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List of Acronyms

ANC – African National Congress
ART – Anti-retroviral Therapy
CBO – Community-based Organisation
DOH – Department of Health
DoSD – Department of Social Development
DOT – Directly Observed Therapy
EPWP – Expanded Public Works Programme
HBC – Home-based Care
HIV/AIDS – Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
ILO – International Labour Organisation
NGO – Non-governmental Organisation
NP – National Party
OVC – Orphans and Vulnerable Children
PHC – Primary Healthcare
PLWHA – People Living with HIV/AIDS
PMTCT – Prevention of Mother to Child Transmission
TB – Tuberculosis
VCT – Voluntary Counselling and Testing
WHO – World Health Organization

Chapter I
Introduction

Research Overview

In 1994, as apartheid came to an end in South Africa, the newly elected African National Congress (ANC) inherited a highly dualistic, ineffective healthcare system. Since that time, one of the key strategies of Government to confront the problems associated with this system has been a strong focus on primary healthcare (PHC). An important part of this strategy has been the utilisation of home-based caregivers – lay health workers who visit people living with HIV/AIDS (PLWHAs) and other ill persons in their homes and provide a range of services to improve quality of life. Through policy and practice, the Government has attempted to capitalise on the benefits of home-based care (HBC) by integrating it into the formal health system as effectively as possible. These attempts have been made due to the realisation that the work and efforts of informal caregivers in isolation are not sufficient to provide adequate care to patients. At the same time, there is recognition that some of the limitations of the formal health sector can be met through services like HBC. In short, by building strong and cooperative links between the formal and the informal, South Africa hopes to improve the effectiveness of its PHC system.

Despite the focus placed on the integration of HBC into the healthcare system and the recognition that this is important, very little research has been done examining this link at the ground level. A large amount of research has been completed on HBC and nearly all of this work does mention the link between HBC and formal health structures such as clinics, but none of them does so comprehensively. In most cases, there is little more than a passing mention of the need to strengthen this partnership. The research, more often than not, deals with the two issues separately.

This research report assists in filling this gap by providing information on the interaction between two HBC organisations and two local clinics in two informal settlements located in the city of Johannesburg. By speaking directly to home-based caregivers *and* clinic staff (as well as Department of Health (DOH) employees), the research explores the formal/informal relationship from *both* sides. Through examination of the experience of both parties, the research provides new insight into how HBC is working in South Africa. Over the course of several months, semi-structured interviews were conducted with 22 caregivers, 6 clinic nurses and 4 DOH employees. The resulting qualitative data sheds light on the feelings and opinions that staff on both sides of the formal/informal divide has about this relationship, the challenges related to integration and any effective practices that help to provide high-quality service to patients.

An additional aim of the research is to examine how degrees of informality affect HBC. Importantly, the two HBC organisations in the study are characterised by different degrees of informality – caregivers from one organisation receive a stipend and training from the DOH while caregivers from the other do not. The research helps to reveal how this varying degree of informality affects HBC service delivery and quality of care, as well as the relationship with the formal health sector and related issues.

The significance of this research is two-fold. At the micro-level, this paper constitutes an essential contribution to the study of HBC. By helping to illuminate the challenges and successes of the system in South Africa, the research findings give practitioners, community members, caregivers and policymakers a better understanding of how and if Government is successfully integrating the two sectors in order to bring about beneficial health outcomes. This information will ideally lead to the provision of more effective care for PLWHAs and other ill persons in South Africa.

At a more conceptual level, the study contributes to greater understanding of the interaction between the formal and informal health sectors in a limited resource setting. Do the formal and informal health sectors complement and strengthen or distract and damage each other? Is the informal essential to the success of the formal (and vice versa)?

By examining the influence of degrees of informality within the formal/informal divide, the research also provides insight on how and if this distinction plays a large role in healthcare provision. In the case of sponsored HBC organisations, how does state support impact the link between the formal and informal sectors and quality of care? This information can then be used to design more effective strategies around healthcare, especially in poor communities.

In general, the research aims to answer three central questions: What are the primary factors that influence the relationship between HBC organisations and local clinics? How does the degree of informality of these organisations affect this relationship? What are the challenges and the most effective practices related to this partnership?

Background

On 27 April 1994, South Africa held the first democratic election in its history, which saw the former liberation movement ANC come to power. This momentous occasion was cause for celebration throughout the country. For millions of South Africans, the relatively bloodless end of the tyrannical system of apartheid was nothing less than the ‘miracle’ that it was being hailed as around the world. For the newly elected ANC, this euphoria was tempered by the reality of what they were inheriting from the National Party (NP). The state was nearly bankrupt, the vast majority of the population possessed only the most rudimentary education and huge numbers of South Africans lived in poverty. The NP’s strategy of segregation and discrimination had created shocking levels of inequality. The new government had much work to do.

The health sector was just one of many characterised by dysfunction, fragmentation and inequity. In 1994, there were fourteen departments of health in the country: one national department, ten *bantustan*[1] departments and three 'own' departments (one each for whites, Coloureds and Indians) to cater for different segments of society. In 1992/1993, 58% of total health expenditure was used in the private sector, which only reached 23% of the population (McIntyre et al 1995). In the same year, 85% of dentists and 60% of doctors, psychologists and health professionals were working in the private sector (*Ibid*). Although nurses were represented more fairly – 21% were working in the private sector – South Africa had a shortfall of 600-1,000 clinics[2] by international standards (*Ibid*). Only 11% of health spending was directed towards PHC, revealing a lack of consideration for the lowest tier of the healthcare system (*Ibid*).

The year before the election, the Steinmetz committee (named after the judge heading the body), produced *The Report of the National Committee to Investigate the Rationalisation of Health Services in the Republic of South Africa and the Self-Governing Territories*. This report identified fragmentation, duplication, inappropriate use of funding and a lack of "adequate primary health care infrastructure" (van Niekerk 2003: 369) as the primary obstacles to healthcare functionality in South Africa. Although the report's recommendations to unify the health services and put more focus on PHC were resisted at the time, when the ANC came to power this resistance fell away. In 1994, the new government integrated the fourteen health departments into a single entity (consisting of one national and nine provincial departments) and set forth to implement a health strategy strongly focused on PHC.

On 6-12 September 1978, the World Health Organization (WHO) and the United Nation's Children's Fund sponsored an international conference on PHC at Alma-Ata in the Soviet Union. Delegates at the conference (representing 134 nations) agreed upon an official definition of the concept of PHC:

> Primary health care is essential care based on practical, scientifically sound and socially acceptable methods and technology, made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is the first level of contact of individuals, the family and the community with the national health system, bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care service. (WHO 1978 in Dennill et al 1995: 2)

In most cases, the first site of PHC implementation is the clinic and other community-level health facilities. PHC fulfils a number of roles, including protecting hospitals from unnecessary admissions, maintaining continuity of care, providing treatment, counselling, support and follow-up,

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[1] Through a number of pieces of legislation – most notably the Bantu Authorities Act (1951) and the Bantu Self-Governing Act (1959) – the apartheid government created ten ethnic homelands, called *bantustans*, where black Africans were forced to live. The homelands took up approximately 13% of the land in South Africa and were home to more than 80% of the population. Almost without exception, these homelands were characterised by severe overcrowding, poverty and lack of basic services.

[2] There were 419 hospitals, 3,141 fixed clinics and 1,053 mobile clinics in South Africa in 1994 (McIntyre et al 1995).

‘wellness’ management and ensuring a continuum of care for patients (Modipa et al 2002: 1). The quality of PHC in any setting is determined by what scholars have noted as the ‘5 A’s’ (Fortuin 1995; Penchansky & Thomas 1981 cited by Cromley 1999). These are availability (sufficient supply), accessibility (within reasonable distance from users), affordability (cost and ability of users to pay), appropriateness (for each given community) and acceptability (user-friendliness). These concepts are in turn determined by resources – material, financial and human – as well as the institutional and structural dynamics of a given state, society and/or community.

Even before taking power, the ANC’s National Health Plan of the early 1990s emphasised PHC (Benatar & van Rensburg 1995). This was followed by the 1995 release of *Restructuring the National Health System for Universal Primary Healthcare*. In short, “South Africa’s health policy since 1994 [has been] based on the primary healthcare approach with a strong emphasis on equity and a commitment to universal access to integrated, comprehensive primary care” (McIntyre & Klugman 2003: 108). Given the resources, institutional arrangements and structural dynamics of South Africa at the time of the ANC’s election victory, the transition from a ‘top-heavy’ healthcare system to a ‘bottom-up’ PHC approach has been a challenging one. Throughout the process, the Government has employed a number of tactics to bring healthcare closer to the people. These include building and upgrading clinics[3], removing user fees at public health facilities and formulating a ‘PHC package’ to provide norms and standards for the provision of PHC (Schneider, Barron & Fonn 2007). All of these strategies have been made with the 5 A’s in mind. The need for available, accessible, affordable, appropriate and acceptable primary healthcare services throughout the country is acknowledged as vital towards improving health and developmental outcomes in South Africa. This need – critical even in the best of times – has been made even more urgent due to the HIV/AIDS epidemic.

The world has never known a disease like HIV/AIDS. Throughout history, terrible diseases have spread across the globe, devastating communities of all sizes. But HIV/AIDS has proven to be more complex, sensitive and pervasive than anything previously known. As the disease has spread to all corners of the earth, it has killed millions of people and affected the lives of millions more. A vast amount of research has been done on the topic, revealing a unique mixture of biological, behavioural, social, economic and cultural factors that are responsible for making HIV/AIDS so particularly challenging to control. Nowhere is this challenge more evident than in sub-Saharan Africa. Although it represents approximately 10% of the world's population, more than 50% of PLWHAs live in the region (Buve 2006). On a country level, South Africa is home to arguably the worst national epidemic, both in the sub-Saharan region and the world.

Between 1990 and 2005, HIV prevalence rates in South Africa jumped from less than 1% to around 29% of the adult population (Hunter 2007). According to the 2006 National HIV and Syphilis

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[3] By 2007, the government had built 1,345 new clinics and upgraded a further 263 (Schneider, Barron & Fonn 2007).

Prevalence Survey (DOH 2007), 29.1% of 15-49 year olds in the country are infected with HIV, representing a total of 5.54 million people. This is the largest number of PLWHAs within the borders of one country in the world. Not surprisingly, the disease is having a severe impact on South African society. Although the full consequences of the epidemic will only be fully known years from now, the effects are already being felt. Life expectancy in the country dropped from 53.7 years in 1970-1975 to 47.7 years in 2000-2005, largely due to AIDS deaths; the number of orphans due to HIV/AIDS was estimated at 1.1 million in 2003 (O'Grady 2004). These sobering statistics speak to millions of work hours lost, broken family structures, loss of knowledge handed down over generations, huge increases in medical and training costs and a host of other problems.

The challenge of HIV/AIDS has been made even more difficult due to its relationship with tuberculosis (TB). For someone who is HIV-negative, there is a 10% chance that they will contract TB during their lifetime. For an HIV-positive person, this risk increases 5-10 times to 78% per year (WHO 2004). Similarly, the TB incidence in people suffering from AIDS is 500 times that of the general population, while TB accounts for approximately 40% of AIDS deaths in Africa (Williams & Dye 2003). Not only is TB one of the most common opportunistic infections for PLWHAs, HIV is also one of the strongest risk factors for contracting TB (Swaminathan 2004).

The close relationship between HIV/AIDS and TB can be seen very clearly in South Africa. After slight decreases in cases for most racial groups in the 1970s, TB notification rates began to climb in the mid-1980s: between 1986 and 1994, TB rates increased by around 43% and HIV was identified as one of the contributing factors (Packard & Coetzee 1995). The climb continued in the 1990s, as TB cases doubled between 1996 and 2002 (Achmat & Roberts 2005). Today, South Africa is classified as one of 22 'high-burden' countries in relation to TB by the WHO, with an incidence rate of 940 per 100,000 people (WHO 2008)[4].

Not surprisingly, the people at greatest risk of contracting TB also have the least access to quality healthcare services (Packard & Coetzee 1995). In many cases, they are living in squatter camps and informal settlements in and around South Africa's urban centres, where adequate health facilities are often insufficient or non-existent. According to estimates by Hunter (2007), these same urban settlements have HIV prevalence rates that are double the national average. In short, South Africa is facing a dual epidemic of HIV/AIDS and TB that is raging most fervently in the places where healthcare services are weakest. It is these areas – where millions of poor South Africans live – that the ANC's PHC approach is most crucial. Improving the 5 A's of healthcare in informal settlements and squatter camps has been and remains a high priority for the state, not in small part due to PHC's potential to make a dent in the country's HIV/AIDS and TB epidemics. The utilisation of home-based caregivers has played a central role in the Government's attempts to do so.

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[4] South Africa has the fourth highest incidence rate in the WHO Africa region (WHO 2008).

