CDOP. However, the results from the diary recordings and questionnaire, reflecting patient factors which may have impacted on the ability to implement CDOP are still discussed below (Figure 58).

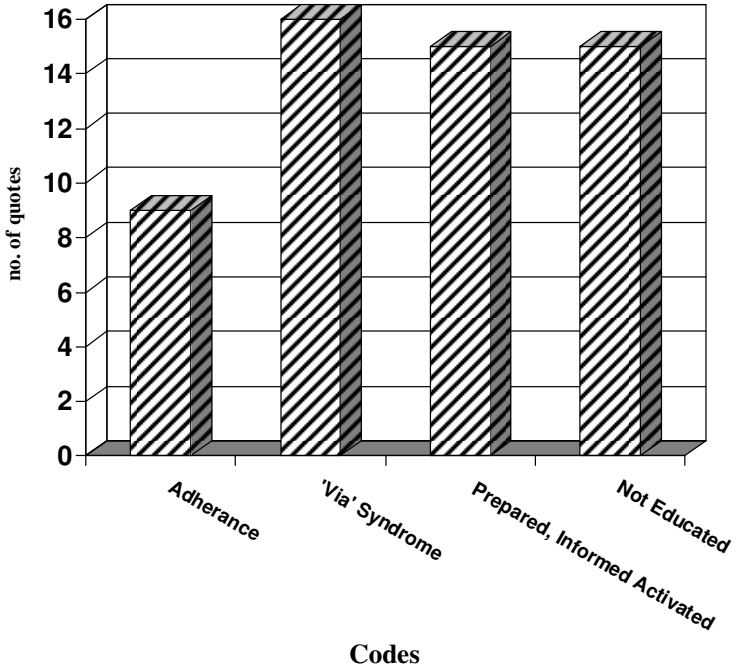


Figure 58. Prepared Informed and Activated Patient
*Thematic codes comprising of quotes extracted from the diary recordings evaluating chronic disease models 'Prepared Informed and Activated Patient'; ** The 'via syndrome' reflects patients frustration with system delays, shortages of medication and a lack of education (see text)

The code, evaluating patient 'adherence', reflects on the difficulty of the program to impact on patients' ability to lose weight and modify CVD and CKD risk factors. Although a number of issues impacting on follow-up were outlined earlier, factors improving outcomes are also dependent on health worker and patient interactions (see figure 4). Patient factors affecting follow up included their failing to turn up for clinic on the medication 'repeat day' and then failure to see the program PHCN. Patients were also documented to have moved to different areas and clinics, this included following their PHCN who had moved to a 'local authority' (city council) clinic. This could have been driven by patients going to these clinics as the waiting lines for medication and evaluation were shorter and quicker. However, it may also reflect the desire for patients to be treated by a health worker with whom they had developed a rapport. Public health clinic working hours also do not allow patients in employment to attend, as clinics are usually in the mornings only. In some clinics PHCNs do start early to allow those employed to attend before work.

> An employed patients may not be able to come back to get tablets that were not available on the day of a check-up and this leads to shopping around and being lost to follow up (NCO follow up visit diary recording).
>
> (PHCNs) Claim that patients are going to the 'Local Authority' City Council clinics and do not come to Dobsonville clinic any longer (Focus Group, clinic 4).
>
> A PHCN challenge outlined was that a patient started job and now cannot attend clinic during week (therefore to follow up), also claim patients are moving away from the area (Focus Group, clinic 13).

A thematic code, the 'Via' Syndrome, further explained the challenge to provide quality care in general and through CDOP. This code describes patients' inability or refusal to embrace improvements in care, and therefore reflects both a lack of patient education and motivation. It may also indicate a lack of motivation to endure an inefficient primary health care system. Patients commonly did not want to participate in CDOP because routine investigations are requested and are seen as 'additional' investigations rather than routine, e.g.. blood glucose HbA1c and urine tests. These tests would prolong their clinic visits. Three factors affected patients enrolling; firstly resistance to 'additional' tests; secondly, these tests resulted in longer waiting times and thirdly, patients may have been concerned that delays could impact on their receiving medication that day. Patients failed to recognise that additional investigations to assess their risk were of value. Instead they saw this as a 'waste of time' in their endeavour to go 'via' the clinic to do their daily activities. Patients only wanted to see clinicians and receive medication as quickly as possible. This 'Via Syndrome' code also reflects the delays and challenges endured by patients in the clinic waiting lines and when medications ran out at the clinic.

> Nurses worried about patients not wanting to wait - via syndrome. Do not seem to see value for waiting for tests…. Patients are not willing to be kept long at the clinic… (they) disappear into the clinic (PHCN, clinic 18)

> I work with a difficult community who verbally abuse staff and reports us if they are waiting for a long period of time to be attended to, even though you explain what you are doing (PHCN, clinic 5)
>
> (Patients) are lost to follow up. Reasons outlined included patient moving or (they) do not want to wait too long for test results or to see PHCN….they do not see the value in waiting (via syndrome)… this frustrates the patients (Focus Group, clinic 15).

Another issue aggravating the 'Via Syndrome' appeared to relate to issues of patient education. Although many patients and PHCNs appreciated the role the Outreach Program played in education, it was not always carried out in the clinic and some patients saw it as another delay. Thematic analysis, in general, documented the poorly developed patient education systems. Clinics use passive education through posters, but also use the well supported, 'patient support groups' as the predominant system of education. Unfortunately 'one on one' patient education through the health promoters, PHCNs and CDOP nurse coordinators was limited. PHCNs claimed it was due to patient load and time constraints, but education during consultations is not encouraged. Patients often also require permission from their partner to be treated and participate in programs like CDOP. This demonstrates the complexity involved in enrolment and adherence. Diary recordings demonstrating these issues are outlined in these few quotes.

> Patients also arriving at (Tertiary Hospital) and do not know what is wrong with them… very poor patient education and PHCN not teaching patients…. PHCNs saying they have no time to educate patients and assess risk factors (CDOP Planning Meeting, diary recording)
>
> This community seemed scared to give consent and said they would like to discuss with their spouses first (Focus Group, clinic 8)

On a positive note, and contrary to some of the diary recordings documented above, the program was shown to have a positive impact on patients being informed and educated about

their disease. This was found in some of the patients when referred to the specialist clinic. CDOP nurse program coordinators also participated actively in patient support groups for DM and HTN at the clinics and during support group education days.

> CDOP team was invited by the clinic to sit in when commencing a support group for hypertensive patients as they have been motivated by a DM support group leader on the program (NCO diary recording, clinic 16 follow up visit).

Summary of the Program Evaluation

Improving functional and clinical outcomes for patients are the goals of the Wagner and WHO chronic illness management models. The results described above are an evaluation of outcomes and health system factors which impacted on the establishment of a chronic disease management program. They also highlight the challenges and successes of the Outreach Program which aimed to link and improve care for patients with HTN and DM in the primary health setting and its referral hospital. Health systems are complex and the success of a program requiring 'voluntary' participation by nurses makes it even more complicated.

Both positive and negative findings are outlined in this chapter. A summary of some of these findings according to its strengths and weaknesses are outlined in Table 26. The program did enrol the appropriate patients who were at high risk for CKD and CVD, although the selection of these patients was not random. The implementation was not as planned. However, the program aimed to replicate the 'real world' and not an experimental one, and so, CDOP adopted the participatory action research model. There were multiple implementation constraints and these have been discussed in detail above and are summarised in Table 26. Patient follow up or return visits, requiring repeat evaluation of their clinical progress on the program, was a definite problem in the primary health care setting, but those with advanced disease requiring a specialist were detected. Most of those requiring referral were referred correctly, and were followed up with successful improvement in the majority of their risk factors. The program had no impact on improving weight control, but importantly the GFR and proteinuria did not worsen.

Nurses who were involved in the program showed better motivation, and improved knowledge as evidenced by better scores in many of the motivational and outcome and determinant domains. The knowledge of the primary health care nurses who participated showed a statistically better score in the patient clinical scenario (see Table 21), which aimed to assess nurses' chronic illness management knowledge and skills. The results highlight how policy affects health care implementation and the problems in existing health organization, including the continuing medical education and development of nurses. The question of whether it was successful or not and if it improved their health status will be discussed in greater detail in the next chapter.

Table 26 . Program and Health system Strengths and Weaknesses

Program Component	Strengths	Weaknesses
Positive Policy Environment	• Development of a regional chronic illness network with government and NGOs e.g. 'senior management', specialist and PHC clinics, groups responsible for chronic illness care • CDOP improves patient management through authorisation of management, medication prescription and referral • CDOP detects weakness in policy and guideline implementation e.g. improved HbA1c testing, insulin initiation training and use of eGFR proteinuria and for CKD detection • Assistance with the development and training e.g. obesity management training, computer skills • Development and Allocation of staff through program e.g. use of health promoters for patient tracking • Sub-specialisation of PHCN skills e.g. development of NPCO and chronic illness skills • Decentralised clinic staff CME	• Inability to become 'fully' integrated into chronic illness health care systems • 'Champion' driven program therefore sustainability questioned • Introduction of 'new' CDOP guidelines instead of strengthening existing guideline implementation e.g. no HbA1c testing • Inability to improve more efficient laboratory results and authorisation of laboratory investigations • 'Vertical aspect' to program with a focus on kidney disease • Failure to implement good audit and research philosophy • No legislation to support nurses with treatment prescription and increasing medication dosing • Health promoter poorly utilised by nursing staff to provide link with patients • Inconsistent funding of primary health care nurses compared to hospital based 'specialist nurses' • Nurses given 'responsibility without authority' to manage illness
Health Systems and Organization	• CDOP was able to provide an alternative integrated model for HTN and DM management • Program nurse coordinators (NPCs) assist with patient management coordination and continuity of care • Improved focus on quality of care	• Poor overall patient follow up • Low skilled tasks not assigned to health promoters or non-professional nurses or clerks • Further aggravates competing demands of nurses by starting a 'new program' • Failure to integrate into 'chronic'

	versus quantity of care • Provides new equipment for patient management e.g. glucometers • Assessment of existing infrastructure for regional management • Provided research and audit of health care system • Link between primary care clinicians and management • Improvement of team work in some clinics	clinics and get full management support • Initial lack of credibility amongst PHCNs • Limited impact on improving team work • Shortages of medication and equipment • Competing demands placed on PHCNs in the clinic
Delivery System Design	• Improved integration of chronic illness management • Link and improved communication between primary and tertiary care • Provided expertise for chronic illness management • Nurse coordinators (NCO) provide link between nurses and specialists and development of 'chronic illness specialist'	• Failure to integrate CDOP as standard method of referral for chronic diseases • CDOP too time consuming to enrol patients • PHCNs clinics in PHC sector function in vertical design and no horizontal integration • No ability to 'step down' patients from hospital to PHC once referred i.e. ensure continuation of medication (anti-lipid)
Decision Support	• CDOP improves patient management through authorisation of management, medication prescription and referral • NCO phone call support • 'Feedback Support' • CDOP provides some 'simplification' of management guidelines	• PHC clinic doctors not functioning as part the PHC team • Not all clinics have doctor for decisions support • Patients have to travel long distances for decision support and if not enrolled on outreach program • No guideline uniformity
Clinical Information System	• Provides an information system data base and structure to support decision making and referral • Tracking system to follow trends of patient care and detect management weaknesses • NPCs ensure data quality capturing is correct	• No electronic information system to capture patient information • No laboratory computers to access laboratory investigations • Slow turnaround time of patient laboratory results • Poor quality of data capture by PHCNs
Prepared, Motivated and Proactive Health Team	• Empowering clinicians through education, authorisation of medications and referral. • Clinicians found to be 'willing' and potentially enthusiastic.	• Failure to involve all PHCNs in CDOP • Failure to improve team work • PHCN feel isolated and disempowered and like '2nd class citizens'
Health Worker Knowledge	• Improved health worker knowledge through 'outreach education' and support • Provides evidence of link between knowledge and motivation	• Poor existing knowledge of diabetes management • Limited access to new guidelines
Health Worker Motivation	• 'Added value' to PHCN work environment • Provides incentives through	• Failure to get doctors to participate on program • Shortages of staff in clinics

	workshops and overseas chronic disease training • Non-statistical improvement in primary care nurse motivation	• Large patient workloads
Informed Activated Patient and Community	• Limited engagement of patients on the program • Good explanation and support education when referred to specialist • Improved waiting times at specialist clinic	• Weak focus on patient and community issues impacting on chronic disease management • Increase of patient time in clinic
Self Management Support		• Failure to address adherence issues • Failure to improve weight loss or reduction in BMI
Patient Education	• Support of existing structures for self management support e.g. support groups • Provides patient education through development of education manual	• Failure to implement patient education and especially kidney function testing • Failure to educate patients about 'value' of waiting for quality of care • Failure of CDOP to improve patient waiting times at the clinic
Productive Interaction - Linking of health team and community	• Improved use of health promoters • Good primary to tertiary care interaction. • Development of traffic light system to help patients recognise urgency of disease • CDOP became involved in with 'patient support groups	• Limited involvement in improving patient health worker interaction. • Poor implementation of 'traffic light' triage system • Poor control of patients with diabetes and utilisation of support groups
Improved Functional and Clinical Outcomes	• Improved clinical outcomes in specialist referral group • Good screening of high risk patients and detection of patients requiring referral • Improvement of clinicians knowledge • Able to harness 'enthusiasm' of motivated nurses	• Unable to determine clinical outcomes for all patients enrolled • Limited impact on patients followed in primary care setting

6 DISCUSSION

Health systems are complex, and changing existing health systems and health workers' attitudes and knowledge proved to be a challenging exercise. This discussion focuses on the three components of evaluation, derived from the Wagner Chronic Illness Care Model (CICM) and WHO Improved Care for Chronic Conditions Framework (ICCC), and includes an assessment of the i) the program's implementation and existing health systems; ii) clinical and functional outcomes; and iii) the 'prepared' and 'motivated' health care team. A comprehensive evaluation of these components, again using the chronic illness models, was carried out using a 'triangulation' process which linked the clinical and functional data with the information gathered from the diary recordings and questionnaire (see figure 25). This comprehensive evaluation process allowed for and provided clearer answers about the successes and failings of the chronic disease outreach program (CDOP), and its ability to integrate into existing chronic disease PHC services.

Program Implementation

The chronic disease outreach program was a success and a failure as an intervention. CDOP was able to successfully implement a vertically independent outreach program using the Wagner Chronic Illness Care Model (CICM) and the WHO Improved Care for Chronic Conditions Framework (ICCC) in 20 clinics. It established an alternative system for assisting primary care health nurses (PHCNs) with the secondary prevention of CVD and CKD, and with the detection and management of patients with hypertension (HTN) and diabetes (DM). These advantages were similar to programs which used these chronic care models in the United States. CICM proved able to be incorporated with relative ease, and was implemented into family practices (Nutting et al., 2007, Glasgow et al., 2001), and was used to run a similar chronic illness program for American Indian and Alaska native populations, suffering from DM and HTN, in the United States (Narva, 2008). The CICM and ICCC models had not been used before in an African setting as a mechanism to improve management of chronic conditions. To a very limited extent the program was able to integrate into chronic disease clinics, mainly HTN and DM, and

to assist some PHCNs with decision making and referral. It provided expertise and training through the development of its 'specialist' chronic disease nurses, the nurse program coordinators (NPC). These specialised nurses provided a new referral link between the primary care sector and its regional referral hospital. Many of the nurses, especially those who had participated in the program, felt that the program had added value to their job, and assisted them with 'decision support' and referral. Collaborative care has been used to guide efforts to improve the quality of chronic illness care in many different healthcare settings (Von Korff et al., 2002), and this was achieved in a limited way in the Soweto setting.

There were many difficulties and shortfalls of the CDOP. Some PHC clinicians, especially the PHC doctors working in the clinics, resisted integration, and this was a great disappointment and a limitation of the study. The responsibility of this falls both on the doctors and us, as implementers of the program. We failed to spend enough time to involve doctors. This limitation of the program was that it lacked diverting and spending more time and resources to involve more doctors. However, there were other factors. Firstly, many clinics did not have doctors and secondly doctors operated independently of the PHCNs and also perceived the program to be a 'nurses' program. This made it difficult to include them in the program.

The Johannesburg Metropolitan Health Region managers, i.e. at director and deputy director level (see figure 44), allowed the program and did support it enthusiastically at 'head office' level, and allocated two nurse program coordinators to help run the program. However, there was an inability of managers at the 'assistant director' level, who provided the support at the PHC clinics to get involved practically and assist with local systems at each clinic. Some of the blame again must lie with CDOP not spending enough time and effort to involve and educate this tier of manager, but also because it was seen as another 'vertical program' in the clinic which would run independently of their involvement. Assistant directors needed to support the program actively and practically as a 'standard' method of chronic disease management at clinic level and they needed to share the final vision, of integrating the important components of CKD and CVD detection into clinical practice. Unfortunately this vision was not achieved, and the responsibility must partly lie with the way the program was implemented and run. The issue of an integrated program for chronic illnesses remains an important issue which needs to be

addressed. This integration could assist with developing health systems horizontally across sectors and this will have a positive affect for all chronic illnesses. In the end the assistant directors viewed the program as a vertical independent program, not requiring their assistance. At the chief director level, where funding and policy were needed, and which could have assisted the programs development in the future, no support was forthcoming. At this 'director and chief director level, they either supported the program 'verbally' in meetings, or else claimed that they had better systems which they were 'planning in the future', and did not value the experience of a program implemented and run at 'grass roots' level. Although it was acknowledged as evidenced by the awards it received. This challenge has been experienced by others such initiatives and where leadership and advocacy were necessary for the implementation of other programs like that of the WHO ICCC, the leadership and management were absent (World Health Organization, 2002a, Kotter, 1990). This was especially noted in this regional health care setting of Soweto. The implementation of CDOP was left predominantly to CDOP's three staff members, and the chronic disease regional assistant director, to orientate and inform all managers and clinicians about the Outreach Program. This was despite the fact that many nurses documented that they would like to see the program implemented as the 'standard' referral process and wished to see greater links with their referral hospital. This problem of poor communication, and extremely hierarchical management structure, was an indication of management's inefficiency and bureaucracy, and resulted in its isolation and lack of direct involvement with the PHCNs at the clinic level. Perhaps CDOP should have focussed on smaller components for integration into clinics like improved systems of up and down referral, or ensuring chronic disease patients with HTN or DM were screened for CKD. Smaller 'bite sized' initiatives may have been easier to integrate. This would have been focussing on longer term health service problems, which may if implemented, have had a permanent institutional influence. This approach has been suggested by De Maeseneer (2008) and colleagues. In conclusion it must be noted that a major limitation of CDOP was the vertical implementation strategy which was adopted. The CDOP initiative in fact resulted in a duplication of disease control, creating its own bureaucracy and increased demands on the PHCNs looking after patients with chronic diseases. This duplication as a vertical program added to the ineffective

utilisation by the recipients, who were the PHC clinicians (doctors and nurses) and patients. The major constraints documented by nurses included large patient workloads and staff shortages. These issues in turn impacted on patient enrolment onto the outreach program. A particular problem, noted by nursing staff and the CDOP nurse program coordinators, was the high turnover of staff in each clinic with over a third of the workforce changing in the clinics over 2 years. A major reason for the high turnover appears to be better working conditions and better salary scales elsewhere in most cases. In some cases, the "upskilling" of nurses involved with CDOP, may even have made them more likely to get jobs with other NGOs or the private sector. This problem is well documented in developing countries where staff retention challenges are widespread and the movement of health workers to 'better' and more well paid jobs is a serious problem (Hongoro and McPake, 2003, Van Lerberghe et al., 2002). The problems of staff retention, an overwhelming patient burden, poor pay and working conditions and especially dysfunctional health systems have been described in the implementation of HIV antiretroviral programs in South Africa (van Rensburg et al., 2008 , Schneider et al., 2006). This was also a problem and a setback of CDOP. Many programs that are implemented in a vertical manner draw staff away from general activities of the clinic to the 'special programs'. This was the case for CDOP, as the program further diverted the PHCNs skills from the tasks at hand. CDOP, a vertically organised program, also potentially resulted in staff moving from one section to the next, or at least diverting their attention from the 'general' HTN and DM clinic patient and this raises concerns regarding equity of care. This problem has been highlighted before (De Maeseneer et al., 2007), and results in an internal 'brain drain', which can undermine PHC chronic disease services. Although CDOP fell into the trap of establishing a vertical program, it was not its intention to focus on a narrow band of chronic illnesses that were linked to a particular special interest in a tertiary hospital. It was started, because it wanted to reduce the burden of a chronic disease which has important implications for CKD and CVD and because CKD is completely unacknowledged as a chronic illnesses. It also based this focus on very strong evidence that CKD is an unrecognised public health problem (Levey et al., 2007a, Coresh et al., 2007, Schoolwerth et al., 2006, El Nahas and Bello, 2005, de Zeeuw et al., 2005, Chen et al., 2005 , Hallan et al., 2006b, Chadban et al., 2003, Iseki et al., 2007), that it has clear strong

links with CVD (Go et al., 2004, de Zeeuw et al., 2005, Parikh et al., 2006), and that addressing these issues at the PHC level is critical (Hoy et al., 2005b, Katz et al., 2006a, Tollman et al., 2008, Coovadia and Bland, 2008). Its aims were to see it integrated as part of the chronic illness CVD initiatives which are made at PHC level and not as an exclusive chronic illness which requires special attention.

Vertically developed programs together with health worker migration, and staff shortages all place a greater burden on the other clinic workers who remain working in 'specialised HTN or DM clinics'. These factors cause clinics not to have the necessary skills mix to handle specialised problems. This places further demands on the remaining PHCNs and affects the efficiency of service delivery. The problem of competing demands and vertical program implementation also affected the outreach program's ability to detect those patients with HIV at high risk for CKD. Despite efforts to enrol patients with proteinuria from any cause (HIV, DM and HTN), this proved not possible because the HIV patients were shifted into a specific 'specialised' HIV only program. A recent study strongly criticised the fact that HIV programs fall outside of the clinic chronic disease system (Tollman et al., 2008). This highlights the need to avoid the development of vertically structured programs or focus on chronic illnesses as individual entities (Beavers and World Health Organization, 2003), in favour of primary care clinicians, both nurses and doctors, seeing all types of acute and chronic illness patients together in a single clinic, just as a family practitioner would do. Tollman and colleagues have restated the need to invest in strengthening the existing 'comprehensive but generally weak delivery platforms' that are common to the public-health sector (Tollman et al., 2008). Integrating chronic disease care by linking CVD and CKD with infectious diseases, through horizontal rather than vertical programs in the primary health care setting is necessary. This demonstrates the need to understand and contextualise these diseases in each community and focus on diseases as chronic illnesses which require sustainable disease control (Manderson, 2008).Through effective PHC, it is quite possible to respond to both 'chronic' infectious and chronic non-communicable diseases (e.g. HIV, TB, HTN and DM) by treating adults with such illnesses as requiring a single method of management. All chronic illnesses should be included e.g. chronic respiratory illnesses, epilepsy and part of the integrated approach. The Soweto clinics need to run like 'family practices', where

PHC clinicians see all patients and all diseases. There may be a practical need for running clinics for chronic illnesses which have similar challenges and overlapping risk factors e.g. HTN, DM and HIV. There may also be a role for sub-specialisation by PHC clinicians, allowing some PHC clinicians may have more knowledge about a single chronic illness. However, the approach should still be to tackle these diseases through a 'horizontal' approach and not in the way that CDOP was implemented. The CDOP, chronic care type of model approach, needs to be broader and also need not rely solely on doctors or specialists. It has to be recognised that non-specialist health workers, such as primary health care nurses (PHCNs), can reliably evaluate and manage risks of chronic disease in settings without doctors (Bodenheimer et al., 2005, Oakeshott et al., 2003, Epping-Jordan, 2001).

Other factors impacting on implementation included nurses complaining of little time to enrol patients, although there were some conflicting opinions about this, implying that the problem may be due to other issues like motivation. There was also a distinct difference in the way some of the clinics worked, enrolled and followed their patients. This also highlights the importance of team work, 'organizational citizenship' and the individual systems which were put in place in the different clinics. Nurses do not recognise the value and importance of audit or research in their environment. Initially, CDOP was seen as a research project and for this the credibility of the program was placed in question. This highlights the inability of health workers to see the value of information systems and continuous monitoring of their work environment. The way this problem was corrected was through persistence and by developing a good relationship with nurses through their training school. CDOP, recognised the value of working with all role players involved in health care delivery in the region, and this included the Soweto PHC School. The School, which trained and had credibility with clinicians, provided an opportunity for a successful approach to correcting this problem. CDOPs links with the school and its team proved to be a turning point for its credibility. However, this relationship highlighted the importance of establishing a chronic illness network, comprising all organizations responsible for managing chronic diseases in the region. It highlighted the importance of strengthening partnerships, as identified in the WHO ICCC framework model (World Health Organization, 2002a).

Program Enrolment

PHCNs perceived random enrolment to be unsuitable, even unethical, and that this would compromise their patients care. Therefore, although participants' were supposed to be chosen randomly by PHCNs, it is possible that choice of enrolment was influenced by PHCNs. They may have entered patients whom they deemed to be at 'high risk' and because they wanted and expected clinical advice through the 'feedback decision support' reports. Considering that the programs aims were to reflect the 'real' clinical situation as much as possible, this may have been interpreted to mean that PHCNs could influence enrolment. They had also participated in the CDOP pilot phase and had experienced the value of quick specialist referral.