Friedman (2005) notes that there is ample evidence that lay health workers can improve PHC services in the developing world. In South Africa, the vast majority of these lay workers are home-based caregivers, although there is a host of other types of workers as well[5]. HBC is defined by the WHO as

> any form of care given to sick people in their homes. Such care includes physical, psychosocial, palliative and spiritual activities. . . The goal of [community HBC] is to provide hope through high-quality and appropriate care that helps family caregivers and sick family members to maintain their independence and achieve the best possible quality of life. (WHO 2002)

This specific care strategy originated in North America and Europe in the 1980s as it became clear that hospital-based care for PLWHAs would be too expensive and the burden of care on family members was too great (Spier & Edwards 1990). As the Committee on a National Strategy for AIDS noted:

> If the care of [PLWHAs] is to be both comprehensive and cost-effective, it must be conducted as much as possible in the community, with hospitalization only when necessary. The various requirements for the care of patients with asymptomatic HIV infection, AIDS-related Complex, or AIDS (i.e. community-based care, outpatient care, hospitalization) should be carefully coordinated. (Uys 2003: 3)

Although its origins lie in the HIV/AIDS epidemic, HBC is not restricted to this segment of society in South Africa. The Department of Health's (DOH) National Guideline on Home-based Care and Community Care (2001[6]) specifically notes that HBC is a strategy for dealing with PLWHAs, those suffering from non-communicable diseases and the elderly[7]. There are three broad categories of HBC according to Uys (2003): informal, single service and integrated. Informal HBC generally refers to families taking care of sick members with the assistance of their neighbours and other relations while single service HBC describes the recruitment, training and mobilisation of caregivers by a single institution (e.g., church, clinic or community-based organisation (CBO)). Integrated HBC, however, is a much more far-reaching model. It aims to link all the appropriate community services to patients with the ultimate objective of providing the continuum of care so closely related to PHC. Integrated HBC "endeavours to enhance mutual support and collaboration between different components (families, [community caregivers], clinics, hospitals, support groups, non-governmental organizations (NGOs), and community-based organizations" (*Ibid* 6). It envisions a holistic system where all of the needs of PLWHAs and other people suffering from illnesses are covered through the cooperation and coordination of all community stakeholders.

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[5] Friedman (2005) counts 20 different types of community health workers and health auxillaries. These include first aid workers, occupational health workers, farm health workers, generic community health workers, village health workers, health educators/promoters, care group members, home-based caregivers, family planning advisors, Mother-to-Child Health workers, Voluntary Counselling and Testing (VCT) counselors, nutrition advisors, water and sanitation workers, traditional birth attendants, Orphans and Vulnerable Children (OVC) workers, community disability workers, HIV/AIDS communicators, peer educators, Anti-retroviral Therapy (ART)/TB Directly Observed Therapy (DOT) supervisors and home nurses.

[6] A new DOH policy on HBC is currently being drafted but is not yet completed.

[7] Surprisingly, the DOH's National Guidelines makes no mention of TB, even though most home-based caregivers deal with patients who are suffering from TB on a daily basis and the Government has recruited home-based caregivers to be based at clinics as DOT supporters for people with TB.

Integrated HBC is not possible without the contributions of a range of people and institutions, but caregivers themselves are the central players in the system. These caregivers – almost always unemployed women (Friedman et al 2007) – provide a range of services to their patients. During their home visits, they provide education on healthy living, ensure patients are taking their treatment correctly and consistently (also delivering medication from the nearest health dispensary at times) and provide informal counselling about a range of issues. For patients that are very ill and possibly bed-ridden, caregivers may wake them in the morning, clean their house and cook meals as well. Caregivers also act as a liaison between the patient and other health and social services in the area. In the case of South Africa, they may help a patient access a social grant by ensuring they have the proper identification and other documentation, work with the children in the home to ensure they have proper school uniforms and stationary (as well as fee exemption where appropriate) and link patients to food supplementation services where necessary. Finally, caregivers are able to refer patients to clinics and/or hospitals when the situation demands more formal, professional care.

For the most part, HBC falls within the preventative and palliative care categories. Caregivers normally do not have the resources or the skills to provide more advanced forms of care. In situations where patients require more expert attention, the formal health system must be drawn on. But just as with HBC, the care provided by the formal sector is not all encompassing. Once patients leave the health facility, they must return to their homes. For people living in poor communities, this often means returning to an environment characterised by poverty, hunger, crime and a lack of basic services; in other words an environment that is not conducive to recovery and good health. In resource-limited settings such as South Africa, the formal health system does not have the resources or capacity to monitor and follow-up these patients in their communities. HBC helps to fill this gap.

In short, as the Committee on a National Strategy for AIDS noted, the work of HBC and the formal health system should be "carefully coordinated." In 2001, following the Government's relative lack of consideration for HBC in the first half-decade of democracy[8], the DOH released the National Guideline on Home-based Care and Community Care[9]. The Guideline represented a welcome step towards integrating HBC into the healthcare system. To begin, the document explicitly notes that "a collaborative effort is fundamental to success" (DOH 2001: 1). There is recognition that the formal South African health system is unable to meet all the needs of society for a variety of reasons,

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[8] The NP gave HIV/AIDS little political attention during the dying years of apartheid. It largely ignored the disease, believing that it primarily affected 'unimportant' groups such as gays or foreigners (Butler 2005). As president of the Republic from 1994-1999, Nelson Mandela also dedicated little time or effort to the epidemic, a fact that he has publicly regretted (Stengel 2008).

[9] In addition to the DOH, both the Department of Social Development (DoSD) and the Expanded Public Works Programme (EPWP) implement HBC programmes in South Africa. In November 2007, the DoSD released its *National Norms and Minimum Standards for Home and Community Based Care (HCBC) and Support Programme*. Although it was created in consultation with the DOH, it is not a cross-departmental document. This research report, and the study it describes, specifically focuses on the DOH's HBC programme. See Lebeloe (2006) for an evaluation of how successfully the DOH and DoSD are integrating their departmental HBC programmes.

including shortage of hospital beds and medical professionals, lack of resources for treatment, drugs and supplies and the rising cost of healthcare. For all of these reasons and more, HBC is recognised as "a basic and essential component of PHC" (*Ibid* 5).

The reasons for integrating HBC more fully are many, including the prevention of expensive institutional care, reduction of pressure on hospital and clinic services, spreading and sharing of costs within the healthcare system, increasing health awareness and awareness of health services at the community level and allowing patients to spend time at home in order to reduce isolation. In order to make all of this happen, the Guideline calls on five partners to contribute. First, the formal health system must play an overall coordination, monitoring and evaluation role. Second, what is denoted as the 'non-formal' health sector (e.g., NGOs, CBOs, traditional healers/leaders) must be responsible for outreach, community assessment and mobilisation and secondary monitoring and evaluation. Third, the private sector should fill gaps where possible, including encouraging medical aid schemes to contribute to HBC. Fourth, what is called the 'informal' health sector[10] should provide basic and palliative care, counselling, health promotion and household assistance services (home-based caregivers fall within this sector.) Fifth and finally, the Guideline identifies the 'client/consumer,' or patient, as an important stakeholder, responsible for open communication and respect for caregivers.

The Guideline identifies a number of core goals and objectives for HBC that these partners should work towards. These include shifting the emphasis of care to the community, improving access and follow-up through an effective referral system, empowering families and communities to take care of themselves, reducing unnecessary visits and admissions to health facilities and being pro-active in approach. Finally, the Guideline lays out the "Three Pillars of Home-based Care and Community-based Care." These are:

- Integrated management and referral service organisation;
- Training and development of community personnel and professional/technical support personnel; and
- Integration into the district health system (*Ibid* 11).

In short, the Guideline provides the background, rationale, principles, purpose and role definition of HBC. It aims to provide an integrated, holistic and multi-sectoral model for HBC in South Africa. It envisions a system where all stakeholders work together to provide effective, efficient and high-quality home- and community-based care to PLWHAs and other patients, with a focus on those living in the poorest and most disadvantaged communities. Perhaps most importantly – and as the Three Pillars of the Guideline makes clear – the DOHs HBC strategy is about bringing together the formal and informal health sectors in a coordinated fashion.

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[10] Although the DOH Guideline makes a distinction between the 'non-formal' and 'informal' health sectors, this paper will refer only to the 'informal' health sector as an all-encompassing term.

Since the early 1970s[11], the idea of an 'informal sector' has received much attention. But despite volumes of literature on the subject, "a generally accepted taxonomy [of the informal sector] has not yet emerged" (Henry 1987: 139). The only wide consensus on the topic is that it is difficult to conceptualise and/or measure (Sindzingre 2006; Smith 1987; Gaughn & Ferman 1987; Chen 2004). In 2002, the International Labour Organisation (ILO) defined informal employment as "all economic activities by workers and economic units that are – in law or in practice – not covered or insufficiently covered by formal arrangements" (Tokman 2007: 4).

In addition to attempts to conceptualise the informal sector in a general sense, a virtual mountain of analysis has been completed on the links between the informal and formal sectors. This research attempts to understand the relationship between the sectors and how they complement and/or damage each other. Although most of the research on the topic refers to informal and formal *economies*, the existing literature is helpful in understanding the wider interaction between these two sectors – specifically from a health perspective in this paper.

In relation to HBC, caregivers' (who are informal workers according to the above definition) first point of contact with the formal healthcare system is usually the local clinic. These facilities are therefore a primary site of interface between the formal and informal health sectors. Analysing and understanding the nature of the relationship between clinics and clinic staff and HBC organisations and caregivers is therefore essential if an effective HBC model and system is to be implemented and maintained in the country. If the formal/informal link – identified by the DOH as an integral part of PHC service delivery – is dysfunctional or weak at the lowest tier, the foundation of the entire system becomes unsteady. At the same time, clearly defining the degree of informality of HBC is also important to ensure that confusion and conflict are minimised. Although HBC is undoubtedly an informal practice, it is not only sanctioned by the state but in some cases it is materially supported by the state as well. This represents a marked deviation from informal *economic* activity and sets the formal/informal health divide apart from much existing literature and experience.

Overview of the Paper

Following this introduction, Chapter II provides a deeper analysis of some of the literature relevant to the research topic. Specifically, this chapter will explore the idea of the informal sector and its links to the formal sector. The chapter will also provide some key findings related to HBC, as well as touching upon its links to the formal health system.

Chapter III deals with the research methodology for the study. It outlines the research strategy and framework, including some discussion on what a qualitative study entails and the tools utilised to

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[11] Keith Hart coined the term 'informality' in 1971, while a publication by the ILO in 1972 was the first to use the word (Sindzingre 2006). Hart's first work on the subject was his research on informal activities in Ghana, published in 1973.

carry out such a study. The chapter will also discuss the study locations[12], including the rationale for choosing them. The sampling criteria will be outlined, as well as the data collection and analysis techniques employed. Finally, the limitations of the study as well as the ethical considerations will be dealt with here.

Chapter IV marks the beginning of the 'meat' of the paper as it outlines the research findings related to the experiences of caregivers and clinic nurses and provides analysis of these findings. It deals with a number of key themes uncovered through the research, including training on the HBC-clinic relationship, referral systems, queuing, communication, reporting and trust.

Chapter V continues with the research findings and analysis, with a specific focus on degrees of informality. Some of the themes identified in Chapter IV will be revisited – as well as new ones introduced – and broken down according to responses given by the sponsored and unsponsored CBOs that participated in the study. In addition, comments from DOH officials and nurses will be incorporated here where appropriate.

Chapter VI provides summary discussion around the research findings and analysis. This discussion aims to help paint a clearer picture of exactly where the situation between clinics and HBC organisations currently stands. This chapter is organised according to the three central research questions listed above.

Chapter VII includes some concluding remarks about the research study. In addition to wrapping up all of the previous information, a number of key recommendations are put forward. It is quite clear from the findings that HBC in South Africa has great potential to improve health outcomes in the country. At the same time, many changes need to occur to ensure that this potential is fully realised. The recommendations found within this chapter are just a few that can help to make this happen. Many of the recommendations provided here come (at least in part) from the research participants themselves. The concluding chapter also provides some information on where South Africa stands today in relation to many of the health challenges the ANC inherited upon coming to power in 1994. This 'update' is included to keep in mind the role that HBC might play towards continued progress. A number of appendices follow the conclusion to provide additional information to the reader.

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[12] The actual names of the informal settlements will not be used in this paper to protect confidentiality. Similarly, the actual region of Johannesburg in which both HBC organisations and clinics are located are not provided. Pseudonyms will be used for all locations.

Chapter II
The Informal, the Formal and Home-based Care

The fundamental objective of this research study is to improve the understanding of home-based care in South Africa, as well as the links between the informal and formal health systems. It goes without saying that doing so entails building off of the work of others. Many scholars have contributed to both the study of HBC and the links between the formal and informal sectors, covering a wide range of themes. Some of this work deals with key issues that are especially pertinent to the study at hand.