The study thus remained as an observational study, following a cohort of high risk DM and HTN patients, and this in itself could viewed as confounding and biasing the study. In defence of these actions, selection bias can be an insurmountable problem in any health care evaluation, because people are selected according to the severity of their disease (Bachmann, 2007). However, the process resulted in an evaluation that took place in a 'realistic environment', and ensured that PHC clinicians felt that they were not under 'trial' conditions (Bachmann, 2007).. As the follow up of the cohort was over 2 years, and consisted of multiple methods of evaluation, there is some confidence in attributing the findings and changes to the intervention.

Health Policy Factors and Implementation

Other health policy issues impacting on implementation include the structure of primary health care facilities in the region. They comprise two separate systems of health care delivery, one being the local city council[7] and the other the provincial government clinics, where the

[7] Local City Council clinics are funded by the Johannesburg City Council. There predominant focus is on immunisation and family planning, but more recently have become involved in chronic disease management, i.e. HTN and DM. These clinics are funded by the City of Johannesburg, whereas the

program was implemented. The clinics are often close to each other and patients may move between them depending on the waiting times for treatment or if a nurse they preferred or with whom they had developed a rapport had moved. Related to this dual system of health provision, different salary structures existed between local and government clinics and between clinic nurses and hospital nurses. The local City Council clinics paid higher salaries. Both these issues affected staff morale. Primary health care nurses were not included in the OSD allowance and this had a particular negative impact on the program's functioning. PHCNs were often engaged on 'go slow' protests against this policy and were loathe to extend themselves for any 'special program' in view of their being dissatisfied with salaries and lack of recognition of their skill and contribution to the health system. This affected both patient enrolment and follow up and also their efforts to get laboratory results or fill in the CDOP follow up forms.

The policy of not making available certain medications in the primary care sector, i.e. anti-lipid medication and some hypertension drugs, together with the policy of not allowing or training nurses to initiate insulin, impacted on program implementation and patients' diabetes and blood pressure control. Nurse clinicians could not increase the doses of certain 'basic' HTN medication. This aggravated our ability to control risk factors as planned, and explained the poor baseline control of blood pressure and serum glucose. PHCNs are expected to manage people with chronic illnesses but are not given the appropriate skills or authority to act. If politicians and health managers expect nurses to take up the call to manage the growing chronic diseases burden, then they have to be provided with the necessary skills to carry out these tasks. Nurse practitioners need to be supported with legislation which would protect and support them, and allow them to act appropriately and in their patients best interests.

The development of staff and appropriate allocation of human resources was an issue, with PHCN taking on the roles of pharmacist, clerk and clinician. Pharmacist shortages meant that PHCNs had to evaluate, prescribe and dispense medication. This aggravated their sense of being overburdened with responsibilities. These are tasks which could be given to trained 'non-

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provincial government clinics are funded through the provincial government and specifically the province of Gauteng Health Department.

professionals', and would free clinicians to deliver a better quality service. This issue together with the fact that nurses were not allowed to refer patients without approval from a doctor in some clinics add to the inefficiencies of the health service. Existing legislation does not allow 'lower level' health workers, such as PHCNs, to dispense medication unless they have been on a dispensing course. This type of policy in a developing world stetting is impractical, as most nurses could not attend training and many PHCNs continued to examine and dispense medication themselves as they had no choice. Having no pharmacists and the fact that they have to examine and dispense themselves makes for lengthened patient consultations. In fact a strong argument exists for allowing more 'unskilled' people to participate in these types of services (McPake and Kwadwo, 2008).

Existing staff development policies are not very well developed, mostly occurring around the centralized 'in-service' education system. Very little effort is given to staff development and, in some cases, nurses expressed that CDOP was one of the only opportunities they had had for development and training.

Developing and strengthening partnerships was not a priority of clinic and regional managers. Although the National Health Laboratory Service (NHLS) is responsible for delivering a laboratory service, providing quick results and supporting PHC clinicians, with access to pathology services and specialist expertise, and efficient service and specialist support did not occur in the clinics. This inefficient and ineffective support service impacted on both patient enrolment and follow up. Delays in laboratory results caused patients qualifying for the program to not be included on the program, and many 'disappeared' into the 'mainstream' clinic environment, often unhappy with waiting for results or delays to be initiated onto the program. This highlights another factor that affected the implementation of the program, the lack of a clinical and management computerized information system. Nurses do not have quick access to patients' results, and cannot use computerised systems to keep and track their patients' clinical outcomes. PHC clinicians often do not even have easy access to telephones to call the laboratory for results on patients. This adds time to each consultation and additional pressure to nurses' restricted time.

According to AbouZahr and Boerma (2005), poor health information systems result in fragmentation of the health sectors, inability to monitor diseases, and assess quality of care. They conclude their review by stating “It is not because countries are poor that they cannot afford good health information; it is because they are poor that they cannot afford to be without it” (page 582). CDOP was able to provide a basic information system which determined shortfalls in patient care, and was a major ‘value added’ service which nurses appreciated. The delivery of typed ‘feedback reports’ was truly unique in this environment, although common in developed world settings. The CDOP data tracking system provided a surveillance of management, allowed for detection of those who needed referral, and improved efficiency when patients were referred (see figure 24). It allowed for regular assessment of the progress of the program, and was used during ‘feedback meetings’ to evaluate the outreach program. This type of system has not previously been described in the South African PHC system.

Other positive policy factors initiated by CDOP included the strengthening of partnerships, the most important of which was the links of tertiary and primary health care. However, it did develop the beginnings of a ‘chronic disease network’, by involving regional health management structures, the Soweto Primary Health Care School, the division of cardiology and later the division of endocrinology. It played an active role in linking and receiving sponsorship for nurse training from non-governmental organizations (see figure 40), and also provided training in computer skills and ‘change management’ workshops for all PHCNs in the clinics. However, although these links were started, this cannot be seen as a true ‘chronic disease network’, which would require many more role players and much broader involvement e.g. HIV services, asthma services etc.

Many of the policy concerns highlighted above explain why nurses indicated in the motivational survey that they felt misunderstood, overworked and impotent in the decision making of their clinics. Although management did support the program through a single regional manager who recognised its value and helped with its implementation, the program and its specific components were was not taken on as an essential requirement to improve quality of chronic care. A lobby was made to broaden the program to include HIV, asthma and general diabetes care through the development of new ‘modules’ supporting these chronic illnesses, this was not

achieved. This was despite efforts to lobby the regional chief director, and then with his support, the Outreach Program was presented to the Gauteng Health Department Executive Committee[8] (see Figure 44 and Figure 37; point no. 24). Although this committee in principle supported the development and broadening of the program and promised funding and support, it never materialised. The failure to provide this support was a result of resources and personnel at head office to support its implementation. It was also affected by the lack of authority which resided in those people who were assigned to help with implementation and scaling up of the program. There was also suspicion that this funding was being used to fund the research for academic reasons alone. Furthermore, managers always needed to consult their 'senior managers' or were hampered by poor communication and integration of activities between departments. This is evidenced by the fact that HIV programs are funded and managed completely independently of non communicable disease programs. The challenges of integration and scaling up the program reflected on the 'top-down' management style which exists in the health service. Regional and provincial managers appear helpless to implement existing policies and to deal with problems such as shortages of human resources, medications and broken equipment. There has to be an improvement in management skills, and communication between the management levels and genuine support at integrating chronic illnesses, before real long term improvements will be noticed. Despite these problems with a small amount of effort and support, many aspects of the program could be implemented. This requires that the proposed models are implemented and regularly evaluated, which would include assessing local feasibility and cost effectiveness. Many of the human and infrastructure resource challenged could be addressed during practical implementation. Resource issues will further be addressed through the strengthening of health systems in the clinics by integrating services of all chronic illnesses e.g. clinics for chronic NCDs and chronic infectious diseases. This would also include computerising data capture which would provide NCD epidemiological surveillance so as to establish the

[8] In order to present CDOP to the Provincial Executive Management Committee, which reports to the MEC for Health for the province, it required the hierarchical support, endorsement and motivation of all the management structures. These structures are outlined in Figure 44, page 166.

population-level burden of NCDs and assess the proportion of cases detected and managed by the health system. The CDOP provided a good indication that only between 10-15% would require specialist referral. This information helps plan future initiatives and what the scaling up of similar programs would entail. It also indicates that continued surveillance would provide more information about the likely load of the problem. Aspects which were successfully implemented like decision support and referral systems could easily be implemented with minimal resources, as is shown in this study. Unfortunately information about useful life years gained from the program could not be determined with such poor follow up, and this type of information is still needed in the future.

Patient Factors

This study did not specifically focus on components of the Wagner Model relating to the community and patient, and this was a major shortfall of the program. This was because it was not feasible. CDOP did not have the resources and easy access to patients to focus on the entire 'comprehensive' chronic illness model. However, two major patient factors arose from the diary recordings which impacted on patient enrolment and follow up. These issues of adherence are well described problems in chronic disease management (Ingersoll and Cohen, 2008). Adherence factors and factors extending the time for patients to wait for service were included in the diary recording analysis, and were described in the results as the 'via syndrome'. There were instances of patients not arriving for follow up, who were documented as having moved out of the area or presenting to the local council clinic because of shorter waiting lines. The 'via syndrome' reflected patients not wanting to be delayed in the clinic and the fact that patients endure long waiting periods before being seen by a clinicians. It also reflects the lack of insight and involvement by patients in their healthcare as waiting for 'additional' investigations was perceived as a hassle, rather than an an improvement in quality of care. Patients did not appreciate, recognise or value the aim of CDOP, which was to improve the quality of care they would receive. Poor diabetes control could be attributed to adherence but could equally be the result of poor knowledge of PHC clinicians and poor electronic monitoring systems tracking glucose control (Cramer, 2004). Few studies adequately quantify adherence to diabetes

medication and much fewer look at compliance in chronic illnesses (Cramer, 2004, Ingersoll and Cohen, 2008). Unfortunately the lack of adherence evaluation was a major limitation of this study.

Adherence issues remain complex, and patient factors form only one aspect of this challenging problem (Ingersoll and Cohen, 2008). In the diary recordings, patients were regularly blamed for poor management and risk factor control, and nurses took no responsibility for this problem. Clinician roles, such as clear communication and time spent educating patients about their diseases, were either not considered important or nurses were just too busy to provide this service. The patient–clinician relationship factors such as trust were also not investigated. A number of diary recordings reflected 'patient frustration', as well as of nurses not being available at follow up, long delays waiting to see PHCNs and patients needing to return the next day because medication was not available and had run out. All these factors indicate that adherence issues were not well addressed at the clinics. Health care delivery factors also played a significant role in non-adherence. Even if one criticizes patients for not wanting to wait for appropriate laboratory investigations or to be seen by nurses trying to offer 'better quality care', these actions should be taken in the context of the clinic system. The inefficiencies, delays and lack of emphasis on quality explain the reasons for patients' actions and therefore one cannot blame health system failings on the patient alone. Therefore, community factors, and patient adherence factors in the Soweto primary health care setting are components of care which are emphasized in the Wagner and WHO chronic disease models, and definitely require further investigation and attention in the future. The program failed to support or addresses the real issues which face patients who receive chronic illness care. It also must be reinforced that the issues of patient care was viewed from the biased perspective of the health workers, through the diary recordings, and that patients were not included as part of the comprehensive evaluation of health services in this study.

CDOP as a Screening Program

Two components of care provided by CDOP required evaluation; i) Were the correct patients screened and enrolled onto the program? ii) Was there accurate referral to a specialist? The Outreach Program follow up was evaluated in several ways. Firstly, it evaluated the PHCNs' ability to enrol the correct patients onto the study according to the inclusion criteria, i.e. those patients at high risk for CKD and CVD. Second, their ability to follow-up these patients' at their follow up clinic visits, assess their progress and carry out appropriate investigations. The third question was to assess whether nurses had referred the correct patients to the specialist clinic.

The factors affecting poor follow up and the inability to achieve DM and HTN control, were similar to the enrolment issues, and included the poor existing health systems in the clinics and competing demands on the PHCNs, by CDOP and other existing 'special programs' e.g. HIV and TB. This was aggravated by the problem of staff shortages and high turnover, especially amongst PHCNs working in the clinics. PHCNs were overwhelmed and frustrated with the number of patients they needed to see, and the shortages of equipment and medication to evaluate and treat patients. They complained that their current primary health care clinical skills were not recognised and acknowledged, and they remained concerned about litigation, as decisions to up-scale medication did not have official support unless endorsed by CDOP. PHCNs criticized the fact that they had responsibility without the authority to act. Current protocols did not allow nurses to increase dosages or prescribe some of the HTN or DM medications. Staff shortages made it difficult for some of them to attend continuing education seminars at a central venue, so they did not have access to the latest knowledge and program changes. Many nurses complained CDOP was not integrated formally, but was, rather, an optional vertical 'special program', this affected its potential impact as it was not endorsed or encouraged as the primary method for assisting nurses with managing patients with difficult HTN and DM control or if they needed hospital referral. Nurses were unaware of formulae to measure GFR or the reasons for measuring albuminuria. 'Quantity of care' was favoured over 'quality of care', with PHCNs complaining they had no time to evaluate patients, by doing 'additional' blood tests or urine investigations. Nurses highlighted the need for better training, integrating care, and even sub-specialization in chronic disease management. The question which arises is whether

CDOP provided them with ‘special skills’. It appears as if it did on some levels and this included the ability to prescribe higher medication dosages for disease control, speed up the referral process to a specialist, and in some cases gains more knowledge about CKD screening, and DM and HTN control. However, on a broader level, it did not provide the skills of overall chronic illness management and an ability to transform the management of a health facility around chronic illness. This deficiency was as a result of CDOP not providing these generic skills to all PHC clinicians and because it was developed in vertical manner focussing only on CKD and CVD.