Links between the Informal and Formal Sectors

As noted previously, nearly all of the relevant literature in this field refers to informal and formal *economic* activity. Although neither side of the formal/informal health divide could be characterised as purely economic, the literature is largely applicable. The parallels between informal and formal economic sectors and informal and formal health sectors are striking[13].

The most basic parallel is the belief that the informal sector's destiny is intricately linked to the formal sector. Throughout the literature, the importance of linkages between the formal and informal sectors is a recurring theme. With the exception of a small number of scholars who assert that the connection between the formal and informal sector is minimal[14], there is general agreement that the two sectors are, at least to some degree, dependent on each other. The central disagreement between scholars, however, refers to the *nature* of this dependency. On one side of this debate lies the benign school of thought, which is opposed by the exploitative camp.

The benign school of thought, most often promoted by neo-liberal thinkers, sees the co-dependency of the informal and formal sectors in a generally optimistic light. This optimism is expressed in two distinct ways. First, some scholars see in the informal sector an "indigenous entrepreneurial dynamism suggesting a potential for employment creation and growth" (Meagher 1995: 262). To them, the only thing holding back the informal sector from becoming legitimate and highly effective is the state. The solution, unsurprisingly, is to deregulate and reduce state intervention in the sector. This will allow the informal sector to interact more freely with the market, which already happens to some degree through the sourcing of raw materials, provision of finished goods and other spillover effects along the supply and production chain (Chen 2004). For these benign

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[13] In some of the quotes in this section of the paper, the word 'economy' and 'capitalism' has been substituted with 'sector' or 'activity' (or some variation thereof) to further demonstrate the applicability of the literature to the formal/informal health divide. These substitutions are clearly marked with brackets.

[14] This school of thought argues that the formal and informal sectors operate largely independent of each other. Chen's (2004) 'dualists,' as well as Hart's (2005) depiction of the informal sector's relationship to the formal 'as division' both speak to this separation. Similarly, Lomnitz (1988) asserts that the ideological foundation of formality and informality are irreconcilable.

advocates, the links between the formal and informal sectors are largely positive for the latter and the inability of the sector to develop is due to bad policy and an overly involved state.

The second 'faction' of the benign school of thought is less interested in the state's role in promoting or blocking the informal sector, and more concerned with the actual benefits that the formal and informal sectors derive from each other. Here, the formal and informal sectors depend on each other for their existence. First, the cheap labour and flexibility of the informal sector actually helps to increase the viability of the formal sector, which would not be able to generate adequate profits (or provide adequate services) otherwise (Centeno & Portes 2003: 14). This might be especially true in a limited-resource setting, where 'cutting corners' is even more necessary.

Second, the informal sector makes the flaws and inefficiencies of the formal sector more bearable. Hoyman (1987) says that "participation in the informal [sector] really becomes a deliberate and critical coping strategy when formal employment fails to meet the individual's economic and psychological needs" (78). Lomnitz (1988) agrees, asserting that "if the formal system [was] able to produce and distribute the goods and services required by all members of society, informal solutions would be less needed and thus less pervasive" (54).

Other authors go even further in their analysis of the beneficial interdependence of the formal and informal sectors. Henry (1987) looks at the connection between the formal and informal as one full of tension. He claims that "not only do informal [activities] emerge from the contradictions of [formality], but they are simultaneously supportive and undermining of [the formal system], as that system is of them" (138). The informal and formal continuously clash with each other, but their respective advantages and disadvantages also work to support each other. Shankland (in Henry 1987) argues that "in a 'healthy society' formal and informal [sectors] 'sustain each other and their relationship should be a symbiotic one of mutual support'" (146).

Finally, Gaughn and Ferman (1987) go the furthest in their understanding of the benign co-dependence of the two sectors. The authors first argue that the informal sector is often an area "of innovation for the emergence of new kinds of production that may prove to be of crucial importance in the evolution of the [formal sector] as a whole" (25). More so, "personal and informal . . . networks are areas where people can explore their own needs and seek to meet them in their own way. In this respect *the informal [sector] might be understood as containing the very foundation of all other [formal] activity and as necessary to the functioning of any social arrangement"* (25, emphasis added).

For these benign thinkers, the formal and informal sectors need each other to survive. On the one hand, the formal sector is able to cut costs, maximise profits and spur innovation through the support of the informal sector. In addition, the inherent shortcomings of the world capitalist system, which creates many 'losers' in addition to 'winners,' are minimised as the informal sector 'fills in the cracks' to a large degree. On the other hand, the informal sector not only benefits from the many spillover effects associated with formality, but also is afforded a certain level of recognition and credibility by linking with the formal sector. Informal workers and business are, by definition, less protected than their formal counterparts, but by working closely with the formal system they are able to strengthen their position, build their capacity and entrench themselves as an integral part of society.

The exploitative school of thought differs markedly from its benign counterpart. It sees the linkages between the formal and informal sectors as highly unequal and problematic: "the rise of informality . . . is seen as an attempt by formal sector capital, acting with the complicity of the state, to reduce wage costs and enhance flexibility by making use of unprotected workers in the informal sector" (Meagher 1995: 260). There are two components to this exploitation: first, the formal sector exploits the labour of the informal sector; and second, the former blocks the development of the latter because it does not want to lose its benefits (or have new competitors). In other words, the formal sector deliberately uses (and abuses) the informal sector to ensure its continued success and profitability. The state supports this endeavor through legislation, lack of enforcement and other means.

This school of thought is supported by a number of scholars. Von Holdt and Webster (2005) explore the idea of the core, non-core and peripheral work zones in today's global economy. Workers who are fully employed and part of the formal sector would fall within the core zone. This zone derives much of its power and success from dominating the non-core and peripheral work zones. The non-core zone is characterised by workers who are employed, but may be excluded from many of the rights and/or benefits normally connected to employment. The peripheral is the weakest of the three zones, where people are 'making a living' rather than 'earning a living' (*Ibid* 22).The latter two zones – non-core and peripheral – represent different degrees of informality, with the more formal enjoying better (although not sufficient) protection and advantage. In general, the authors argue that these zones are "asymmetrically dependent" (*Ibid* 27), with the peripheral zone exposed to increasing marginalisation.

Chen (2004) also describes the exploitative nature of the relationship when he notes that formal businesses often prefer informal activity due to its lower costs and flexibility. This outlook would fall within what Chen calls the 'structuralist' school of thought, which asserts that the formal and informal sectors are intimately linked, but that the relationship is unequal as the former uses and dominates the latter for its own purposes.

Ishengoma and Kappel (2006) speak to a similar idea in their discussion of the obstacles facing the informal sector. In their analysis, the informal sector is unable to take-off and become more formalised due to a lack of access to financial services and training. In addition, those in the informal sector often live and operate in areas characterised by poor infrastructure, which increases operating costs, hinders linkages and reduces the ability to meet quality standards. This, as well as a lack of political or financial bargaining power, diminishes the overall competency and capacity of informal workers. In almost every case, the informal sector depends on the formal sector and/or the state to provide these things, or at least provide access to them.

Both the benign and exploitative schools of thought provide valuable information and observations about the relationship between the formal and informal sectors. Not only do they reveal the inherent co-dependence within this relationship, but also they can assist in the analysis of the formal/informal health sector divide in South Africa.

Home-based Care and Links to the Formal Health System

There is a relatively large amount of literature on home-based and community-based care, covering a variety of topics. Mahilall (2006) provides information on the motivations of why people decide to become home-based caregivers. She identifies seven broad categories of motivation, including altruism, unemployment, hope for future reward (e.g., financial, social), religious considerations, personal experiences with HIV/AIDS (e.g., a family member dying of the disease), previous experience with community and/or health-related work and hope of securing employment.

Friedman (2006), Friedman et al (2007), Padarath et al (2006), Beukes (2005) and Russel and Schneider (2000) all provide broad overviews of HBC in South Africa. These works discuss the challenges, constraints and experiences of HBC organisations and caregivers in the country and elucidate many themes:

- A lack of stable, sustainable funding for salaries/stipends, transport and other supplies, which greatly hinders the ability of caregivers to provide adequate care;
- Non-standardised and varying levels of training received by caregivers;
- Poor managerial and administrative capacity of HBC organisations;
- Lack of monitoring and evaluation of HBC programmes;
- Lack of clear role definition between different stakeholders (e.g., caregivers, local government, formal health structures);
- Stigma, affecting both PLWHAs and their caregivers; and
- Poor communication and networking between different stakeholders in the community.

Unsurprisingly, many of the recurring themes identified in the literature are strongly related to HBC's links to the formal health system. With this in mind, many scholars have attempted to analyse the nature and importance of these linkages. As with the formal and informal economic literature, there is wide consensus that the two are dependent on each other. Once again, the core of the debate is whether this co-dependence can be characterised as benign or exploitative.

The first 'faction' of the benign school of thought is, for the most part, not applicable to the HBC literature. In short, one would be hard-pressed to find a serious academic, practitioner or policymaker who would argue that de-regulation and the reduction of state intervention is necessary to make HBC more effective. The second 'faction' of benign thinkers, however, is highly pertinent to

HBC and its links to the formal health sector. For this group, the informal and formal health sectors should complement each other to improve health outcomes. In addition, both sectors derive benefits from the relationship: the gaps in the formal health system are filled by informal workers and organisations; these same informal workers and organisations receive some level of recognition, support and (in some cases) resources, thus improving their credibility and capacity.

Dworzanowski (2004) discusses the importance of HBC in ensuring PLWHAs remain socially embedded and receive holistic care. She stresses that PLWHAs, perhaps more than other ill people due to the unique nature of the disease, need both physical and psychosocial support. She notes that conventional care, which is mostly biomedical, usually occurs within formal health structures. Unconventional care, which is much less structured and more social in nature, usually takes place in the home. Caregivers are ideally placed to provide this latter type of care, which can combine with more conventional forms to provide holistic, quality care.

Loewenson (2004) recognises that organised community health responses – such as HBC – can reduce the HIV/AIDS burden at the local level. Modipa et al (2002) argue that integration between the formal and informal health systems can increase efficiency, improve staff retention (of both professionals and caregivers), reduce stigma related to HIV/AIDS and increase trust along the continuum of care. Russel and Schneider (2000) stress that HBC can increase awareness of the availability of services within the formal health sector[15], while Friedman et al (2007) claim that community participation through informal structures can improve the formal health system's credibility in poor communities. Representing the public sector, the DOH (2004) notes that "when properly trained and supported, [caregivers] can play a major role in closing the gap between professional services and patients" (8).

Campbell et al (2008) believe that the collaboration between informal and formal health structures is necessary in order to build an "AIDS competent community," which is defined as:

> One where community members work collaboratively to support each another in achieving: sexual behavior change; the reduction of stigma (a key obstacle to effective HIV/AIDS management, often deterring people from accessing prevention and care services); support for people living with AIDS and their caregivers; co-operation with volunteers and organizations seeking to tackle HIV-prevention and AIDS-care; and effective accessing of health services and welfare grants, where these exist. (515)

In other words, there is little chance of pushing back the tide of the HIV/AIDS epidemic without the cooperation and coordination of both professional and lay health workers. In her "Construction of a Model for Home Based Palliative Care for People Living with HIV/AIDS," Kganakga (2003) stresses the importance of building effective systems to integrate services and facilitate this coordination. The outcome should be "collaboration between public and private organisations, CBOs and NGOs,

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[15] Increased awareness is, on the whole, a positive outcome. However, there may be negative consequences as well. Steinberg (2008) describes one of the main problems with increased awareness: heavier workloads for already overburdened nurses in clinics. He writes of a nurse: "the activists and laypeople in her clinic are drawing patients in their numbers, and she begins to resent their presence. In an attempt to regain authority over her clinic, she wages quiet war against the laypeople, and begins to ration her workload by sending patients away" (101).

supported by an adequate referral system and government support" (227). This model would be "based on the systems theory, where different units, namely public and private sector hospitals, district health and social development services, local CBOs, NGOs, FBOs [Faith-based Organisations], volunteers, traditional healers/leaders, families and communities function together as a system to facilitate HBC [and quality health outcomes]" (*Ibid* 229).

Finally, Nugent and Swaminathan (2006) see an even stronger complementary relationship between the formal and informal health sectors. They argue that "the informal sector is a potentially important vehicle for unlocking human potential by producing appropriate kinds of public goods, especially health and education services" (212). In other words, caregivers and the informal health structures that they form part of, if utilised effectively can help countries improve not only their healthcare systems, but also their human capital as a whole. Strategies such as HBC can play a central role in improving overall developmental outcomes, of which education and health are foundational.