Some novel systems were developed and adopted by the nurses in the clinics, as a result of the Outreach Program. Tollman et al have highlighted the need to improve our primary health-care systems which have mainly evolved in a pre-transitional era and have adapted little to the growing demand for continuous, long-term care (Tollman et al., 2008).The CDOP stimulated developments, included the ‘chronic stamp’ developed by the PHC School, to help focus clinicians’ on the key CVD and CKD risk factors which required close attention. It also resulted in the development of a ‘traffic light’ triage system to help make decisions about who needed ‘special’ focused care and who should be referred. Stickers were also used to try improve follow up by helping to locate the enrolled high risk ‘patients quickly and prevent them becoming lost in the mainstream clinic system, although from the results the latter initiative did not work.

Despite the bias which may have developed during the enrolment process, the clinic nurses, with the assistance of nurse program coordinators (NPCs), were still able to accurately screen and enrol ‘high risk’ patients. Less than ten percent of patients enrolled did not fit the inclusion criteria. The enrolment process required nurses to capture the data themselves and relay the clinical information to the data centre through the nurse program coordinators. The slow process of capturing the information, transferring the data from the clinic to our central data capture point, analysing it and delivering feedback reports, contributed to the lack of specificity of CDOP. There were often poor quality data captured by nurses, and this included missing variables and illegible writing. This resulted in a small number of incorrect inclusions. However, in a program aiming to capture those at risk, a higher sensitivity resulting in the inclusion of a few

patients at lower risk would be considered acceptable. It is better to have false positives than false negatives, because these can be sorted out by the specialist, the “gold standard”. It could have also been related to nurses’ attitudes towards data audit as they were never demonstrated the value of capturing information. It was seen by nurses as a chore. However, clinical time demands and large patient loads also contributed to poor data quality. It was for this reason that nurse program coordinators were used as a mechanism to ensure quality control, as they checked all the patient data sheets. This highlights the value of computerised systems, which could have prevented this problem by ensuring that nurses enrol the correct patients by instant computer assisted evaluation of the inclusion criteria. A electronic information system will also prevent ‘missing’ data., PHCNs worked under pressure and, at times, the slow turnaround of laboratory results, also contributed to patients not being enrolled or evaluated at their next follow up clinic visit. Delays also occurred on the part of the outreach program nurse program coordinators, as with only two program coordinators to evaluate and write ‘feedback reports’ (see Appendix 5), this resulted in delays to inform nurses about patients who were incorrectly enrolled.

The ability of ‘the program’ to refer the correct patients to the specialist clinics was much better. The specificity of detecting the correct patient according to the specialist referral criteria was 100% (see Table 10). The failure in the system was making sure that they arrived at the clinic. In the case of referral to the ‘renal outpatient clinic’ (ROPD), the success of referral was lower at 75%. In principle, it is more important for a screening test (in this case the referral process) to be sensitive than specific, i.e. for PHC nurses to refer inappropriate cases rather than miss those who should have been referred. In our case, we had excellent specificity, but at the cost of sensitivity (cases were missed). This reflects the resource strapped nature of the PHC as well as the referral system, where implicitly, rationing is being applied (limiting time on assessing and referring patients). Factors which affected a patient’s ability to arrive at the specialist clinic included the many factors already discussed which explained poor follow up. Importantly, no patient who needed referral at baseline was lost to follow up, indicating the success of the program as a screening tool for ‘red’ high risk patients needing specialist evaluation and care.

Clinical and Functional Outcomes

Related to health care organization and to the assessment of 'functional outcomes' of a chronic illness program, the aims of this CDOP evaluation were to establish if those high risk patients had arrived at the specialist clinic, they had been referred, and to establish if they had been followed up and treated correctly at the hospital based clinic. These questions are addressed in this section.

Baseline Characteristics

The numbers enrolled were slightly lower than the original target, with more patients with hypertension (HTN) than diabetes (DM). This reflects the attendance at the 'chronic' clinics in the region. Women were also more likely to be enrolled than men, which is in keeping with the gender distribution of attendance at primary care clinics nationally (Levitt et al., 1997) and from previous Soweto audits (Mohammed and Mthombeni, 2000). The baseline clinical data reflect a 'high risk' group as targeted, with patients having both uncontrolled HTN and DM together with significant risk factors. Only one quarter of patients had a controlled blood pressure, only slightly better than that demonstrated by the South African Demographic Health Survey (SADHS) (Steyn et al., 2001), and worse than international data (Chobanian et al., 2003). This problem remains despite the availability of many effective, cost-effective and well-tolerated drugs in primary care, indicating that factors other than availability of medication determine control. The problem of HTN control in DM patients is even more of a concern, as less than 16% of patients had blood pressures meeting the current recommended guideline criteria, i.e. <130/85mmgHg. This is much worse than international figures, which are themselves also poor (Hajjar and Kotchen, 2003, Hyman and Pavlik, 2001, Wong et al., 2007). Obesity demonstrated by both BMI and waist circumference was found to be a significant problem in the cohort, with women affected more than men. This has been shown in other communities in South Africa and demonstrates that lifestyle modification issues are a problem in this community (Vorster, 2002, Puoane et al., 2002). Cultural factors impacting on obesity in women includes an inaccurate perception of body weight and being overweight also has many positive connotations in the African community in

South Africa. It reflects both affluence and happiness, and in women indicates the ability of the husband to care for his wife and family, and related to HIV/AIDS, being overweight reflects being both healthy and HIV free (Mvo et al., 1999, Clark et al., 1999). The cohort was slightly older and the obesity rates were in keeping with findings that increased age, and higher levels of obesity are found in urban African women (Puoane et al., 2002). Lifestyle factors included little exercise, high intake of fatty foods, smoking and high levels of cholesterol amongst patients enrolled onto the program.

Dyslipidaemia is a particular problem, as 12.5% of patients required a lipid lowering agents according to national guidelines and this medication is not available in the primary care clinics. Again, women had levels that were higher than men and were more likely to require referral for raised cholesterol. The cholesterol problem was also more likely to occur amongst patients with diabetes, and women with diabetes were most likely to have this problem. Considering that referral to the specialist clinic for high cholesterol is a clinical issue, and that not all patients had baseline serum cholesterol measurements, these figures may under represent this problem. If one considers that the use of lipid lowering therapy has been clearly demonstrated to reduce the risk of cardiovascular morbidity and mortality in subjects with CVD or type 2 DM and also for primary CVD prevention (Baigent et al., 2005, Colhoun et al., 2004, Sever et al., 2005, Collaborators, 2008), then treatment for dyslipidaemia needs to be given a high priority of attention in the future. The use of lipid modifying drugs like the statins are considered too costly in South Africa, and so the emphasis is on lifestyle modification, but clearly neither of these goals of weight control or dyslipidaemia management are being achieved (Seedat et al., 2006), and this was demonstrated in this study. This is not unique to South Africa, as currently only one third of people with dyslipidaemia's in general are receiving treatment, even in well resourced settings (Fox et al., 2004b, Stacy and Egger, 2006). Patients specifically with CKD and ESRD should be targeted (Expert Panel on Detection, 2001, Nogueira and Weir, 2007).

There is no evidence of the extent of the burden of CKD in South Africa, and this study is one of the first showing significant proteinuria and CKD in people with DM and HTN. Considering that CVD and CKD are commonly associated with these chronic diseases, it was no surprise.

Levels of proteinuria are not better detected and reported since the tools for clinical diagnosis of CKD have become simplified, as there is still a failure of clinicians to check urine for protein. This is despite the fact that current recommendations suggest yearly testing and monitoring of people with DM, HTN or HIV (de Zeeuw et al., 2005, Gupta et al., 2005).The mean albumin-creatinine ratio was 59mg/mol, with over 25% of patients having levels ≥30mg/mol, and which are levels strongly associated with CVD disease (de Jong and Brenner, 2004). Patients with DM were again at higher risk of having levels ≥30mg/mol and overall under 10% required referral for significant albuminuria of ≥200mg/mol. The albuminuria referral level was much higher than suggested in guidelines (>100mg/mol) (International Society of Nephrology, 2005), but this level was used to avoid overwhelming the specialist clinic. Many patients with significant proteinuria also had a low GFR and they did not qualify for dialytic support and were therefore not referred. In some cases, it was felt they could be managed with decision support and follow up as per guidelines (K/DOQI, 2002).

In South Africa in patients with type 2 DM, CKD is most likely a major cause of death, but the extent of the problem remains undetermined. Twelve percent of patients had an estimated GFR (eGFR) <60mls/min/m^2. Patients with diabetes were much more likely to have a low eGFR or have end stage renal disease (ESRD). Higher rates of CKD occurred amongst diabetes patients, together with poorer blood pressure control, and higher cholesterol and albuminuria levels, indicating that focussing on people with diabetes is particularly important in the PHC sector and also an area of great concern. Women also appear to be at higher risk, so requiring special support. The levels of albuminuria and the eGFR were appropriately high if one considers this was a 'high risk' group compared with data from general population screening (Coresh et al., 2003, Lamiere et al., 2005), and were in the region of 2 to 4 times higher than the general population data available in the international studies. A comparison with the general SA population is not available. Assessing risk in patients with HTN and DM should include an eGFR and determining the level of albuminuria, and especially considering that patients in all stages of CKD are a high risk of CVD (Menon et al., 2005, Go et al., 2004). Further studies are needed to determine the general population risk of CKD and ESRD. Linking risk factors like obesity, dyslipidaemia, HTN and DM with the determination of serum creatinine level and a spot urine

sample for albumin–creatinine ratio (ACR) are sufficient to detect CKD and evaluate risk for CVD (K/DOQI, 2002, de Jong et al., 2003, de Zeeuw et al., 2005) and should therefore be carried out in all patients. The observations in this study do have limitations, including basing prevalence estimates on single serum creatinine measurements, which are subject to variations owing to differences in calibration systems between laboratories (Clase, 2006, Levey et al., 2007b, Coresh et al., 2002). Another limitation was that only 70% of patients had serum creatinine testing, which was needed to calculate the eGFR, and a population specific GFR calculation has only recently been determined (van Deventer et al., 2008).

Baseline Medication Prescription

Considering the strong evidence for using an angiotensin converting enzyme inhibitor (ACEi) to treat individuals who are identified from screening as having microalbuminuria, or are at risk for CVD (Asselbergs et al., 2004, ADVANCE, 2007), it was disappointing to see such low rates of use of these agents for patients with diabetes. Only 39% of these patients were using an ACEi, whereas ACEi use in HTN was significantly higher. This is in keeping with international data which shows sub-optimal use in many patients with DM and or CKD (McClellan et al., 1997, Kausz et al., 2001, Nissenson et al., 2001, Cooke and Fatodu, 2006). However, the problem in this study was linked to the poor knowledge and understanding of diabetes management and specifically treatment targets, and the fact that nurses had not been exposed to the recent diabetes guidelines. It is also related to the incorrect, confusing and convoluted algorithms which they are taught at the Soweto PHC School and appears in their PHCN training Manual (Pein et al., 1999) (see Appendix 13). The fact that blood pressure for those with HTN and DM was generally so poor, could be explained by the manual and PHC School guidelines and the limited use of ACEi, Calcium channel blockers (CCB) and multiple drug combination therapies. A factor underlying this low level of use could be the lack of authorisation and support provided for nurses to prescribe these agents, prior to CDOP, and a lack of confidence and knowledge. The same reasons explain the low use of insulin at baseline despite very poor diabetes control, although this was surprisingly similar to data from the United States (Koro et al., 2004, Turner et al., 1999, American Diabetes Association, 2008). The American Diabetes Association (2008)

has highlighted that there is a need for improving health care professionals' standards of education regarding standards of care, simplifying and ensuring access to latest guidelines, improving systems and patient tracking systems as well as improving quality of care. These system changes are incorporated in the Wagner and WHO chronic care guidelines and were instituted by CDOP.

Cohort Follow-up

Overall, the cohort follow up was poor and this was a very disappointing aspect of this study. A major limitation and concern was the high attrition rate after enrolment (68.7%) and the 20% of patients whose outcomes remain unknown. Fortunately, at baseline none of those patients lost to follow up needed referral, but this is not to say they would not have required referral later. The results, and in depth evaluation of the clinic systems, highlight the reality faced by PHC clinicians. Tracking people at high risk over time is an important feature of chronic care management, encouraging movement by physicians away from the 'find and fix it' models (Epping-Jordan, 2005)..

On the positive side, the program was able to detect those who needed referral and refer them to the specialist clinic (see Table 19 and Table 20), and most (71.8%) arrived at this clinic. Importantly, only 'high risk' patients screened required referral, indicating that with the correct support and available medication, most patients can be managed in the primary care setting. Of those who arrived at the specialist clinic, there was a full 2 years of follow up. This reflected positively on the specialist centre and its systems. It also reflects well on the programs' success of detecting those patients with advanced disease, being able to refer them and follow them well once referred.. This evaluation further demonstrates the ability of the PHCNs to use the program effectively. There was a problem with the program, because although the specificity was perfect, this was at the cost of sensitivity, and not all patients who should have been referred to a specialist arrived. CDOP was able to correctly detect people with disease but this was dependent on the health and program systems being intact, hence the lower sensitivity. Although this was a small group compared with the total enrolled. The study was a sober reality check of what is possible to achieve in the existing primary health care system. The findings

suggest that long term cohort follow up should be considered very carefully in the current Soweto PHC environment, and the focus should be placed on regular screening and detection rather than prolonged follow up. This is not because follow up studies are not ideal or better but because the primary care facilities do not have the capacity to handle complex follow up processes at this stage. Intermittent comprehensive screening at individual clinics would counter some of the existing health system limitations, and this should be a consideration for the future.

Specialist Referral Group

Despite the weaknesses in follow-up in the clinics, outcomes on the specialist referral group revealed some interesting and positive findings. The program had no ability to impact on weight control, despite great efforts at training nurses about obesity management. This is relevant to chronic illness management worldwide (Stevens et al., 2001). Even if achieved, weight loss is seldom maintained and considerable effort and resources are required to achieve and maintain weight loss (Stevens et al., 2001, Lindstrom et al., 2003, Diabetes Prevention Program Research, 2002). It appears that, even though the benefits of weight reduction are known, the chances of achieving weight loss remain a major challenge. With rates of diabetes and obesity rising, the development and delivery of interventions that promote weight loss and increased physical activity among people at high risk for diabetes or with diabetes are needed (Center for Disease Control, 2008). Public health interventions, including environmental and policy changes which encourage a healthy lifestyle (e.g., creating or enhancing parks, walking trails, and access to healthier foods) and maintenance of healthy weight, have been suggested (Center for Disease Control, 2008). The question needs to be asked if this is a possible reality in South Africa. However, there does need to be a greater emphasis placed on exercise and lifestyle in the PHC clinics. From personal experience there is no evidence of such activities. Support groups often focus on education, provision of food and social interaction rather than exercise. Perhaps, exercise and lifestyle classes could become a focus at PHC clinics.

The Outreach Program demonstrated, at least in this very small sub-group, that access to appropriate medication and aggressive treatment can control many risk factors. Improvements were seen with blood pressure, diabetes control and cholesterol reduction. The fact that 'ideal

targets' for DM control were not achieved in the specialist clinic setting indicates that controlling DM in the best settings is a challenge and that specialists also need the same systems and support as PHC systems. This study highlighted the importance of utilizing support services for DM control, at any level of service and especially in clinics like kidney clinics where a major proportion of patients have DM. Neither proteinuria nor eGFR declined over the two year follow up. This was despite the fact those patients referred were the worst of the 'high risk group' and these patients are usually considered to be a challenge to manage (Hoy et al., 2005b). This was a small group however and conclusions from this sub-group should be guarded. Of concern was the inability of the specialist clinic to carry out spot urine albuminuria measurements, although it has been demonstrated that urine dipsticks are a useful surrogate when resources are constrained and prevalence is high (Hoy and McDonald, 2004, de Jong and Brenner, 2004). Those patients who died all required referral, but died in the PHC setting before they were referred. This highlights another limitation and disappointment of the study, our inability to determine the morbidity and mortality overall in this cohort due to the overall poor follow up.

Specialist Group Medication Prescription

This group showed a much higher use of ACEi at both baseline enrolment and two years, reflecting the more advanced disease present in this group. There was also greater use of loop diuretics (furosemide) compared with thiazide diuretics (hydrochlorothiazide). This is partly explained by the poorer kidney function in the group and thiazide diuretics are ineffective with a low GFR. However, the better control of blood pressure, glucose and cholesterol control is best explained by the greater use and availability of anti-hypertensive, anti-lipid and insulin medication. There was also a greater range of anti-hypertensive medication available in the specialist setting.

Clinicians Knowledge and CME Support

The results from the evaluation of primary health care nurses' knowledge, continuing medical education support and the motivation survey (discussed in the next section) draw attention to both the challenges and successful components of the outreach program.

The 75% response rate from PHCNs for completing the survey, and the homogeneity of the nurses evaluated, makes this component of the program evaluation very meaningful. The clinicians were also both experienced and committed, as evidenced by their work experience and years qualified. A very exciting finding was the better scores achieved by the CDOP PHCNs (CD) compared with the non-CDOP PHCNs (NC) for the clinical scenarios. This strongly supports the value of the program in improving clinical knowledge and patient management. The advantage of the CD-PHCNs was particularly obvious in the scenario evaluating both HTN and DM care, where these CD-PHCN nurses scored significantly better scores. However, the meaning and benefit of this significance needs to be evaluated in greater depth. Clinic nurses are more likely to consult a colleague, when faced with a clinical problem, rather than a doctor in the clinic or contact the referring hospital specialist. Many nurses indicated that they would prefer to ask a PHCN who had been participating on the outreach program i.e. CD-PHCN, rather than a nurse who had not. This highlights the importance of PHC nurses in managing chronic conditions, with the appropriate knowledge to management and refer (Yawn, 2000, Bodenheimer et al., 2005).

However, PHCN knowledge varied, which was reflected in the poor baseline HTN and DM control in the cohort and from the answers in the questionnaire. Most nurses had participated in a learning activity over the past month, but most relied on the 'in-service' education for their CME, where issues clarifying HTN, DM and CKD management were not necessarily covered. A broad array of guidelines was being used for patient management and a number of nurses had not consulted the latest guidelines on DM and HTN. Many of the guidelines and especially the PHC School Training Manual were overly complex and management algorithms convoluted. This fact, together with the number of guidelines used, highlights the need for simplification of guidelines as well as the clinical targets. Treatment

decisions should be simplified and expedited using a restricted number of drugs in each class, but systems ensuring fast scaling up medication must also be implemented (Hoy and Kondalsamy-Chennakesavan, 2004, Ho et al., 2008).This is supported by the better knowledge of the HTN blood pressure target compared with the diabetes target mentioned earlier. The fact that DM treatment, serum glucose and HbA1c targets are not well known by PHCNs, together with little knowledge of 'compelling indication targets', such as those with HTN and DM (Seedat et al., 2006), probably explains poor diabetes and risk factor control overall and limited use of insulin. However, these findings are not dissimilar to findings from other studies (Hajjar and Kotchen, 2003), suggesting that this may be a universal problem (Berlowitz et al., 1998, Hajjar and Kotchen, 2003, Wong et al., 2007).

The CD-PHCN nurses were much more likely to know about HbA1c as a method used for managing diabetes, again highlighting the value of the program. However, knowledge deficiencies were evident during the evaluation of worker behaviour and performance in the thematic analysis. Analysis highlighted nurses' lack of knowledge about HbA1c, initiating insulin, doing urine testing for proteinuria, and calculating an estimated GFR. This highlighted the particular problem of poor knowledge of CKD, and difficulties in addressing the growing burden of CKD in the primary health care setting to prevent end stage kidney failure (El Nahas and Bello, 2005).

The last question is how continuing education should be delivered in the PHC environment. There is great pressure on nurses to deliver a service, and together with staff shortages and patient loads, the area of staff development and education is important (Chen et al., 2004, Padarath et al., 2003). Greater support and commitment by health managers to support nurses' training needs to be provided, especially as many PHCNs complained they were unable to participate in the CME and were not provided with transport to access the training. Educating nurses about improving chronic illness through CME is an important mechanism to impart knowledge about the management of diabetes and especially about CKD as a public health issue.

Role of Primary Health Care Nurses in Chronic Illness Care

The delivery of health care in the PHC setting is heavily dependent of functioning primary health care nurses (PHCNs). Ensuring that nurses are informed and motivated to deliver teh best possible care is critical to achieving these goals. It is for this reason that evaluation of the nurses' motivation was only carried out in the primary care setting using the health motivation survey and diary recordings. The comprehensive evaluation of nurses confirmed the crisis which nurses face with respect to large patient workloads and staff shortages. Nurses clearly indicated that they were unhappy with management and that management did not appear to understand their predicament. Human forces drive health-system performance (Chen et al., 2004, Franco et al., 2002), and the crises in workforce numbers, poor knowledge and inadequate training is undermining the health system in many developing countries (Liese et al., 2003, Hongoro and McPake, 2003, Padarath et al., 2003). In the Johannesburg Metropolitan Health Region B clinics, there was evidence of low staff morale amongst the nurses, although many PHCNs still appeared ready and willing to be 'activated and motivated'. An overwhelming number of nurses were still proud to be a nurse and work in the clinics. Most expressed a sense of achievement and satisfaction from their job. Nurses still showed they shared the values of the health service.

There was clear inconsistency between the domains which involved self evaluation i.e. 'motivational determinants (individual characteristics)' and that which involved evaluation through diary recordings i.e. 'worker behaviour and performance'. Most nurses, CD-PHCNs and NC-PHCNs felt they were hard working and "doing their job made them feel worthwhile". They were also confident that they were hard working and their work was of high quality. These domains were however contradicted in domains assessing 'worker behaviour and performance', most of which of this information was obtained from diary recordings. The contradiction between these domains reflects a difference between how the nurses see themselves and how they are seen from the outside, in this case by the CDOP team. A domain should not contradict a domain to this extent, but this difference is explained by an evaluation from different perspectives and is a result of the triangulation of data. This reflects an advantage of using triangulation of data as

part of the evaluation. The one domain was evaluated by nurses themselves whereas the other was evaluated by the CDOP team.

Low staff morale and quality of patient management can be closely related to workload (Penn-Kekana et al., 2005), and low levels of staff morale do not create an environment conducive to policy interventions. However, there was lack of concordance with what the nurses "would do" for CDOP or the clinic and with what they "were able to do" i.e. their personal resources which they possessed to achieve these goals (Franco et al., 2004). Compared to NC-PHCN nurses, CD-PHCN nurses had better scores for the motivational outcome domains. The latter were more personally motivated to achieve the program's goals, policy goals of the clinic and their managers' goals. This may have been a contributing factor for their choosing to participate on the program, i.e. the results may indicate a self selection of the most motivated nurses, rather than that the program influenced motivation (a problem of reverse causality).

The evaluation of the 'intention to leave' domain reflected high mobility of nurses; this was confirmed by a nearly one third reduction of PHCNs over the 2 years of the program and high staff turnover shown in the results. This demonstrated that the nursing staff in Soweto and Region B shared similar sentiments expressed by other South African nurses previously evaluated by a similar motivational survey (Penn-Kekana et al., 2005). In that study, it was also not discussed where nurses intended to go to, although it was known that some moved to local clinics and others overseas or to better paid local jobs. That study, like ours, demonstrated a need for more work to be done to better understand the reasons for nurses leaving their jobs and what action needs to be taken to prevent this (Penn-Kekana et al., 2005, Hongoro and McPake, 2003). Migration and high nursing staff turnover was a strong factor which could have impacted on the implementation and success of the program. A greater focus is required on the issue of human resources in health care, especially in relation to the increasing requirement for nurses to help provide the platform to support chronic illness management.

The PHCNs in the clinics were unmotivated, frustrated and intended to leave, but equally disturbing, the nurses working in the clinics were also demoralised and suffering burn-out. This impacted not only on their commitment to provide quality care in the clinics but on their commitment to work on the outreach program, and might explain why those nurses who did

choose to participate had better motivational scores in many of the domains evaluated. Burnout, and particularly emotional exhaustion is strongly related to job dissatisfaction (Piko, 2006). The majority of nurses were still pleased that they had chosen the vocation of nursing, but this domain was not evaluated with the same depth as in the Penn-Kekana study (Penn-Kekana et al., 2005). The lack of depth to the domains in general in this study, as demonstrated by the factor analysis, may be another study limitation.

The questionnaire did find nurses to be confident in their ability and the majority of nurses perceived themselves to be hard working. Nurses universally claimed to still have a good attitude towards patients and their job, and were not affected by the increased number of HIV patients. These findings were again found to be conflicting with those of poor worker behaviour and performance in the thematic analysis.

A more complete evaluation of determinants of motivation would have been possible if all components of the Wagner and WHO models had been investigated i.e. the patient and community together with health workers. Perhaps a more inclusive study might have revealed patient unhappiness with the health service and their clinicians' skills, as in other studies in similar environments (Gilson et al., 1994). This problem was alluded to in the 'patient evaluation' and adherence codes in the thematic analysis, but was not adequately assessed in this study.