Not all scholars and activists see the relationship between the formal and informal health sectors in such a positive light. Advocates of an exploitative analysis of HBC in South Africa often accuse the Government of attempting to save costs by utilising informal health workers. The DOH (2004) itself has noted that HBC has become more and more necessary due to the increasing burden of HIV/AIDS, a lack of hospital beds, a shortage of medical and nursing staff and the limited resources of the health sector in general. Despite this, the Government also asserts that "HBC is not intended to be 'second class care' for those who cannot afford to be in hospital" (*Ibid* 6). 'Exploitative' supporters do not buy this argument. Hunter (2006) places HBC in the context of the ANC's neo-liberal policy stance. She argues that HBC is indicative of a Government strategy of shifting the burden of care to communities, families and individuals, without shifting the necessary financial resources. Bakker (in Munakamwe 2008) agrees with this analysis, contending that Government has placed added responsibility on the private sphere in the form of HBC, which she calls the "reprivatisation of reproduction" (22).

This shift is felt most intensely in poor communities, where poverty, unemployment and a lack of adequate basic services conspire to create poor health outcomes. Both Russel and Schneider (2000) and Cullinan (2000) note that there is a major concern that Government is placing too much emphasis on 'community' health solutions, thus placing too great a weight on the shoulders of the poor. Controversially, Hunter (2006) goes as far as to claim that "the government's approach to care needs is not very different from the Apartheid government's successful attempts to get the African poor to carry the vast bulk of the social reproduction costs" (*Ibid* 15).

The exploitative school thought most often points to issues around stipends and resources as proof that the formal health system is taking advantage of home-based caregivers. It argues that these workers are being asked to perform a wide range of duties on behalf of the formal health sector, without being given the proper recognition or resources (both financial and material) to do so effectively. In short, they are tasked with performing a vital service, without being treated as vital personnel.

The importance of the linkages between the informal and formal sectors – whether in relation to economies or health – is unquestionable. Whether one believes that these linkages are benign or exploitative, the theoretical understanding of any existing relationship is only helpful in as much as it assists in evaluating the actual situation on the ground. Despite the relative plethora of research that discusses the importance of linkages between the formal and informal health sectors in relation to HBC, very little literature attempts to analyse these connections in practice. At the same time, a surprisingly small amount of the literature mentions clinics' role in the system, even though this is more often than not the primary point of interface between informal and formal health workers at the community level[16].

The research described in the following chapters aims to help fill this gap.

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[16] As a clear demonstration of this fact, Uys and Cameron (2003) published an entire book on home-based HIV/AIDS care aimed at helping people establish and maintain effective HBC programming in their communities. The book provides a great deal of helpful information and advice and should be required reading for anyone interested in moving into this type of work. Despite this, clinics are only mentioned a handful of times in 191 pages.

Chapter III
Research Methodology

The reliability and validity of any research depends first and foremost on methodology and design. Much thought must be put into how to construct a study to ensure that it can achieve its set goals and answer the central research questions.

Strategy and Framework

This is an inductive, or theory-building, research study. De Vaus (2001) describes theory-building research as "a process in which research begins with observations and uses *inductive* reasoning to derive theory from these observations" (5, emphasis in original). Although the literature on both HBC and formal/informal linkages provides a general background on the issues at hand, the ultimate goal of the research is to build an understanding of the clinic-HBC relationship through the actual research.

In addition to being inductive, the research undertaken is qualitative in nature. Strauss and Cohen (1990) define qualitative research as "any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification" (17). This definition is sufficient, but it does not fully reveal the appeal and utility of qualitative research strategies. Taylor (2003) argues that qualitative research requires deeper involvement in the lives of participants, unlike more detached quantitative methods. The end result is an attempt "to reproduce aspects of the 'lived experience' of the subjects." (*Ibid* 10). This reproduction is more interested in the viewpoint of participants rather than any statistical correlations or relationships. Numerical data can play an important role in qualitative research, but this must be coupled with the voices and experiences of participants to have full impact.

Weiss (1995) lists seven reasons for undertaking a qualitative study: developing detailed descriptions, integrating multiple perspectives, describing process, developing holistic description, learning how events are interpreted, bridging intersubjectivities, identifying variables and framing hypotheses for quantitative research. At least four reasons out of this list are applicable to this study, but 'developing holistic descriptions' is most pertinent. In his description of this category, Weiss says that "by putting together process reports from people whose behaviors interrelate . . . we can learn about systems. Qualitative interview study may well be the method of choice if our aim is to describe how a system works or fails to work" (*Ibid* 10). By looking at the perspectives of both caregivers and nurses, this is precisely one of the study's primary goals.

Study Location

The research locations were selected to study the experiences of home-based caregivers and clinic staff in highly challenging environments. It is hypothesised that the challenges and most effective practices in these areas will be applicable to both high and low burden areas, whereas experiences in low burden areas may not be conducive to high burden areas. In other words, what works in the most severe conditions may likely work anywhere.

The study took place in two wards within two informal settlements located in one region of the city of Johannesburg[17]. The respective wards are referred to here as Location 1 (L1) and Location 2 (L2) to protect the confidentiality of participants. These locations were selected for three reasons. First, both settlements – characterised by high population density, high poverty levels, high unemployment rates and poor service delivery – are representative of many settlements in and around the city of Johannesburg. Second, although the official HIV/AIDS rate of the two settlements is not known[18], both are hypothesised to suffer from high prevalence rates for the following reasons:

- Dyson (2003) notes that there is strong evidence that HIV/AIDS prevalence is associated with urbanisation and high population density; and
- Hunter (2007) claims that the HIV prevalence rate is estimated to be double the national average in informal settlements.

Third, access is a consideration for any research. The researcher has established relationships and a long-term presence working in both informal settlements.

Table 1 provides a comparison between L1 and L2 for several key indicators according to statistics from the 2001 Census. The table reveals that although L1 is significantly better off in regards to factors such as water, electricity and sanitation, both L1 and L2 are characterised by extremely low levels of education and income and high levels of unemployment.

Table 1: Key Indicator Comparison between L1 and L2

Category	L1 (% of population)	L2 (% of population)
Education – completed at least matric	22.1	15.3
Electricity in household	73.0	47.8
Two most dominant languages	47.0 – isiZulu 28.5 – seSotho	29.2 – isiZulu 26.4 – seSotho
No toilet in/at household	4.1	15.4
No water access	4.2	12.1
Water access in yard	30.0	2.8
No income in household	37.6	38.2
Less than R9600 annual income in household	58.9	62.5
Unemployed/not economically active	72.0	68.6

Data Source: Statistics South Africa – Census 2001

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[17] Johannesburg is made up of seven regions (A-G). The actual region studied will not be noted to protect the confidentiality of participants.

[18] Despite numerous attempts to find the official HIV/AIDS prevalence rate for the study locations, the researcher was unsuccessful. It is very likely that these statistics do not exist as even the Operational Manager for HIV/AIDS Programmes in the region noted that she had never seen such statistics in her 13 years on the job.

Study Sample

Unlike many quantitative or even qualitative survey-based research studies, a large sample size is not necessarily required or preferable for a study of this kind, which is based on interviews. As Shuman (2002) notes, the most important factor is not the size of the sample, but how it is obtained. Weiss (1995) concurs, adding that the amount of information generated through interviews is so considerable that large samples can often become unwieldy.

With this in mind, a sample must be chosen that will not only provide an adequate amount of data, depth and detail on the subject matter, but also one that is applicable in a wider context. Strauss and Cohen (1990) argue that one of the most important aspects of a qualitative research study is that it should be generalisable over a broader scope than the one being studied specifically. At the same time, the sample must be chosen with the specific research objectives and questions in mind. To achieve this, random sampling is not appropriate. Instead, purposive sampling must be used. Tuckett (2004) notes that purposive sampling “attempts to select research participants according to criteria determined by the research purpose” (53), while also “seeking a richness of data about a particular phenomenon” (49).

In the case of this study, the research purpose is to determine the factors and systems that affect the relationship between home-based caregivers and local clinics, examine some of the most effective practices related to this relationship and investigate the impact of degrees of informality on these issues. With all of these considerations in mind, the following sample was targeted.

Two HBC organisations and two local clinics were identified for participation in the research. Organisation A (OA) and Clinic X (CX) operate exclusively within L1 while Organisation B (OB) and Clinic Y (CY)[19] operate exclusively in L2. The rationale for targeting two separate HBC organisations and clinics was two-fold. First, although the study is a relatively small one, it was essential to make it as generalisable to a wider context as possible. Only interviewing one clinic and one HBC organisation would have reduced generalisability to an unacceptable level.

Second, it was crucial that HBC organisations representing different degrees of informality were targeted in order to achieve all research objectives. Throughout South Africa, there are generally two types of HBC organisations operating. The first are organisations that are sponsored by the Government. Caregivers at these organisations receive Government stipends (which vary in amount by province), have access to and attend numerous Government trainings and are more strongly linked to the formal health sector. The second type of HBC organisations are unsponsored ones. The DOH only sponsors one HBC organisation per catchment area (which may or may not be the size of a ward, depending on population). In many cases, numerous organisations within one catchment area apply to be sponsored, but only one receives funding. The successful applicant is selected based on a variety of criteria, including financial and human capacity, governance, site visits and the opinion of a selection

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[19] The actual name of both HBC organisations and clinics will not be used to protect the confidentiality of participants.

committee. In most cases, unsuccessful organisations do not ‘close up shop’ if they fail to receive funding. Instead, they continue to provide HBC services in the community without Government funding and training. These organisations generally have weaker links with the formal health system.

OA is an unsponsored HBC organisation. It operates without any form of Government support. It does not receive any funding from the DOH (or any other department), its caregivers do not attend Government training sessions and no members of the organisation receive Government stipends. OB, on the other hand, is officially sponsored by the DOH. All OB caregivers receive a Government stipend and attend numerous Government training sessions on a range of topics. Within the context of this study, OA is considered to have a higher degree of informality as compared to OB.

The actual organisations and clinics were selected for the study because they were operating exclusively in the targeted locations. CX and CY are operating in L1 and L2, respectively. OA is one of several HBC organisations (both sponsored and unsponsored) operating in L1. There are three HBC organisations (all sponsored) in operation in L2.

Profile of Organisation A (operating in L1)

OA has been in operation since 2004. According to its profile, the organisation’s mission is “To stop the spread of HIV/AIDS in our community and help those infected with or affected by the disease to face their struggles with knowledge, support and strength.” OA’s primary programme focus is HBC, but like many CBOs, it provides other services as well. These include HIV/AIDS awareness workshops at schools, HIV/AIDS counseling and support groups, OVC after-school programming and targeted food support for both PLWHAs and OVC.

OA has seven caregivers, ranging in age from 29 to 51 years. 6 of the 7 caregivers are female and 5 of the 7 caregivers are single. None of the caregivers have any other form of employment, but 2 of the 7 live with someone who is employed. These 2 caregivers, as well as 2 others, receive 2 Child Support Grants of R200 each from the DoSD on a monthly basis. One of the caregivers has an Adult Basic Education and Training diploma, 2 caregivers have completed their matric and the remaining 4 caregivers completed school up to Grade 10 or 11.

Caregivers from OA provide services for a total of 42 patients, who range in age from 3 to 52 years. All 42 of these patients are PLWHAs, and some of them also suffer from TB and other illnesses. 14 of the 42 patients are males and 28 are females. The amount of visits each week for each patient depends on the condition of the patient as well as the workload of the caregiver, but on average caregivers visit each of their patients at least 2 times each week. The distribution of patients to caregivers is not equal, as one caregiver provides services for 11 patients and another only 4, with the rest falling between these two extremes. The amount of patients does not correlate to the amount of time spent working at the organisation, which ranges from 8 months to 4 years. Appendix A provides a staff breakdown of OA’s caregivers.

As stated previously, OA is not sponsored by the DOH and therefore does not receive funding or training from Government. They are sponsored by another NGO, which provides monthly stipends for 5 of the seven caregivers, ranging from R1,000-2,700. Each of these 5 caregivers combine a portion of their stipends to ensure that the remaining two caregivers receive R500 per month. Crucially, this funding is *not* connected to OA's HBC activities, but is instead related to its OVC programming.

All seven caregivers were interviewed as part of this study.

Profile of Organisation B (operating in L2)

OB has been in operation since 2000. According to its profile, the organisation's mission is to "work hand in hand with the department of health to see a better and healthy society." In addition to HBC, which is the organisation's primary focus, OB has a feeding scheme for OVC and income-generation projects (e.g., sewing, carpentry) for the elderly. OB was first established in order to confront the high TB rates in the community. Although there is currently a greater focus on HIV/AIDS than previously, the majority of OB's patients suffer from TB or other chronic illnesses and are not co-infected with HIV (or their HIV status is unknown).

OB has 15 caregivers, ranging in age from 22 to 49 years. All caregivers are female and 10 of the 15 caregivers are single. None of the caregivers have any other form of employment, but 7 of the 15 live with someone who is employed. 6 caregivers receive between 1 and 4 Child Support Grants of R200 each and one caregiver receives one Disability Grant of R800 from the DoSD on a monthly basis. One of the caregivers has an Early Childhood Development Diploma, 3 caregivers have completed their matric and the remaining 11 caregivers completed school up to between Grades 7 and 11.