Amongst the questions evaluating the individual characteristics of motivation, dissatisfaction with pay and the exclusion of the PHC nurse clinicians of the scarce skill, occupations specific dispensation allowance (OSD), allowance were again highlighted. This exclusion from the scarce skill allowance affected staff morale and did not create an environment conducive for policy interventions or 'external programs' like CDOP. It was both a blatant mistake and lack of insight on the part of government not to recognise the value of the PHCN, and their role that they as nurse practitioners played in South Africa. The PHCNs are central health care in Soweto (Health Systems Trust et al., 1999), and the 'slap in the face' by government policy was a major blow for nurses. This is especially in view of findings that the nurse practitioner, in our case the PHCN, has an important role in managing chronic illnesses (Laurant et al., 2005, Peters and Davidson, 1998, Aubert et al., 1998a, Bodenheimer et al., 2005). This issue also emphasized the need for managers to pay greater attention to their staff

when introducing reforms, new policies and programs (Penn-Kekana et al., 2005). This type of policy creates resentment and bad feeling in the workforce and was evident by the fact that nurses, during this 'scarce skill allowance' confrontation with management, refused to enrol and see patients on the outreach program.

The knowledge demonstrated by nurses in the clinical scenario appeared to correlate with the nurses' motivational score from the questionnaire. This is an area requiring further investigation. The PHCNs' conscientiousness and work quality did have an impact on the program, as errors in the data captured by nurses required follow up and correction and missing baseline data affected some of the analysis. The doctors and some of the PHCNs reluctance to participate on the program also reflected motivational problems relating to worker behaviour and performance. A major problem noted was the PHCNs' inability to find solutions to their existing health system challenges. This problem was coded as the 'Bara syndrome', reflecting apathy when confronted with large workloads, where health workers abandoned quality and preferred to offer a 'quick fix service' or nothing at all. In circumstances like those experienced in the PHC clinics, work quality seems to be lost when health workers are overwhelmed. This is another area within the clinic where action research methods may be able to play a role. Increasing efficiency and productivity at a clinic could be enhanced with improving and developing nurses 'time management' skills and their ability to apply 'lean thinking' mechanisms to address health system problems (Young et al., 2004). It might be possible to identify better pathways to improve nurses' ability to cope with patient workloads and lower staff numbers by 'working smarter' and 'eliminating waste' in the clinic processes. Providing health workers and managers with skills to tackle their work challenges, by teaching them to measure or identify 'process defects' analyse these problems and make corrective changes, may be an answer for some the health system and motivation problems (Young et al., 2004, Kelly, 2005). It could also empower nurses and give them a sense of autonomy in the work place.

Closely related to empowerment of staff were the managers' needs to create a positive working environment in the clinics. Nurses were frustrated with too many changes, and they felt 'out of control' with their 'senior' managers' involvement in the clinic work environment, especially related to starting new programs and policy implementation. PHCNs perceived that

managers did not understand their working conditions and did not consider the effects of their decisions on them. This distrust of management was not unique to this study (Penn-Kekana et al., 2005), and managers have to be aware of clinicians when implementing new policy or programs (Penn-Kekana et al., 2004). The working environment, supervision, management and collegial support all shaped nurses desires to participate in the program and their desire to improve the service. Performance is not only dependent on nurses' skills, but also on system support (Franco et al., 2002). Finding better methods to manage and support staff is an area requiring attention. Providing adequate resources such as medication, supplies, and equipment will also go a long way to improving workers motivation and better health care delivery. Managers need to be seen as valuing the role that PHCNs play in the health service, and seen to acknowledge the importance that nurses' play in delivery of primary health care. This was not the case in 'outreach' clinics. Nurses have to be recognised as part of the solution to the resource challenges, and to feel that they are critical to the implementation of the health department policies and service delivery. The outreach program appeared to have a positive effect in this regard, it recognised the role that the nurses played, provided incentives to improve service delivery, and conducted workshops on change management. However, despite some of these positive aspects, it failed to be adopted or integrated by 'senior management'.

Additional Issues Arising from this Study

Role of Specialist in the Primary Health Care

This study raised some interesting questions about the role of the specialist in the PHC setting. There is a growing burden of poorly managed chronic illnesses in 'transitional' communities like Soweto (Sliwa et al., 2008, Levitt et al., 1999, Bradshaw et al., 2007). Specialists are seen as playing a role downstream, at the end of the process, and are supposed to rescue people form a long line of health system failings. This project demonstrates another more active role that specialists can play, by participating more actively in primary care and through enabling mechanisms to link primary and specialist care better. This is not at all to suggest that the specialist should take over the role of the primary care clinician, it merely

acknowledges the role and value that they can add to the PHC clinician. It is also clear that for patients at higher risk of complications or who may require further investigations that the increased role of the specialist could be both appropriate and cost effective (Fox, 1996). Collaboration is required when it is “necessary for the management of a particular condition” (Couper, 2007)(page 8). The evidence is clear that for a condition like CKD, at a particular point in the progression of this disease, the role of the PHC clinician is limited. The continued care by a PHC clinician is not in the interests of the patient, resulting in increased morbidity and mortality and at a greater cost to the health system (Levin, 2000, Roubicek et al., 2000). This is not to say that specialist cannot work well with PHC clinicians. Clearer referral guidelines, improved communication and decision support can improve outcomes with CKD (Lee and Forbes, 2009) , and this approach may be applicable to other specialty areas. The diary recordings documented the PHCNs calls for improved outreach from specialists, integration of CDOP methods as the ‘standard’ method of care for the chronic illnesses and expansion of the program to other specialities including HIV. CDOP offered an opportunity for specialists to play a more meaningful role in the PHC sector, without affecting the role that they play in their ‘comfortable’ high technology environments.

The role of CDOP in no way suggests that they should replace that of the PHC doctor or nurse practitioner. It suggests that they should rather work together as has been shown to be of value in a number of studies (Peters and Davidson, 1998, Aubert et al., 1998a, Bodenheimer et al., 2005, Nutting et al., 2007). The models proposed strongly support the role of the PHC clinician as the primary point of patient management, the use of nurse practitioners where resources may be limited and the incorporation of the specialist for decision support and collaboration about management. This integrated model should further improve patient care. The role of direct referral could also be considered in the system, especially where it can improve efficiency and continuity of care. However, it is not an all or nothing phenomenon, but all these possible systems need to be considered depending on the environment. ‘Task shifting’ is an example where systems were used to transfer clinical responsibility to health workers in Ghana and Mozambique where resources were poor or even absent (McPake and Kwadwo, 2008). This may not be applicable for all countries.

Role of Guidelines in Chronic Care

It arose in a number of areas of this study that the guidelines available to clinicians were confusing, conflicting and even overwhelming. Some of these issues have been highlighted earlier. Many of the guidelines are written by specialist far removed from the primary care setting, at meetings sponsored by pharmaceutical companies with agendas which may not always be supported by the best evidence. It is for these reasons that the issue of guidelines in general, their role and use, as well as the relationship they play in the PHC setting needs to be examined. Although standard treatment guidelines exist for all chronic illnesses, and it is not necessary to establish new management approaches at PHC level, some flexibility and simplification is required (Couper, 2007). There must be a balance between protocol driven care and the individual needs of the patient. It is here that we propose a 'simplification' or broadening of the approach. The Wagner and WHO chronic illness care models demonstrate that managing chronic disease requires the involvement of multiple sectors and role players. This approach is supported from the findings of the Australian Outreach program, which has documented that most people with chronic disease have more than one co-morbidity e.g. hypertension and diabetes or diabetes and obesity. It is this overlapping of co-morbidities which justifies an integrated rather than disease specific approach (Hoy et al., 2005a).

Regional and national networks could serve as a mechanism to implement coordinated and simplified guidelines. Current clinical guidelines for chronic illnesses require more time than PHC clinicians have available (Ostbye et al., 2005), therefore streamlined guidelines and alternative methods of service delivery are needed to meet recommended standards for quality health care. Considering that similar problems were found in PHCN knowledge regarding diabetes and CKD knowledge, it is important to develop clear, simplified and integrated protocols which make decision making easier for clinicians managing chronic diseases (Figure 59).

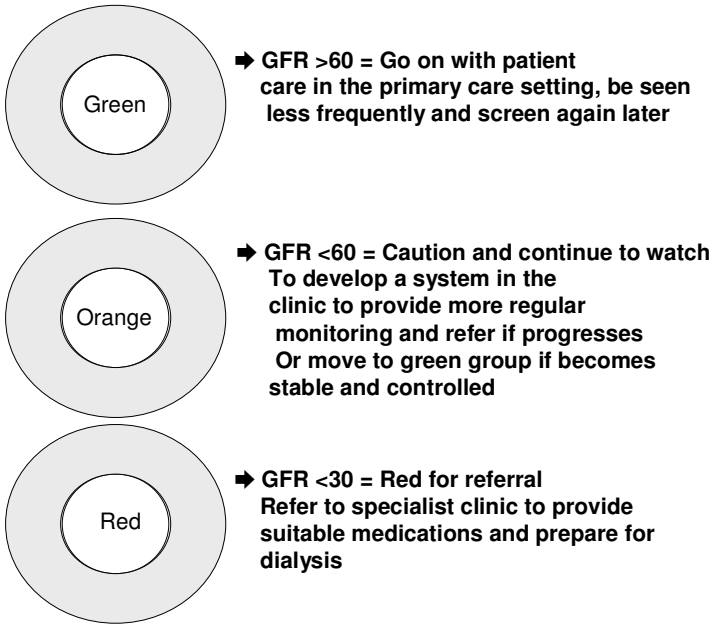


Figure 59. Simplifying Management and Referral Protocols
GFR – glomerular filtration rate measured in mls/min/m2
Note: A simple 'traffic light' approach link primary and tertiary care and assist clinicians with decision making

However, it should be noted that guideline implementation and adherence is a major challenge in the health sector and multiple interventions to improve guideline or protocol driven care are better than one single approach (Weingarten et al., 2002 , 1999). However, a more integrated strategy is also required to achieve our goals, especially in view of the complexity of protocols for different chronic illnesses, and this will also enable the PHC clinician to follow guidelines (Harris and Zwar, 2007a).

Challenges Scaling up

The increased burden of chronic illnesses requires programs, like CDOP to be scaled up to meet the challenge. Health systems in the clinics are functioning in a predominantly curative and 'find it and fix it, framework. A comprehensive and integrated system is needed, such as systems that adopt the Wagner and WHO chronic illness methodologies.. The problems with scaling up these services relate more to policy and attitude than resource shortages (Schneider et al., 2006). This is demonstrated in the success of HIV anti-retroviral programs where performance and successful scale up has not related to resources (Van Damme and Kegels,

2006). Most studies highlight the need for good policy decisions which improve health systems and control the scaling up according to existing resources (Victora et al., 2004). The successful aspects of the chronic disease outreach program like decision support, early detection of CKD and improved referral systems, failed to be endorsed by policy makers. This was despite the fact that these systems were successfully implemented in the challenging Soweto environment. There was however, significant limitations to its ability to scale-up to involve more clinics in other regions or the province. CDOP has demonstrated that multiple factors impacted on the ability to implement the program in the PHC sector in Soweto. The major limitations include the poor existing health systems, the fact that it was 'driven' by a single individual or 'champion', and that it only had two nurse coordinators to drive the process in clinics serving over 40 000 'chronic' patients. There is no substitute for formal health structures (Einterz, 2001), and without policy and funding from governments, Einterz argues, even if programs are good, they will not be sustained or scaled up. Sustainability and scaling up require government support.

Chronic disease continuing care must be delivered by a well-functioning team (Epping-Jordan, 2001), but also within a functional policy and health care organizational environment. These components remain as important as adequate funding. The program discussed in this thesis, required no specific funding to be implemented and sustained over two years, but it was not adequately integrated and was not scaled up to other regions. For true integration and scaling up, it would have to be actively incorporated into the formal health structure and have genuine management support and financial support.

Certain basic fundamentals are required for program implementation, integration and scaling up, and many of these can be learned from programs which have worked for HIV, TB and malaria. The lessons learned from rolling out these programs include the importance of gaining political support and developing a strong and workable strategy. It also requires implementation of uniform and consistent strategies, and ensuring regular audit and evaluation of whether defined targets or outcomes have been achieved.

This evaluation demonstrated the importance of chronic disease surveillance, treatment and education as essential and major elements of primary care. It highlights the need for programs to be adequately funded and staffed over the long term, and that when there are

health care resource and staff shortages then activities perceived to be elective, such as chronic disease care, are the first to be abandoned (Hoy et al., 2005b). Programs like CDOP require good management support and staff who are well trained, well supported and fairly paid. They have to feel that they are highly valued and respected for the role that they play and the health systems need to provide a supportive and enabling environment (Von Korff et al., 2002, Hongoro and McPake, 2003).

7 CONCLUSIONS AND RECOMMENDATIONS

This study has demonstrated that there is a high burden of kidney disease and cardiovascular risk factors in patients with uncontrolled DM and HTN in Soweto and its referral clinics. Chronic kidney disease satisfies the criteria as a public health issue in that it possible to act on the condition at both community and public health levels, thus making a strong case for its recognition as part of the continuum of chronic illnesses alongside CVD. It has also shown that factors like obesity, dyslipidaemia, and proteinuria are more prevalent than previously considered in the community, and that these risk factors remain poorly controlled. There is also very poor control of chronic illness risk factors in the primary health care sector with improvements when referred to a specialist. It was also demonstrated in this study that many patients in the PHC clinics already had advanced CKD and some with ESRD. The majority of these did not qualify for dialysis. However, the program only screened a very small number of people who are at risk and for those referred, it was often too late. This project was an attempt to ensure that CKD is recognised as a more serious public health problem amongst the other existing chronic diseases. It is not an attempt to make kidney disease the most important chronic disease but rather that it is included in an integrated approach to manage chronic illnesses in the PHC setting. Secondary prevention strategies focusing on an individual high-risk approach in developing countries could prevent many deaths, but there is a cost and infrastructure requirement which needs to be considered. This might involve opportunistic screening and treatment with a multi-drug regimen in people with CVD or CKD.

Additional public health efforts to address CKD are needed, and an effort needs to be made to integrate CKD monitoring, education and awareness into the existing structures used to manage chronic illnesses like DM, HTN and HIV where the greatest burden of CKD is found (Dirks et al., 2006). Unfortunately, the extent to which we have applied this knowledge remains disappointing (Zoccali, 2006). Specialists are obsessed with technology and ‘machines that go

ping'[9], whereas simpler approaches using existing resources but improving health system function will have a greater impact than the development of new technology or machines. A comprehensive integrated public health system approach is required to effectively address this issue. People with chronic illnesses often present when the disease is advanced. An integrated health care system, involving all 'structures' including prevention and treatment components, is particularly appropriate for the ongoing care of any chronic illnesses, whether tuberculosis, DM or HIV (Epping-Jordan, 2005). Prevention strategies would include focusing on those at highest risk for disease and utilising a mass strategy of prevention and management to shift the whole population distribution of that risk variable (Rose, 1981). However, many questions have yet to be answered with regard to health systems and chronic illnesses, such as ensuring the availability of low-cost generic drugs for people at high risk of CVD or CKD and ensuring their uptake and long-term use without financial burden. Other questions include the identification of people at high risk in primary health-care settings and appropriate referral. A simple set of indicators for monitoring progress in implementing strategies to manage chronic conditions is also needed. Here good information systems play an important role (Beaglehole et al., 2007). In relation to this, there is a strong argument by Couper (2007) that the PHC facility or family practice should be better structured to tackle the management of chronic diseases. A framework of principles which could inform the future models and health systems for chronic illness management has been proposed. If these are implemented with the incorporation of the experience of managing HIV, TB and malaria and scaling up such programs, then it may be possible to improve quality of patient care and the effectiveness of our health service.

The implementation of programs like CDOP using chronic illness management models like the Wagner and WHO models, offer a potential template and solution for improving the standard of care. The relevance of chronic communicable illnesses like HIV/AIDS, tuberculosis and malaria, for diseases like CKD, heart disease and asthma, have not yet been fully recognised. No attempts have been made to link these two challenges using an integrated

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[9] Quote from Monty Python's 'The Meaning of Life": Part I, The Miracle of Birth, Written: Graham Chapman, John Cleese, Terry Gilliam, Terry Jones, Eric Idle and Michael Palin. A Methuen paperback Humour, ISBN 0413533808

response. Furthermore, chronic diseases which are the major cause of adult illness and death in all regions of the world have not been included within the global Millennium Development Goal (MDG) targets. Publications on health and the MDGs have recognised this oversight. There is scope for considering chronic diseases within existing MDGs, such as Goal 6 incorporating HIV/AIDS, malaria and other diseases. Alternatively they could be considered more broadly in Goal 1, which aims to eradicate extreme poverty and hunger. This acknowledges that chronic illness prevention would contribute towards poverty reduction worldwide (World Health Organization, 2005a). It remains important that chronic diseases be included in WHO and government programs.

It is important to link both disease management and prevention. However, the concept and understanding of prevention is constantly changing and possibly being distorted. With the emergence of risk factors and diseases to be considered as the same entity, we now need to critically evaluate what is meant by prevention (Starfield et al., 2008). It has also been suggested that we shift the focus on the 'population' as a whole rather than the individual with CVD risk factors. This needs to be considered when initiating screening and 'prevention' programs. Furthermore, Starfield (2008) has suggested that population-attributable risk should be the priority over individual (relative) risk, and the focus should be on defined populations with strong evidence to support an intervention. Interventions should be shown to be cost effective and reduce morbidity and not just the 'disease'. Integrating the therapeutic and prevention roles has improved care for obstetricians and paediatricians (Rose, 1981). This has also occurred with HIV where integrating treatment and prevention has been shown to have a greater impact on outcome (Salomon et al., 2005). Success has been achieved in Australia and the United States from the late 1970s where this focus resulted in the reduction of mortality from coronary disease (Rose, 1981, Lenfant, 2003). For coronary disease, although both primary and secondary prevention and treatment components are necessary to maximise health care, the greatest benefit is seen with primary prevention (Unal et al., 2005). This may also be true for other chronic diseases. Essentially, strategies should focus on primary prevention, particularly tobacco control and healthier diets and interventions which have a clear population benefit.

CDOP and the Soweto Chronic Disease Health System

In South Africa, chronic disease systems for managing HTN, DM and TB are well established, although those for HIV/AIDS are better funded and receive more attention for political and emotional reasons. The health system in South Africa requires significant strengthening given the epidemics both of non-communicable chronic disease and HIV. Research and evaluation of health systems has taken place in developing countries (Joint Learning Initiative, 2003, Sanders et al., 2005), and especially with regard to HIV (McCoy et al., 2005, Schneider et al., 2006) but also non-communicable chronic illnesses (Abegunde et al., 2007, Epping-Jordan, 2005). Tollman et al. (2008) have warned that PHC systems managing chronic diseases like DM, HTN and HIV, need to be strengthened, integrated and scaled up to address the growing problem. .

This thesis examined the integration of an Outreach Program into the PHC clinics for improving HTN and DM management and to improve links between the PHC and hospital sectors. Despite many of the program's failures, it achieved some successes, and may contribute to the development of future frameworks to tackle many of the chronic illness challenges. The data measured at baseline successfully characterized a group of patients with hypertension and diabetes in the primary health care clinics in the Soweto region. It demonstrated the baseline control of these diseases and their risk factors, and the prescribing characteristics of the primary care clinicians. The program proved successful in supporting primary health care nurses (PHCNs) working in the clinics which participated in the program. It was effectively implemented, but was poorly integrated into the existing chronic clinic system, although it did offer an alternative pathway for patient management. There was a perception and evidence from the better clinical management scores amongst nurses participating in the program that it improved awareness of appropriate referral and efficiency for referral to a specialist. The PHCNS indicated that the program did add 'value' to the nurse's clinical practice. It assisted PHCN clinicians in their management of patients with chronic illnesses through the systems of decision support and patient referral. Certain clinics showed excellent initiatives in team work and integration, but this reflected local 'drivers' or 'champions' and not clinic managers. A success of the program was its ability to detect those patients with advanced

disease and ensure early referral in the majority of cases. Those referred demonstrated improved risk factor control and monitoring at the specialist referral clinic. The program also had a positive effect on the existing PHCNs knowledge and motivation, which was most significantly demonstrated in those nurses who actively participated on the program. The nurses improved knowledge was reflected in their ability to manage chronic disease problems, scoring better in the clinical scenarios. There was also evidence of better motivation in those nurses volunteering to participate on the program, and this may have related to their improved knowledge. The success and failures of the program related to both 'internal' CDOP factors and to factors 'external' to CDOP. The program did function, and those PHCN participating did well, although it should be noted that this was with a great deal of assistance from the dedicated CDOP nurse coordinators. On the basis of the evidence outlined above, this program was not fully integrated into the existing clinic system, although it did add value and show certain benefits.

Many system factors negatively impacted on our ability to implement the program and affected its success. Most of the problems related to the poor existing health systems and infrastructure. There was poor and inadequate integration into the chronic illness clinics in general. Despite an expressed desire by both management and nurses to integrate and scale up the program, this was not achieved. It must be noted that only a very small group of patients showed improvement and therefore the program would need substantial improvements before it can be scaled up and have significant impact.

Management approved the program and verbally supported it, but did not actively adopt it or integrate it into the existing clinic systems. Some of the problems related to poor communication between regional, provincial and local clinic managers. The clinicians also were not actively consulted on the implementation of new policy and programs. An evaluation of the nurses revealed an overworked, poorly supported, frustrated and burnt-out primary health care team. These factors resulted in a high turnover of clinic staff. This, together with patient load, severely impacted on the ability of the outreach program to enrol and follow up patients, integrate into the chronic clinics, and extend it. Although the PHCNs and nurse program coordinators correctly enrolled 'high risk' hypertension and diabetes patients', a major shortcoming was that the cohort was not successfully followed.

Existing acute and chronic illness services in the clinics are run as vertical services and not in an integrated manner. The clinic does not function as a single primary health care unit, as would be the case for a private family or general practice. CDOP was also implemented as a vertical program and this together with the other 'vertical' services and programs that are taking place in the clinics resulted in competing demands on the nurses. This impacted on the implementation of CDOP. This was a criticism and weakness of the 'Outreach Program' and it must be noted that a major limitation of the program was the vertical implementation strategy which was adopted. It could be argued that the program was an 'integrating activity', as the aims were for nurses to recognise the commonality of the risk factors (HTN, DM, obesity, dyslipidaemia, proteinuria etc.) in relation to CVD and CKD. The implementation strategy adopted directly affected the programs' ability to enrol patients with HIV and possible kidney disease. Staff shortages often meant that nurses moved between clinics and programs, and this placed an increased demand on these nurses who were unskilled in managing these diseases and hampered continuity of patient care. There was a particular problem with nurses' knowledge and ability to recognise the importance of quality care. This was evidenced in their inability to manage diabetes, and almost a complete absence of knowledge with regard to kidney disease at the outset. Nurses lacked the skills, knowledge and commitment to measure HbA1c levels, initiate insulin, measure proteinuria or albuminuria or calculate an estimated GFR. When nurses were assigned to work in a 'specialised clinic', they were not given the authority or support to use all medications. This, together with complicated management protocols, resulted in nurses lacking confidence and feeling like 'second class citizens' in the health care team. This is despite the fact that they are often the only clinicians available to deal with the problems, as not all clinics have doctors. It highlights the need to have 'a positive policy' environment to ensure the goals of the organization are achieved. This also highlights the need for managers to develop and allocate their human resources appropriately, as without a well functioning motivated health care team, no care can be provided.

Elements of the Wagner and WHO chronic care models were applied in the clinic health care system with CDOP and the program demonstrated that it could provide some of the systems and framework to better manage chronic illnesses. What it lacked was the ability to

implement the models in their entirety and the resources to implement and expand the outreach program. This is where some of the principles of Couper (2008), for managing chronic illness at a facility and individual level may have been of assistance. Additional models or tools are required to establish chronic illness programs in the PHC setting which will draw on past experience of programs established for HIV, TB and malaria. This will include better identification and management of treatable risk factors, improved screening for common non-communicable diseases, and the diagnoses, treatment, and follow-up of patients. PHC clinicians also need to know when it is necessary refer patients with common standard and simplified protocols.

PHCNs overwhelmingly felt the program had added some value and helped them with patient management. There were also numerous limitations, many of which have been discussed and are summarized in Table 26. It was effective in determining those patients who had advanced disease and who needed referral. It effectively assisted PHCNs with management decisions, referral and improving some knowledge about chronic illnesses, but this was in a very limited population. One of the most positive features detected amongst the primary care clinicians was that, despite all their personal and work challenges, they remained motivated to deliver a better service. What is required is that management develop policy and implement an enabling environment to take advantage of this enthusiasm

This study was an attempt to introduce a program for the management of chronic diseases (diabetes, hypertension and chronic kidney disease) in a very difficult environment. Its originality lies in the detailed investigation of the working conditions and potential contributions of the primary health care workers. Its emphasises the many system problems that face health services for 'transitional societies' in situations of continuing poverty but is unable to evaluate them all in great depth.

Program Strengths and Limitations

The main value of observational studies like the chronic disease outreach program is its effectiveness to provide care for chronic conditions in a realistic situation, instead of in trial conditions. Standardising qualitative research is more complex as validity depends on the quality

of data and the ability to control for bias and confounding factors. However, this study did have limitations.

The thesis described the CDOP management of high risk CVD/CKD patients with DM and HTN, which is potentially more cost effective than usual clinical practice in such an environment. This thesis describes the baseline risk and control of patients with DM, HTN and its consequences which included CKD and CVD. The factors affecting good HTN and DM control in the clinics were evaluated, as recorded in diary accounts and an administered questionnaire. The CPOD served as an effective link between primary and tertiary health care systems and provided both clinical and educational support for PHCNs. The 'program,' together with the PHCNs, proved to be a successful mechanism for detecting and referring high risk patients, despite the loss of some patients during the referral process. It documented health system weaknesses, including challenges in retaining, supporting and educating PHC clinicians. A very important component was the improvement of clinical knowledge and better motivation amongst PHC nurses participating in the program.