Caregivers from OB provide services for a total of 205 patients, who range in age from one to 80 years. Only 49 of these patients are PLWHAs as OB was first established as a TB-focused operation. The remaining patients suffer from TB and other illnesses. 54 of the 205 patients are males and 151 are females. The amount of visits each week for each patient depends on the condition of the patient as well as the workload of the caregiver, but on average caregivers visit each of their patients at least 2 times each week. The distribution of patients to caregivers is not equal, as one caregiver provides services for 30 patients and another only 4, with the rest falling between these two extremes. The amount of patients does not correlate to the amount of time spent working at the organisation, which ranges from 1 month to 8 years. Appendix A provides a staff breakdown of OB's caregivers.

As stated previously, OB is sponsored by the DOH and receives funding and training from Government. Every caregiver is entitled to a stipend of R1,000 each month, with the Director and Supervisor receiving R3,500 and R2,500, respectively.

All 15 caregivers were interviewed as part of this study.

Profile of Clinic X (operating in L1)

Clinic X first opened in 1992 in an old house donated by the National DOH by a local farmer. The original building was replaced by a brand new structure in November 2007. The clinic is open Monday to Friday, from 07h00 to 16h00 each day. It services approximately 200 patients each day. The clinic provides a range of services, including ante-natal care, prevention of mother to child transmission (PMTCT) of HIV/AIDS, well-baby, family planning, mental health, physiotherapy, social worker outreach, youth services, acute and chronic illness, TB DOTS and VCT. There are a total of 12 nurses on staff.

Clinic X falls under the jurisdiction of Gauteng Department of Health. In the region where the study took place, there are 26 clinics, 12 of which are classified as provincial clinics and 14 which are classified as city clinics. The clinics are run in a similar manner regardless of which level of Government they fall under. Clinic coordinators at both provincial and local government collect the same stats and consolidate them before submitting monthly reports, as well as communicate regularly.

Three of the 12 nurses were interviewed as part of this study. These nurses were chosen based on the guidance of the DOH and the Facility Manager. The researcher was informed that these nurses worked more closely with home-based caregivers than any other nurses at Clinic X, and therefore would be the only appropriate participants.

Profile of Clinic Y (operating in L2)

Clinic Y first opened in 2006 in a pre-fab structure, replacing the mobile clinic that previously serviced the area. The clinic is open Monday to Friday, from 07h30 to 16h00 each day. It services approximately 60 patients each day. The clinic provides a range of services, including ante-natal care, PMTCT, family planning, acute and chronic illness, TB DOTS, VCT, child health immunisations, health assessments and cervical and prostate screening. There are a total of 3 nurses on staff.

Clinic Y falls under the jurisdiction of City of Johannesburg Department of Health. In the region where the study took place, there are 26 clinics, 12 of which are classified as provincial clinics and 14 which are classified as city clinics. The clinics are run in a similar manner regardless of which level of Government they fall under. Clinic coordinators at both provincial and local government collect the same stats and consolidate them before submitting monthly reports, as well communicate regularly.

All 3 nurses were interviewed as part of this study. Due to the small size of the clinic staff, all nurses work closely with home-based caregivers, unlike at Clinic X.

DOH Employees

Four DOH employees were interviewed as part of this study. These employees were identified by other Government officials as the employees who come into closest contact with both clinics and home-based organisations. The operational managers for both the TB Control and the

HIV/AIDS programmes were interviewed at both provincial and city level (due to the fact that the targeted clinics fall under different levels of Government). These employees are in charge of overseeing the implementation of these programmes at their respective clinics, which includes training staff members, ensuring clinics are fully resourced with equipment and medication, collecting relevant statistics and monitoring overall clinic performance. In addition, they are responsible for liaising and working with all stakeholders that come into contact with clinics on a regular basis. This includes HBC organisations in the community, which operational managers meet with on a monthly basis.

It is important to draw attention to the issue of scale in relation to the study sample. The sample clinics and HBC organisations are of distinctly different sizes. OA is smaller than OB (unsurprisingly given its lack of Government support). Similarly, CY is much smaller than CX. Also of interest is that the smaller HBC organisation (OA) works in an area with the larger clinic (CX), whereas the larger HBC organisation (OB) works in an area with the smaller clinic (CY). At first glance, the disparity between the sample clinics and organisations is noticeable. However, after collecting and analysing the data, the impact of this disparity on the research findings is believed to be minimal. The experiences and responses of participants throughout the study revealed that similar issues and experiences were being dealt with across the board, and there was never mention of the size of organisations and/or their counterparts as a principal factor in the formal/informal relationship (with the important exception that *all* participants mentioned they were overburdened with work).

In addition, it is also important to draw attention to the issue of OA's stipends. Although the majority of OA caregivers do receive a stipend that is similar to that of OB caregivers, it is crucial that this funding is completely unrelated to their HBC activities. The stipends are paid in relation to OA's OVC after-school and feeding programme, which was only established in the last 18 months. The stipends certainly make the lives and (by extension) work of OA caregivers easier, but HBC is *the* core activity for OA, for which it receives no funding.

Data Collection

In addition to the literature review and examination of a number of Government documents related to HBC, data for this research study was collected through semi-structured interviews. This strategy allowed for more in-depth information to be collected than would be possible through, for example, survey research. Taylor (2003) provides a short, yet clear description of this strategy when he writes "there is no set interview structure, no boxes to tick, little input from the researcher and interviewees answer in their own words" (11). Similarly, Weiss (1995) notes, "if we depart from the survey approach in the direction of tailoring our interview to each respondent, we gain in the coherence, depth, and density of the material each respondent provides. We permit ourselves to be informed as we cannot be by brief answers to survey items" (3).

The flexibility of semi-structured interviews also makes it easier for rapport to be built between the researcher and participant. This is the case because, as Taylor (2003) explains, these interviews "are much more like ordinary conversations" (11). The somewhat informal nature of the interview can help to put the participant at ease quickly, which is an important consideration when both time and resources are limited, as was the case with this research.

Separate interview schedules were developed and used for home-based caregivers and nurses as part of this study. (These schedules can be found in Appendix B.) Both schedules covered a variety of themes related to the topic at hand, including human and material resources, referral systems, trust, support, role definition, challenges, constraints and general thoughts about the HBC-clinic relationship. Crucially, many of the same questions were asked to both caregivers and nurses. This allowed the research to reveal how workers from both sides of the formal/informal divide felt about the exact same issues, as well as to uncover where there might be communication and/or systems breakdown.

A total of 34 interviews were completed by the researcher, each lasting approximately one hour[20]. When necessary, a translator fluent in both isiZulu and seSotho was utilised to ensure that participants were able to respond in a language with which they were comfortable. All interviews took place at the relevant place of business. In other words, all clinic interviews took place at the clinic, all caregiver interviews took place at the organisation's headquarters and all DOH interviews took place at DOH offices.

Data Analysis

After all interviews were completed, the information was analysed as part of a three-step process. This strategy made it possible to sort through the information collected to adequately tackle the central research questions. First, all data was sorted according to its source (e.g., OA, OB, CX, CY, DOH). This sorting took place according to the general themes noted above that were targeted through the interview schedule. Second, the data from similar sources was combined (e.g., all HBC data, all clinic data). This provided an overall picture of what each side of the formal/informal divide thought and felt about the HBC-clinic relationship, without taking into account degrees of informality. Third, the data was analysed with particular attention paid to degrees of informality. In other words, the researcher looked specifically for marked differences between the experiences and/or opinions of caregivers, nurses and/or DOH employees depending on the degree of informality of a given HBC organisation.

Weiss (1995) states that data analysis as part of qualitative research relies less on counting and correlating and more on interpretation, summary and integration. This is certainly true, but some numerical component of qualitative research can be quite helpful. For this study, there are both numerical and purely qualitative components. The numerical components (percentages) are utilised to

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[20] The Directors of both OA and OB were interviewed twice.

demonstrate the similarity and/or dis-similarity between responses on either side of the formal/informal divide or in relation to degrees of informality. These experiences and opinions are complemented by more qualitative descriptions, interpretations and summaries, often supported by quotations from participants.

Ethical Considerations

Ensuring that any research study is ethical is vital. For this study, confidentiality of all participants was guaranteed. Although the names of participants have been recorded for filing purposes, this information is only accessible to the researcher. Written consent was obtained from every participant before interviewing. In cases where participants were comfortable with tape-recording (which was the case the majority of the time), a separate consent form was signed giving permission to do so.

Ethical clearance was obtained from the University of the Witwatersrand ethics committee. Written consent to carry out the research was obtained from the directors of both HBC organisations as well as from the Department of Health at both provincial and city level. Finally, this research report uses pseudonyms for people, organisations, clinics and locations and to protect the confidentiality of all particpants.

Limitations

The main limit of this study is its scope. As noted, it focuses on only two communities, two clinics and two HBC organisations. The study locations are representative of informal settlements in an urban setting, but a larger study might reveal additional factors and issues that can impact the relationship between the informal and formal health sectors.

A second limitation of this study is the choice not to include the voices of patients – PLWHAs – in the research. Although patients certainly play an integral role in the efficacy of any healthcare system, especially PHC, the decision was made to focus exclusively on home-based caregivers and clinic staff. It is believed that getting the relationship between these stakeholders ‘right’ is an important first step in improving the healthcare system. This process will undoubtedly include the contributions and participation of PLWHAs, but much of the negotiation, compromise and work needs to happen between the two partners, removed from their patients.

Chapter IV
Research Findings & Analysis – Clinics and Home-based Care Organisations

Through interviews conducted with home-based caregivers, nurses and DOH employees, data was collected pertaining to participants' experiences regarding how HBC organisations and clinics work together. Through these interviews, primary focus was placed on a number of specific issues and/or themes that play a central role in this working relationship for both sides. This chapter outlines each of these issues from the perspective of all three stakeholders (DOH employee responses are included only where appropriate). No distinction is made between responses from the different HBC organisations or clinics in this chapter. The findings are presented as a whole in order to paint a general picture of the experiences and perceptions of caregivers and nurses.

Of the 22 caregivers interviewed as part of this study, all but 3 of them regularly visit a local clinic[21]. The remaining 19 caregivers visit the clinic between 1-4 times weekly, with most visiting twice per week. These visits happen for a variety of reasons, including escorting very ill patients during emergencies, accompanying patients to receive treatment and/or medication (especially TB DOTS), bringing community members for VCT and scheduled check-ups or blood tests. During these clinic visits, caregivers and nurses come into close contact and their working relationship is formed and shaped depending on a number of factors. Before detailing the specifics of this relationship, however, it is important to set the broader picture.

Government Perception and Support of HBC

Although HBC organisations work most directly with clinics, they are part of the larger South African healthcare system. The overall coordination of this system falls under the DOH. It is therefore impossible to separate the activities and effectiveness of HBC organisations from their relationship with and perception of the Government in relation to their work. If caregivers believe that they are receiving adequate support and acknowledgement from Government, this may contribute to improved performance. Rendall-Mkosi and Phohole (2005) uphold the view that Government support is crucial for HBC effectiveness. Similarly, both Nsutebu et al (2001) and Hunter (2006) note that without Government support, both quality and coverage of care in relation to HBC may suffer. This support is not only financial, but material and symbolic as well. Caregivers need to have adequate resources in order to do their jobs properly, and must also feel like a valued, important part of the healthcare system in the country.

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[21] Two of these caregivers (who work at OA) do not visit the clinic because, up to the time of interviewing, their patients have not required clinic services. The third caregiver (who works as a supervisor at OB) started working a month before the interviews took place and had yet to visit the clinic.

The majority of caregivers (63.6% - 14/22) did believe that the Government appreciates the work that they do. Only 13.6% (3/22) of caregivers believe outright that there is no appreciation from Government, with the remainder falling somewhere in between these two extremes. Despite the relatively positive outlook of Government's perception of HBC, caregiver responses regarding actual support received from Government was much more negative. 77.3% (17/22) of caregivers believed they receive little to no support from Government, while 100% (22/22) noted that more support from Government is necessary.

The most frequent complaint for caregivers was related to their stipend. These complaints, which were voiced by 100% (22/22) of caregivers, focused not only on the level of the stipend, but also the consistency of receiving it. Much of the literature on HBC discusses the insufficient stipend amount paid to caregivers. Many participants in this study echoed these sentiments and had strong complaints about how little they were paid for the amount of work that they do each month. Surprisingly, however, the *amount* of the stipend was not the most frequent complaint. Instead, 60.0% (9/15) of OB caregivers (who receive a DOH stipend) noted that the *consistency* of the stipend was the biggest problem[22].

In many cases, caregivers do not receive their stipend each month. This may occur for a number of reasons. Both the director of OB and one DOH employee noted that stipends are sometimes paid late because HBC organisations fail to submit their reports on time. Late submission is especially problematic because the DOH does not release funds until *all* HBC organisations in a payment area have submitted. In other words, even if one organisation does submit on time, if their counterparts in another nearby catchment area do not, *both* organisations will receive their funding late. Another reason for late payment, noted by another DOH employee, is bureaucratic red-tape from Government's side. Sometimes, the proper procedures are not completed in time, leading to payment delays.

OB caregivers reported going from as short as 2 months to as long as an entire year without receiving a stipend from the DOH. Although the caregivers are paid back if a month is missed (i.e., they would receive R2,000 if the previous month was missed), the fact that they are not guaranteed a steady salary each month wreaks havoc with their budgeting and quality of life.

> *"Like when the last time you got your money was several months ago. So how are we surviving? What are we eating? And you know if you're hungry you can't perform well."*
>
> - Ethel Thelejane[23], OB caregiver

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[22] OA caregivers do not receive a Government stipend, but all of them noted that they would like to receive one. OA has also experienced delays in receiving stipend money from its NGO sponsor on a consistent basis, but this is unrelated to their HBC activities.

[23] Pseudonyms are used for all respondents. Where necessary, quotations have been translated from isiZulu or seSotho into English.

"We do need to work with the patients but we can't if we're also hungry because [Government] provides a stipend whenever they want to."

- Refiloe Mothabela, OB caregiver

"No stipend, sometimes after 5 months, sometimes 3 months, sometimes the whole year."

- Martha Matsaneng, OB caregiver

In addition to issues regarding remuneration, the most frequent complaints focused on the lack of resources for equipment and protective/safety supplies (63.6% - 14/22)[24], as well as the need for more training for caregivers (54.5% - 12/22).

"I can say that [support from Government] is not enough, but we do appreciate it."

- Dieketseng Molope, OB caregiver

"[Home-based care] is not considered really . . . by the Government by giving us the proper everything. [Home-based care] is not provided by the Government with anything. Everything the home-based care must struggle for everything."

- Refiloe Mothabela, OB caregiver

"It's like they don't care about home-based care. There are many donors for children, but they forget about older people and home-based care."

- Ntokozo Radebe, OA caregiver

"I can't say how the Government sees home-based care but we are the most people who are working hard, but we're not getting nothing . . . And the Government the only thing that I know from us they just want the stats from us at the end of the month. They don't care who's who or they are coming where or what. They just need the statistics. They don't care about anything."

- Dimakatso Selebe, OB caregiver

The feelings of the caregivers stood in stark contrast to the responses provided by DOH employees during interviews. Without exception, Government employees believed that HBC was not only an important service, but is actually an essential contributor to the healthcare system as a whole. There was general agreement that HBC improves healthcare accessibility, awareness and monitoring and lessens the burden on the formal health system.

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[24] Both participating HBC organisations are tremendously under-resourced from a supplies point of view. Caregivers at both OA and OB rarely have even the most basic supplies, such as rubber gloves to do their work safely. The lack of supplies, problematic by itself, is made even more striking when comparing it to a recommended Home-care Kit that all caregivers should have, an example of which can be found in Appendix C.

> *"As health professionals, sometimes [community members] see us as strangers. But with [caregivers], they are part of them so that when we come, we connect to the community through them. Then it's easier. You are being more accepted when you go through them than when you go direct . . . During our work, [HBC organisations] are our, you know, our partners . . . They help us, they trace our TB defaulters, they trace ARV defaulters, they help us with awareness campaigns and they DOT our patients."*
>
> \- Jeanette van der Merwe, DOH employee

The disconnect between caregivers' opinions of how Government views HBC, and the actual perception of Government points to serious systemic problems. Somehow, the actual feelings of Government employees are being 'lost in translation.' The reasons for this discrepancy are complex, but are undoubtedly related to the HBC organisations' relationship with their local clinic. Some of the key issues raised, such as stipend inconsistency and lack of supplies, are not the responsibility of the clinic, but as the most immediate representation of the DOH for caregivers, clinics and the relationship between clinics and HBC organisations, have a crucial role to play in building linkages between the formal and informal health systems. If this relationship is weak at the ground level, the overall perception of Government's efforts towards supporting and acknowledging HBC's contributions to healthcare are likely to be damaged.

Roles and Responsibilities

Rendall-Mkosi and Phohole (2005) note that:

> no matter how much funding can be sourced for the continued development of [HBC] organizations, the question still remains to what extent the projects should be complementing government services, rather than replacing or overlapping with them . . . Clear roles and responsibilities of the different service providers from government, private and civil society organisations, across the key service provision sectors, need to be identified and strengthened." (54)

This statement refers clearly to role definition. For the partnership between informal and formal health structures to be effective, both sides of the divide must understand and accept their part to play.

At the most basic level, the findings revealed that the division of work space was very clear to all respondents.

> *"The nurses stay at the clinic. They don't know how people are living at home, how the situation is. We caregivers, we go into their rooms."*
>
> \- Malebo Khazela, OA caregiver

> *"[Home-based care is a good strategy because] we are in the office, in the clinics, and they are at the grassroots level and can find people in the houses."*
>
> \- Zandile Tladi, DOH employee

> *"They can't leave the clinic and come to the community and look after the people. So it's better that we are here in the community."*
>
> - Ntokozo Radebe, OA caregiver

Beyond *where* caregivers and/or nurses worked, the understanding of the actual work of each stakeholder was also relatively clear. There was rarely substantial overlap between the responses of the caregivers and nurses when asked to outline the responsibilities of both sides. However, there was a marked distinction between the extensiveness of the services provided at the clinic according to caregivers versus nurses. Every caregiver (22/22) interviewed believed that the role of the clinic was simply to diagnose illnesses, give treatment and do counseling. Importantly, caregivers stated that the counseling given by the clinic was short-term and only focused on HIV/AIDS. Only 4.5% (1/22) of caregivers noted that one of the clinic's main responsibilities was to disseminate information about health to the community.

Nurses, on the other hand, believe that their role is much more comprehensive. Respondents listed a variety of responsibilities, including identifying defaulters, assessments and examinations, prescribing medication and treatment, social support through referral to social services, immunisation, family planning advice and provision of a range of curative, preventative and palliative care. DOH employees also noted that clinics are responsible for facilitating communication with the community and with HBC organisations. 40.0% (4/10) of nurses and DOH employees noted that information dissemination and education is an important responsibility of the clinic.

Caregivers generally believed that their responsibilities were more extensive than nurses. These included door-to-door monitoring of patients, ensuring adherence to medication, escorting patients to the clinic, understanding and knowing the community fully, educating patients about healthy lifestyles and cleaning, cooking and washing at patients' homes. In relation to counseling, a strong distinction was drawn between clinic counseling and HBC counseling by all respondents. HBC counseling was on-going, covered a range of topics and was more informal in nature.

> *"The work of the caregivers is more than the work of the clinic because we take a sick person who is smelling, who hasn't bathed, who hasn't cleaned their house . . . and then the [nurses] find that person clean and right because we cleaned them before."*
>
> - Dimakatso Selebe, OB caregiver

> *"Because us, we just talk to our clients. By the time you visit her or him you give hope."*
>
> - Nikelwa Matji, OB caregiver

Nurses and DOH employees stated that the role of caregivers was to visit the homes to monitor patients and their medication, report any major challenges to the clinic and/or Government and to provide general support. In addition, caregivers are sometimes called on to help with awareness campaigns organised by Government in the community. There was also frequent mention of the counseling services provided by caregivers.

The responses provided by participants on both sides of the formal/informal divide revealed that there is a relatively clear understanding of where one stakeholder's job ends and the other begins. At the same time, the caregivers distinctly short list of clinic responsibilities may point towards a lack of education and/or respect for formal health sector services. In a PHC setting, the clinic should be seen as the central health hub in the community. It should be viewed as a place to go for a range of services and relatively comprehensive assistance (within reason). Caregivers in many instances are the most informed members of the community, especially in regards to the availability of different health services. Therefore, if caregivers believe that the clinic is only a place for examinations and prescriptions, there is little chance that their patients (or their patients' families or their own families and neighbours) will view it differently. The eventual impact may be that the clinic is not seen as a core of activity, but instead a purely medical site that does not play a central role in the overall health and social well-being of the community.

Clinic Support of HBC and Vice Versa

63.2% (12/19) of caregivers believed that they receive no support from the clinic whatsoever. The remaining 36.8% (7/19) agreed that they do receive some support, most notably information and education materials to give to patients, advice when there is a difficult challenge and informal training from nurses. One caregiver from OB noted that nurses provide the caregivers with extra medication from time to time to provide to their patients, although this is a rare occurrence.

More often than not during interviews with caregivers, discussion about support received from the clinic turned into discussions about the support that caregivers *would like to receive* from the clinic. Caregivers would like to receive equipment and protective supplies from the clinic. There was a frequent complaint that clinics rarely provide caregivers with gloves or other materials in order to make their job easier. This was corroborated by the clinic nurses, who noted that they often do not even have sufficient supplies for the clinic, which makes it impossible to provide to HBC organisations as well.

In interviews with DOH employees, there were mixed opinions of how to deal with the supplies issue. All were of the opinion that it is not possible to supply HBC organisations at the present moment, but moving forward there were several suggestions. Two employees believed that the present system of depositing a quarterly budget to the HBC organisations so that they could source their own supplies was sufficient. Another employee believed that Government should provide clinics with extra budget that is earmarked for HBC supplies, which can then be distributed at the community level. A fourth employee argued that the best system would be for Government to supply HBC organisations directly.

Caregivers also noted the desire to receive formal trainings from nurses in order to build their capacity further. Although one nurse did note that there are training sessions from time to time (on such topics as PMTCT), there was general agreement that training normally happened in an informal manner and only with a minority of caregivers. Counseling for caregivers, access to clinic phones in order to call ambulances when necessary and simple recognition were other types of support desired by caregivers.

Nurses listed several types of support provided to HBC organisations. This support included providing supplies when there is an excess available, allowing Health Promoters (who are DOH employees) to work with the caregivers during organisation events, attending to patients and putting pressure on the DOH when caregiver stipends are delayed. In addition, one nurse noted that having an approachable attitude with caregivers is an important type of support. From the reverse side, nurses also identified support received *from* caregivers and their organisations. This support fell neatly in line with the roles and responsibilities discussed above, including monitoring of patients at home and generally reducing the burden on understaffed clinics.

A majority of caregivers believe they do not receive any support from their clinic and the remainder believes the support they do receive is not sufficient. There is real acknowledgement from clinic staff that lack of support is a major concern, as they too struggle with limited resources, minimal staff and a difficult working environment. These problems point towards structural challenges in the way HBC is supposed to link with the formal health sector. In short, neither side is receiving the support that they require, which inevitably leads to frustration, confusion and negative feelings. These feelings unsurprisingly affect caregivers more intensely than nurses, as they reside in the informal sector, which receives less support, resources and recognition from Government.

Describing the Relationship

Before discussing many of the finer details between HBC organisations and clinics, participants were asked to describe this relationship in general terms. This relatively open-ended question further revealed the gap between different sides of the formal/informal divide.

21.1% (4/19) of caregivers noted that they had no relationship with the clinic whatsoever. Although they did bring patients to the clinic and did interact with nurses on a regular basis, they would not describe this as a ‘relationship’ in the normal understanding of the term.

> *“There is no relationship between the nurses and the caregivers.”*
>
> - Judith Cele, OB caregiver

> *“There should be a bond. There’s no bond, that bond, between the caregivers and the people at the clinic . . . It seems there is a gap.”*
>
> - Esther Thelejane, OB caregiver

Another 21.1% (4/19) of caregivers stated that the relationship with the clinic was outright bad. These caregivers had very negative experiences working with the clinic. These experiences related to both their personal interactions with clinic staff – which is often characterised by negative attitudes – but also their perception of how clinic staff treated their patients. In either case, the end result is a breakdown in the relationship and an aversion to working together.

> *"Sometimes the nurses tell us 'flies can't come in here.' We are flies. [The nurses] do not have any love."*
>
> - Portia Mboweni, OA caregiver

> *"When we go there to the, maybe we give [the nurses] the client that is very, very sick, before they can attend to that [patient] they must first shout at us as if it's our problem that patient get sick."*
>
> - Nikelwa Matji, OB caregiver

> *"As a caregiver when you think you are seeing some signs or symptoms then when you are going to the clinic [the nurses] are saying 'now you think you're better than us.'"*
>
> - Dikeledi Gopane, OB caregiver

> *"When you come back from the clinic, you come back angry. Angry because they treat our patients so bad."*
>
> - Ntokozo Radebe, OA caregiver

> *"I would send patients somewhere else than the clinic if I had money, but I have no choice."*
>
> - Malebo Khazela, OA caregiver

Despite these negative sentiments, 36.8% (7/19) of caregivers noted that the relationship with the clinic was a good one. These caregivers worked well with the clinic staff, recognised the importance of working together and appreciated the contribution of both stakeholders.