The program cohort was small relative to the disease burden, and scaling up such efforts will require significant resources. A high number of patients were lost from baseline, and the sample was relatively small. This fact did affect the programs ability to compare groups and was another study limitation. This together with CDOP's inability to follow patients successfully, meant that I was unable determine the overall morbidity and mortality. This also limited the study's potential to evaluate its impact on clinical outcomes. In addition, we relied on estimated GFR equations, which have their limitations; this approach may over diagnose CKD, although this is less important in a high risk cohort. Not all patients enrolled had testing carried out and estimating kidney function by eGFR was based on single serum creatinine measurements. The eGFR equation had not been standardised to this population.Participants were chosen randomly by PHCNs, but it is possible that choice of enrolment was influenced by PHCNs. It should be noted that detecting advanced disease such as ESRD does not necessarily mean treatment access, and issues like these need to be addressed in the future.

Other limitations included that managers, doctors and some nurses were resistant to program integration. CDOP should have invested more time and effort to incorporate all PHC

clinicians and managers before and during the process of implementation. The fact that these groups of health workers were not questioned more comprehensively, and that these groups were not included in the evaluation is a limitation of this study. This problem was affected by the large work load, patient numbers and competing demands which exists for PHC clinicians and for the researchers. Due to time and resource constraints, it was not feasible to implement or investigate all components of the Wagner and WHO chronic illness models. This resulted in an inability to adequately evaluate these frameworks for chronic illness management and there was only a small focus on the community, patient factors and administrative managerial factors which impacted on chronic disease management and the program implementation. Failure to investigate these groups more comprehensively and how they impacted on patient outcomes and the outreach programs ability to improve health system and adherence factors was a weakness of this study. It should also be noted the interpretation of these factors which impacted on the program and chronic disease management was that of the nurses or program managers, and this is a flaw in this evaluation. The evaluation of the 'health care team' was also limited in this study and was really an evaluation of primary care nurses.

The program did have some impact on outcomes, but again this was in a very small number of patients, and only in those followed up at the specialist clinic. Patients with advanced disease were detected, but this is only a very small number of patients at risk amongst the thirty to forty thousand patients with HTN and DM in Soweto. In this small group of patients in which clinical risk factors were improved, it should be noted that another major limitation was the lack of effectiveness on weight control. Although a limitation, it also reflects the complexity of managing chronic illnesses in particular obesity.

In relation to the health workers knowledge and motivational survey, the lack of depth to the motivational outcome and motivation determinant domains in this study, as demonstrated by the factor analysis, reflects another limitation.

The fact that the program was also implemented in a vertical manner, and did not include all chronic illnesses under a single banner, proved to be a limitation. HIV, HTN, DM, chronic obstructive airway disease, asthma and epilepsy account for more than 90% of chronic illnesses at PHC clinics. There is a strong argument for integrating these illnesses into one stream of

care. This weakness could be attributed to the way the program was implemented and the failure of all management structures to support the initiative. The outreach program was also due to only a small number of dedicated program staff, funding, and staff limitations in the PHC sector in Soweto.

Due to poor patient follow up, the impact on morbidity and mortality could not be determined and the approach to this program may have been too broad. It may have been better to focus this 'pilot' program in a smaller number (or even a single clinic) with full support from management and where an integrated program for chronic disease control could have been comprehensively studied..

Policy factors, poor leadership and advocacy from provincial government managers, inconsistent funding and poor allocation of human resources at the PHC clinics may also have impacted on the program.

Recommendations

There is no integrated electronic medical record system in Soweto, and none linking the PHC, secondary and tertiary hospital settings. This significantly impacted on the Outreach Program's ability to monitor and track patients. The implementation of such a system should be a priority. It would ensure continuity of care, improve cost effectiveness and efficiency and assist with clinical audits. Implementation policies and clinical protocols need to be developed in partnership with clinicians working 'on the ground', including specialist services, and should not be instituted in a 'top down fashion. For example, such systems could immediately ensure the provision of anti-lipid agents to patients at high risk in the PHC clinics and develop methods to 'refer up' and 'refer down' to and from primary care clinics. The present emphasis is on 'quantity of care' and not quality of care in the Soweto clinics. There is a great pressure on politicians and managers in South Africa to demonstrate that they are delivering health care to all communities. There needs to be a greater emphasis placed on health care managers and clinicians to place a greater focus on the delivery of quality care and not 'quantity care'. The measurement of health outcomes is critical. This relates to the need for better systems of audit and research.

Currently there is only verbal support for better research and audit but this has not been actively funded, and no specific resources have been allocated to these challenges.

Despite the availability of guidelines to address problems of obesity, diabetes and hypertension related to lifestyle, there is very little practical 'action'. It is clear that more active and innovative approaches are required which could include incentive driven weight loss programs and the establishment of exercise programs at clinics and in departments managing chronic diseases e.g. diabetes and hypertension clinics.

Guidelines and protocols of management provide an effective means to achieve disease control and these should be followed for improved management of chronic illnesses. There was evidence in this study that guidelines are not being used or are not known to practitioners. There is a need to simplify and integrate these protocols for patient management.

The management of chronic illnesses requires political will to provide a comprehensive health system, which includes strengthening the health system through developing strong leadership in each PHC facility, resource mobilisation and allocation, policy development and implementation. PHC clinicians need to detect and manage those patients with chronic illnesses, and refer them on to specialist if the protocols support such referral. Primary health care nurses require more support, confidence and reassurance where their management has shown to be more efficient and effective.

The balance between the individual patient care and general population requirements needs to be addressed in such systems. Interventions have to focus on population outcomes and not always on individual outcomes. Protocols should also be adapted and validated for particular settings and populations. Recognizing the existing health system deficiencies in the Soweto health region, early detection and management programs should focus more on regular comprehensive clinic screening with the aim of detecting patients needing referral and more intensive monitoring. This change of emphasis recognizes that current clinic systems in Soweto cannot cope with intensive follow up. The results of this study suggest that long term cohort follow up should be considered very carefully in the current PHC environment, or at least until systems for long term follow up are strengthened. Grant funded cohort follow up remains the most likely successful method which can be utilised until health systems are strengthened.

In the immediate future, the focus should be placed on regular screening and detection of complicated illness rather than intensive follow up. It is also suggested that strategies as provided for in figure 59 are used to assist with follow up, by categorising patients according to priority. Improved follow up will also be achieved when electronic clinical data is available for clinicians and clinical notes become more reliable. These initiatives are generally referred to as the strengthening of the health system.

The limited capacity of the health organization and health systems needs to be taken into account. In this regard the interaction and roles of the PHCN or nurse practitioners and doctor needs to be clarified. Doctors are needed to support nurse practitioners but the boundaries and protocols of interaction need to be clarified. In this regard there is also a role for the specialist in the primary health care sector, and the nature of this role requires further debate and investigation.

Clinical processes have to be supported by the regular and constant supply of medication. The regular interruption of treatment as a result of erratic availability of medication leads to poor quality care, increased morbidity and a reduction in adherence. The current pharmacy support and capacity needs to be strengthened in the primary care setting e.g. private public partnerships for medication supply should or could be considered.

The study indicates that clinicians are not well informed regarding chronic kidney disease (CKD). There needs to be a greater emphasis on CKD as part of the chronic disease continuum, and more education for the patient/public and health professional on its diagnosis and management. Linked to the efforts to highlight CKD is the need, to integrate management of all chronic illnesses into a single clinic or 'stream' at the primary health care level. All clinicians in the PHC team need to work as part of a single unit, managing chronic illnesses together. Sub-specialising to develop the skills required for a particular disease e.g. HIV or CKD, should occur within this team, so that programs for chronic diseases are integrated horizontally into PHC family and community practices and not vertically. .

In health systems, like in Soweto, where nurses manage most chronic diseases, some need to develop 'specialist' skills within the team e.g. CKD or HIV. Not all nurses will have the knowledge or inclination to specialise in a particular disease, but sub-specialisation will serve to

motivate clinicians to develop and focus on developing unique skills for the PHC team. These PHCN, could develop as specialist PHC clinicians within the team, and provide a link up with specialists' up-stream in the health system.

As part of the strengthening of ties between PHC and specialist care, there needs to be a development of coordinated 'outreach programs' involving all specialties which manage chronic illnesses. Hospital specialists need to assist the PHC team and their 'PHC clinician sub-specialists' or chronic disease 'program nurse coordinators'. These coordinators will provide the link between primary and tertiary care e.g. HIV, diabetes, hypertension, CKD, asthma, epilepsy, and TB.

It was evident in this evaluation, that basic skills such as capturing demographic or audit information, weighing, measuring blood pressure, blood glucose and urine testing was being carried out by highly skilled clinicians such as professional nurses. Managers in PHC facilities, regional and provincial offices need to focus on improving team work. This would include utilizing non professional nursing staff, or trained community health workers to do non-specialized tasks e.g. weighing and blood pressure measurement, recording demographic and data capture.

The evidence of high turnover of doctors and nursing staff in clinics and hospitals is an indication of a serious human resource problem within this health care environment. Managers are needed who can take responsibility for providing an organizational environment which motivates health workers to achieve the goals of their organization. This would involve the acknowledgement and importance of health workers and especially primary health care nurses in the PHC system. Improving staff commitment might be achieved by creating incentives, providing change management and by developing and training health workers to improve motivation and skills to deliver on organization goals i.e. investment in staff by developing skills and providing training. As part of the motivation of health workers, managers need to provide and ensure the constant supply of appropriate equipment and medication. They also need to take a greater interest in the health workers environment, looking at ways to improve efficiency and quality of health care.

Both this study and other have demonstrated the high turnover and migration of nurses from public health facilities. Further investigation is required to better understand the reasons for nurse's 'migration' from their jobs and what action needs to be taken to prevent this problem.

It was demonstrated, in this study, that despite nurses feeling unmotivated and feeling 'burnt out', they were still willing and wanted to deliver good health care and achieve their organizational goals. It needs to be recognised that health workers in the clinics do not want to fail and are enthusiastic to do their job well. Therefore, managers need to take advantage of nurse's pride in their work and capitalise on this situation. This could be achieved by acknowledging their important role and providing continuing education and incentives to deliver better care.

Professional bodies and government health departments also need to develop policies which empower and authorise nurses to provide the appropriate level of care, e.g. initiating DM insulin or scaling up HTN medications and dosages. This empowerment should include appropriate skills development and therefore greater effort needs to be placed on continuing medical education.

The loss of motivation amongst health workers is further exacerbated by the failure to provide a 'scarce skills allowance' in the form of the occupations specific dispensation' (OSD). This issue also resulted in many PHCNs protesting and refusing to work. There was evidence of poor staff motivation and burn out in the motivation survey. This is a serious problem that needs to be urgently addressed.

The Wagner and WHO chronic illness care models are well researched models and have been adopted as a framework for managing chronic illnesses. There was evidence in this study that at least some components of these models may be of value in the management of chronic illnesses in Soweto. The application in the clinical environment was demonstrated by using components of decision support, delivery system design with direct referral and the supply of audit information had a direct impact on PHC clinical environment. These types of applications of these models were relevant to the individual clinician. In order to see improvement of the health system managing chronic illnesses, other chronic illness frameworks or at least some components of the Wagner and WHO models should be supported and implemented.

This study showed a distinct problem between the communication of regional health managers and PHC clinicians. The communication of health policies is an important component of health care delivery. Managers and clinic coordinators need to make an effort to improve communication between the different levels of care in the health system and also within levels of health care. This could be achieved by improving health information systems and providing computer literacy skills to all members of the health care i.e. managers and clinicians. The use of email would be a simple, accessible method to improve communication.

Although it was demonstrated that local regions like Soweto, lack the resources and skills to follow up patients over long periods, it was also clear that there is inadequate information about kidney disease in South Africa. National epidemiological screening programs to determine the burden of chronic kidney disease and other chronic illnesses are necessary to determine the true chronic disease burden and especially the extent of CKD in the country.

A limitation of this study was its focus on the 'health care team', and more specifically on primary health care nurses, and not the patient and their community. It was found that very little emphasis and focus is occurring on the community and patient. There is currently a good 'support group' system for diabetes and hypertension, but more effort and research needs to be developed to improve existing systems which utilise health promoters and support groups in the Soweto clinics. In keeping with this focus more studies are needed to focus on the community and patient factors described in the Wagner and WHO chronic care models, but also on 'task shifting' (McPake and Kwadwo, 2008), where tasks in health-system delivery for chronic conditions, are shifted to the least costly health worker capable of doing that task reliably.

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APPENDICES

Note: All appendices are available on the CD in the pocket on the inside back cover

Appendix 1	**Patient Consent**
Appendix 2	**Patient Education Booklet**
Appendix 3	**Initial and Yearly Visit Form**
Appendix 4	**Follow Up Form**
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