> *"We are working hand-in-hand with the clinic . . . [because] the most people that can help us are the sisters if we've got problems outside we can just take a patient and run to the clinic . . . [The nurses] help us with our patients because we can't do nothing with our patients if the patient is sick. We can't do nothing without [nursing] sisters."*
>
> - Dimakatso Selebe, OB caregiver

> *"We should work together. They can't work without us and we can't work without them."*
>
> - Ntokozo Radebe, OA caregiver

> *"It's very good [the relationship]."*
>
> - Thembeka Phiri, OB caregiver

Perhaps most importantly, however, 42.1% (8/19) of caregivers – the largest number responding in a particular way – remarked that the relationship with the clinic was highly dependent on the nurses that happened to work there at the time. In other words, the relationship changed, sometimes dramatically, when the nurses changed. In a clinic like CY, where nurses are rotating every 1-2 years, these changes can happen quite frequently, with the potential to create frustration and confusion. If the relationship is dependent on specific personalities, rather than systems, there is no sense of continuity or consistency, which is problematic.

> *"At the moment we are working very nicely . . . but it depends on the sisters because they used to move in and out."*
>
> - Dieketseng Molope, OB caregiver

> *"They used to change the nurses . . . They don't treat us the same because some of them are nice and some of them are not good."*
>
> - Nikelwa Matji, OB caregiver

> *"I can't say we have a specific relationship because we don't stay with the same sisters. The sisters change and some are okay and others are not okay."*
>
> - Dipuo Phahlane, OB caregiver

On the other side, nurses have an overwhelmingly positive view of their relationship with HBC organisations. 100% of nurses interviewed (6/6) described the relationship as a good one characterised by few (if any) problems.

> *"[The relationship] is first class!"*
>
> - Lerato Mngomeni, CX nurse

> *"I can say it's a smooth relationship . . . because if they do need help, we help. If we have more job that we are supposed to do we always ask them to give us in terms of campaigns and everything they do help in such instances."*
>
> - Suzan Mchunu, CY nurse

DOH employees responses were more mixed than nurses, but generally were positive as well. 50% (2/4) of respondents believed the relationship between clinics and HBC organisations was strong. One respondent believed that the relationship was encouraging, but that they are still working through challenges and learning what works best.

> *"[Clinics] should close the gap between the [HBC organisation] and the community. They should be working together in a way, but it's still new, we're still having those teething problems."*
>
> - Martha Lipholo, DOH employee

Another respondent noted that the relationship was a good one, but it was overly dependent on leadership, both at the clinic and the HBC organisation. This is yet another example of the 'individualisation' of the relationship, which can also be seen through the frequent staff changes at clinics. Perhaps most noteworth, were the assertions by two DOH employees that the best performing clinics (from a statistics and user-friendliness point of view) are usually those that have the strongest working relationship with local HBC organisations.

> *"What I have seen, the [clinics] that are working well with their local NGOs, they are performing very well, especially when it comes to DOT-ing their patients and supervising TB in their community."*
>
> - Jeanette van der Merwe, DOH employee

Once again, the findings from the study reveal that the relationship between clinics and HBC organisations is experienced very differently by stakeholders on opposite sides of the formal/informal divide. This is a very substantial problem, which points to a lack of systems and a generally weak structural foundation for the relationship.

Training on the Relationship

One of the primary themes throughout the HBC literature relates to training. Formal training of home-based caregivers has been happening in South Africa since 1999 (Friedman 2005), and nearly every study completed on the subject discusses the need for improved training to fill skills gaps. In her checklist of what is needed in order to establish a HBC project, Defilippi (2003) notes that training is a must. Similary, Friedman et al (2007), Russel and Schneider (2000) and Mahilall (2006) all stress the importance of on-going, standardised training (ranging from topics such as caring for PLWHAs to financial and programme management) in order to guarantee quality of care.

Although these training needs are important and necessary, there is less attention paid to the need to create spaces where nurses and caregivers can be trained on how to work together. Cameron (2003) speaks to this when she discusses the importance of placing caregivers in formal health structures for some period of time. During these training placements, the caregiver's "role at the hospital or clinic is to observe and evaluate the level of care provided, *so that he or she has a better* *understanding of the role of each organization in the continuum of care* and can facilitate referral of [PLHWAs] to other health providers" (36, emphasis added).

In the same spirit, Kganakga (2003) recommends that HBC should form part of the curriculum at nursing school throughout South Africa. Modipa et al (2002) stress the need for specific training sessions on networking between caregivers and nurses at PHC facilities.

Participants in the study were asked if they had ever received specific training on how they are supposed to work with their counterparts on the other side of the formal/informal divide. In other words, did caregivers receive training on how to work with nurses and vice versa?

44.4% (8/18) of caregivers had never received any sort of formal training regarding their working relationship with nurses. This is a minority, but the remaining 55.6% (10/18) that had received training all indicated that what they learned theoretically during this training – which took place as part of a 69-day DOH HBC training course – does not happen in practice. The training sessions spoke of special queuing systems and regular communication between clinics and HBC organisations, none of which occurs in reality, as we shall see below.

The fact that theory is not translating into practice is hardly surprising given the responses of nurses to the training question. Only 16.7% (1/6) of nurses had received any sort of training on how they are supposed to work with caregivers. Instead, the majority of nurses noted that they simply learned on the job and implemented systems and/or procedures that worked best given their experience.

Training that pertains to a working relationship, but only reaches one half (at best) of the partners in that working relationship, is unlikely to be adopted or entrenched. *All* stakeholders must have the relevant information in order to implement effectively in a collaborative and cooperative way. The partnership between caregivers and nurses specifically, and the interaction between the formal and informal health sectors generally, are both incredibly complex issues. There is little chance that these issues will 'sort themselves out' through trial-and-error activities carried out by individuals on the ground. Instead, systems must be in place and both nurses and caregivers need to be trained on how these systems are supposed to be implemented and maintained. This is not happening currently in regards to the HBC-clinic relationship, but 100% of respondents (24/24) noted that trainings specifically focused on how to work together would be beneficial.

> *"Training would be helpful so everyone knows how to operate. It can be very much helpful."*
>
> \- Mokete Mngwandi, CX nurse

Introductions and Communication

Perhaps the most important factor in making a working relationship succeed is knowing who you are working with. If one does not know who their colleagues are, the chances of building a successful relationship of trust and cooperation are reduced. The findings from the study reveal that this simple, yet crucial fact is too often overlooked by caregivers and nurses as they set out to work together. Participants were asked if they had ever been formally introduced to their counterparts on the other side of the formal/informal divide.

84.2% (16/19) of caregivers had never been formally introduced to the nurses at their local clinic. Instead, these caregivers just arrived at the clinic and began work. Even those caregivers that *were* introduced did not necessarily have a better experience starting off working at the clinic.

> *"[Being introduced] was not helpful because [the nurses] don't give a damn if you are there you still have to queue as everyone and they forget that you still have other clients to take care of."*
>
> \- Refiloe Mothabela, OB caregiver

On the other side, 66.7% (4/6) of nurses had been formally introduced to their local caregivers, in one case on a one-to-one basis with each of them. This finding is curious, given that so many caregivers had never been introduced to clinic staff and none of them mentioned one-to-one meetings, but it can be read as yet another symptom of poor communication and lack of effective systems.

33.3% (2/6) of nurses had never been formally introduced to their local caregivers, but thought that this introduction would be very helpful towards improving the working relationship between caregivers and nurses.

> *"I think that introduction, maybe it can help because I'll know I'm working with so-and-so, you see. Just like now I know them by looking at them but I don't know their names."*
>
> \- Margaret Zindela, CY nurse

Introductions are in large part about establishing strong communication channels. If one knows who they are working with, it immediately makes communicating and collaboration easier. But at the same time, introductions are not sufficient. There must be mechanisms and procedures in place to facilitate regular communication that is relevant and beneficial to the working relationship. This communication may take place verbally through meetings or through written reporting. Regardless of its form, communication is vital in building and maintaining a strong working relationship. Participants were asked to discuss the regular, formal communication that took place between caregivers and nurses.

0.0% of caregivers (0/19) have regular, formal verbal communication with the clinic, including the directors of both HBC organisations. The director of OB previously held a monthly meeting with the facility manager of CY, but since the clinic staff had changed 4 months earlier, these meetings had not continued (both the director and the current facility manager of CY noted that they were planning on starting up monthly meetings, but this had not happened up to the time of interviews). The only regular meetings for caregivers are staff meetings, where work-related challenges are discussed (including those with the clinic). However, if these issues are not communicated to the clinic through a formal channel, opportunities to fix identified problems will be hard to come by.

The only regular meetings where the HBC organisations participate are known as NGO Forum meetings, which take place on a monthly basis. These meetings are attended by all of the NGOs in the region and are used as an opportunity to network, disseminate information and discuss challenges. Staff members at both OA and OB noted that the NGO Forum was a valuable space, but *not* in regards to the relationship with the clinic because no clinic representatives attend these meetings. DOH employees are in attendance and are responsible for passing on any relevant information to clinics.

> *"At the forum meetings we talk about our problems [with the clinic], but when you come back, still the same."*
>
> \- Malebo Khazela, OA Caregiver

> *"Long time they say they will discuss this thing that the caregivers must work together with the sisters but that thing never happened."*
>
> \- Nikelwa Matji, OB Caregiver

In addition to the Forum meetings, DOH employee participants had differing opinions about regular meetings between HBC directors and clinic facility managers. One DOH employee believed that these meetings are only necessary in case of emergency. Another employee believed that they should be holding weekly meetings and also noted that Government was working towards holding formal meetings between HBC organisations and clinic sisters in order to strengthen the relationship. The remaining two DOH employees believed that communication should happen through a monthly community meeting in the specific area where the clinic is located.

At CY, none of the nurses (3/3) have regular meetings with caregivers or the HBC director. This includes the facility manager, although she is planning on implementing a monthly meeting with the HBC director in future. At CX, 2 of 3 nurses interviewed attend a monthly meeting with caregivers from an HBC organisation working closely with the clinic, but this is *not* OA. Although some nurses are having regular meetings, the facility manager does not hold a monthly meeting with the caregivers or the HBC director of this organisation, and only calls her in case of emergencies.

"[A monthly meeting] would be helpful because [caregivers] can give their point of view . . . what they are expecting or anything they want to say. Even on our own side we can say anything we want to say."

- Margaret Zindela, CY nurse

From a written point of view, all caregiver written reports are submitted to the director of the organisation. These reports include information about the number of households visited, new patients, defaulters and other relevant statistics. For OB, these reports are then sent to the DOH at both the district and provincial level[25]. No reports or statistics are sent directly to the clinic. A number of caregivers at OB noted that they submit a monthly report, but they had limited knowledge of what happens to the information after submission. Although the director of OB did not find the reporting requirements too cumbersome, reporting was a source of dissatisfaction for DOH employees. Two of these employees complained that too much time and effort was spent on reporting for HBC organisations, which created confusion and inefficiency.

"Reporting is all over the show."

- Ntsako Msimango, DOH employee

"There's so many reporting that has to be done in the [HBC organisation] and then it's consuming their time. I think it's taking the patients' time . . . because the NGO, it's core duty is to work and empower the community, but I think because of so many papers that are done they can't empower the community."

- Martha Lipholo, DOH employee

Overall, the findings revealed a general sense of frustration regarding communication. Stakeholders on both sides of the formal/informal divide noted that communication was non-existent or insufficient and left them feeling as if they were working in isolation to a certain degree. It was also noted by all participant groups that fixing the communication issue must be one of the highest priorities for all involved.

"Nurses need to work with us properly. We are working the same job. The difference is we are not well-trained like them. What I need is just a communication, working together. It's the only support I need. Working together. Helping each other."

- Jabulile Ndaka, OA caregiver

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[25] The monthly reports submitted by OA caregivers to their director are not submitted to any Government officials (as OA is not sponsored by Government), but are kept for internal purposes. OA does submit a monthly report describing its OVC activities to its private funder, but this is unrelated to HBC activities.

"There's no communication, there's no channels that we can communicate."

- Agnes Modisane, CY nurse

"Right now we are working and we don't know where we are going."

- Dimakatso Selebe, OB caregiver

"If they don't communicate, they are not going to take care of each other."

- Martha Lipholo, DOH employee

Referrals

As noted in Chapter I, one of the three pillars of the DOH's HBC strategy is "integrated management and referral service organisation." The HBC Guideline elaborates on the need for strong referral systems when it notes that "the broad objective is to establish an effective referral system at all levels, i.e. hospital, clinic and community and/or home" (DOH 2001: 12). According to the Guideline, an effective referral system entails a significant number of activities, including:

1) Assess clients' readiness for referral;
2) Inform the home care provider to which the client is being referred to, to allow notification and preparation to receive the client;
3) Provide written or pictographic instructions on medication, purpose for use and dosage;
4) Observe the understanding of the caregiver and/or client of the usage of medication;
5) Send a referral form to the primary care site that will take over the care of the patient;
6) Inform client and/or caregiver of follow-up care, appointments, details on patient-retained card, etc.;
7) Advise on any specific care, e.g. nutrition, hygiene, oral health, pain control, infection control, mobility, wound care;
8) Give contact details of the referral role players as well as primary role players;
9) Provide assistive devices, e.g. mobility and/or self-care aids as required;
10) Provide pharmaceutical supplies and dietary supplements as required;
11) Provide sick leave certificates, social assistance forms;
12) Arrange transport for patient to home on discharge and for referrals;
13) Define formal/informal/non-formal partnership and lines of communication by contract or agreement; and
14) Referral from community level should be accepted by the recognised referral facility.

The DOH's emphasis on effective referral systems is supported by the wider literature, where referrals are consistently noted as an essential part of any HBC programme (e.g., Kganakga 2003; Russel & Schneider 2000). The important question, as always, is if this is being translated in practice. A brief overview of the literature reveals that it usually is not. Rendall-Mkosi and Phohole (2005) find that clinics only have informal referral systems with HBC organisations, Russel and Schneider (2000) find few examples of well-developed referral systems in their rapid appraisal of HBC in South Africa and Modipa et al (2002) note that clinics are often characterised by having weak referral systems both 'upwards' (to tertiary hospitals) and 'outwards' (to community organisations like HBC). Similarly, Ogden, Esim and Grown (2006) assert that referral linkages between different levels of the healthcare system are weak and it is unclear how one is supposed to move across the continuum of care (of which HBC plays a vital part).

Participants in the study were asked to explain how the referral system between the clinics and HBC organisations operated in both directions (from clinic to HBC and from HBC to clinic). 100% (19/19) of caregivers and 100% (6/6) of nurses reported that caregivers do refer to the clinic on a regular basis. From the other direction, 15/19 (78.9%)[26] of caregivers and 100% (6/6) of nurses reported that the clinic does refer to the HBC organisations. At surface level, these are encouraging numbers that demonstrate some level of partnership between the clinics and HBC organisations. A closer examination, however, reveals that the actual referral process varies widely depending on the caregiver and/or nurse involved.

Interviews with caregivers revealed four different referral strategies being employed by HBC staff. The majority of caregivers (73.7% - 14/19) refer patients by simply escorting them to the clinic, queuing in line with them and filling out the necessary paperwork with the administrative clerk at the clinic. Two of these caregivers noted that the organisation does have official referral forms, but they are not used because the organisation is located so close to the clinic that it is unnecessary[27]. 10.5% (2/19) of caregivers simply send patients to the clinic without escorting them, while a further 10.5% (2/19) escort the patient and provide a referral form from the HBC organisation explaining the patient's situation. Finally, 5.3% (1/19) of caregivers escort the patient to the clinic, but instead of going to the administrative clerk, they take the patient to another caregiver based at the clinic[28] for instructions.

Nurses also had varying experiences with referrals from caregivers. 66.7% (4/6) noted that caregivers send or escort patients with no referral forms or other paperwork. 33.3% (2/6) noted that caregivers do provide referral forms with their patients. One nurse noted that there are times when a referral involved the nurses actually going to the patient's home to assess the situation.

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[26] The four caregivers who reported not receiving referrals from the clinic all work for OA. This and other issues of difference will be dealt with in more detail in Chapter V.

[27] See Appendix D for an example of OB's official referral form.

[28] Around June 2008 (the actual month of implementation differed depending on the clinic), the DOH began implementing a new HBC strategy, which places caregivers at the clinics for approximately 3 hours a day each morning. In addition to regular home visits in the afternoon, the job of these caregivers, known as "DOT Supporters," is to help clinic staff DOT TB patients and act as a liaison between the clinic and the HBC organisation. More discussion of this system will be made in Chapter V.

Caregiver experiences with referrals *from* the clinic were even more diverse than those to the clinic. The findings revealed 7 different referral procedures from clinic to HBC organisation. These procedures are as follows, listed in order of frequency:

1) The clinic sends a list of patients that require a home visit. This list includes the full name and address of the patient, but no other information. (26.7% - 4/15)
2) The clinic sends patients to the HBC headquarters with no paperwork to seek assistance. (20.0% - 3/15)
3) The DOT Supporters bring a list of patients and addresses to the headquarters, which is given to the secretary in order to assign the home visits. This list has no additional information. (20.0% - 3/15)
4) Nurses tell caregivers about a patient and their address during a visit to the clinic. There is no paperwork and the caregiver goes to the house at the earliest available time. (13.2% - 2/15)
5) Patients are sent by the clinic to the HBC headquarters with a letter explaining the situation, but this letter is not an official referral form. (6.7% - 1/15)
6) The clinic sends a list with patient names and addresses, accompanied by a letter from the nurse explaining the situation, but this letter is not an official referral form. (6.7% - 1/15)
7) The DOT Supporter receives the list of patient names and addresses from the clinic and assigns caregivers to visit the homes. (6.7% - 1/15)

According to nurses' responses, 2 different referral strategies were used. 66.7% (4/6) of nurses referred by sending the list of patients to the HBC headquarters without any referral letter. The remaining 33.3% (2/6) of nurses did use an official referral letter when sending patients to the HBC organisation[29].

The wide variety of referral methods in both directions is remarkable given the small size of the institutions. Even within CY, a clinic with only 3 nursing staff, nurses use different referral methods. In many cases the referral methods described by stakeholders on one side of the formal/informal divide do not match those described by the other side. These findings reveal a lack of any mechanisms or procedures in place to make referrals work in a systematic way. Instead, each individual operates in his or her own way according to what works best for them at the time. Not only does this cause confusion and inefficiency, but it has a negative impact on the continuity and quality of care of patients, which ultimately leads to poorer health outcomes.

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[29] See Appendix E for an example of an official City of Joburg referral form. (The original document was unaligned and cut off, not the scan of the document for this report.)

> *"My problem is coming to a patient not knowing nothing. Maybe it's a first time. I don't know anything. I don't know where to start, what to say. You just come with a blank head."*
>
> - Jabulile Ndaka, OA Caregiver

> *"[A referral system] would help because you know how's the process of the patient and what is supposed to be done . . . At least there's a continuity of care: [caregivers] did do until here and we are supposed to start from here until there. But if there is a new patient without any file or anything then you start from scratch."*
>
> - Margaret Zindela, CY Nurse

Queuing

When a patient comes to a clinic without a scheduled appointment, they normally stand in the queue waiting for service. When they get to the front of the queue, they fill out any necessary paperwork and go into the examination room for their time with the doctor. After the examination, they leave the clinic and return home. This very simple procedure, familiar to anyone who has spent time in a clinic, hospital or doctor's office, was one of the strongest sources of discontent for home-based caregiver participants in the study. The findings revealed that issues around queuing create major problems for the caregivers and contribute greatly to their relationship with the clinic.

100% (19/19) of caregivers had to stand in the queue with their patient when they escort them to the clinic. The only time that the caregiver might be able to jump the queue is when their patient is extremely ill, but one caregiver noted that even in such cases she has been forced to stay in line. All caregivers also noted that there is no special system for caregivers at the clinic to help make their work easier. This is in marked contrast to what 21.1% (4/19) of caregivers asserted *should* be happening at the clinic. These caregivers, all of whom had undergone the 69-day HBC training course, explained that during the course they were told caregivers escorting patients should not fall into the general queue, but should be expedited to the front of the line in order to allow them to spend a minimal amount of time in the queue and more time visiting homes/patients in the community.

> *"Sometimes the sisters are very difficult because . . . they will tell you to wait until the queue moves so you feel painful because the client is very sick."*
>
> - Refiloe Mothabela, OB caregiver

> *"We just wait. We wait and wait and wait. We're not supposed to make a queue because we are working with the nurses."*
>
> - Jabulile Ndaka, OA caregiver

Surprisingly, 83.3% (5/6) of nurses noted that caregivers *do not* have to queue in the main line when they come to the clinic with a patient. The nurses' explanation for this concurred with the assertions of caregivers, noting that it was better for caregivers to spend the bulk of their time outside of the clinic. Only one nurse stated that caregivers must queue like anyone else in order to avoid unhappiness with other patients.

> *"[Not queuing] is good because most of the time [caregivers] are working. It won't be fair for them to stay on the queue with these sick patients when they are expected to be somewhere doing other work."*
>
> \- Suzan Mchunu, CY nurse

> *"We don't give priority to any other clients because that might cause chaos at the clinic."*
>
> \- Mokete Mngwandi, CX nurse

Once again, the study findings reveal a major disconnect between the experiences of the caregivers and nurses at the clinic. Whereas none of the caregivers feel they receive special treatment when they arrive at the clinic with a patient, a significant majority of nurses insist that they are not required to queue like anyone else. This finding reinforces the existence of poor communication and a lack of systems in place to facilitate the working relationship between both stakeholders.

Trust

In any working relationship, trust is absolutely essential. If you do not trust your colleagues, the likelihood of building strong, effective relationships is greatly reduced. In the case of health systems, trust not only affects the attitudes of users towards the system as a whole, but also the partnerships between different internal stakeholders such as nurses and caregivers. Modipa et al (2002) note that a lack of trust limits continuity of care. Going one step further, Campbell and Foulis (2004) note that "people are most likely to be healthy in communities characterised by high levels of trust, reciprocal help and support, positive local identities and participation in informal and formal social networks and organisations" (11). The trust, reciprocity and participation noted here can all be directly linked to the relationship between caregivers and nurses, who play a central role in creating a healthy community environment.

The findings revealed that despite the existing problems in the relationship between nurses and caregivers, the majority of stakeholders did trust their counterparts on the other side of the formal/informal divide. 73.7% (14/19) of caregivers said that they did trust nurses to provide high-quality, appropriate care to patients. Similarly, 83.3% (5/6) of nurses trusted home-based caregivers to do a good job working with patients and providing services.

> *"If we can't trust the clinic staff, who can we trust?"*
>
> \- Sibusiso Tau, OA caregiver

For the five caregivers who did not fully trust the nurses, the major issue was confidentiality. These five respondents all discussed situations where they felt the nurses were not protecting the confidentiality of their patients sufficiently (especially in regards to HIV-status). They all noted it was difficult to trust because they were not sure what the nurses would do with the information about the patient and where that information might end up. The nurse who did not fully trust the quality of care provided by caregivers noted that a lack of monitoring of caregiver activities made it impossible to know exactly what happened in the homes. This nurse recommended that DOH employees and/or nurses should make monitoring home visits from time-to-time to assess the quality of care provided by caregivers.

It is an encouraging finding that there are significant levels of trust between nurses and caregivers. There is no doubt that trust is an essential ingredient to any working relationship. The fact that this trust exists despite many of the other problems identified by the study may suggest that levels of trust are in actuality extremely high. At the same time, this finding must be viewed with a certain level of doubt, or at least uncertainty. All of the other research findings point to a breakdown in the relationship between caregivers and nurses. There are bad attitudes, poor communication and lack of systems. All of these factors lead to negative experiences and feelings about the formal/informal partnership (especially for caregivers). The fact that such a high percentage of respondents still noted that they trust their counterparts may reveal a discrepancy between what ‘trust’ meant to the participants as opposed to the researcher. In addition, there may have been an inclination for participants to provide the ‘right’ answer to this question – that they do trust their counterparts – as it was posed in a relatively direct way. There is a possibility that trust levels do remain high between nurses and caregivers, and if this is the case it must form the foundation of improving the system as a whole. But the existence of strong trust is, unfortunately, not beyond doubt.

Easier or Harder

Near the conclusion of each interview, participants were asked if their counterparts on the other side of the formal/informal divide made their job easier or harder. Although the concepts of ‘easier’ or ‘harder’ may be somewhat subjective, this question was posed in order to provide participants with a space to discuss their ‘gut’ feeling about the impact the clinic and/or HBC organisation has on their everyday work activity. In an ideal working relationship, each person should feel that their job is made easier by those he or she is working with as each stakeholder contributes to the overall goal – in this case high-quality care and support for PLWHAs and patients suffering from other serious illnesses.

Once again, the perceptions and experiences of caregivers versus nurses differed greatly. 63.2% (12/19) of caregivers claimed that, at the end of the day, the clinic made their job harder. The reasons for this included:

- The negative attitudes of nurses towards the caregivers;

- Having to stand in the queue, which is a waste of time for caregivers;
- The feeling that patients are not treated well;
- Lack of communication; and
- Being overburdened with patients referred by the clinic.

The 36.8% (7/19) of caregivers who believed the clinic made their job easier overall provided the following reasons:

- Nurses are the experts and can help with difficult medical challenges;
- The clinic provides necessary medicine to patients; and
- The clinic is a support system that is there to handle very ill patients.

> *"Harder, because you always have to fight for what you want."*
>
> \- Malebo Khazela, OA caregiver

> *"Easier, because I have a place to refer the client and get help if I don't know the problem."*
>
> \- Thembeka Phiri, OB caregiver"

By contrast, 100% (10/10) of nurses and DOH employees noted that caregivers made their job easier. The importance of HBC to their jobs was stressed by all participants. In many cases, respondents went as far as claiming that their jobs would be nearly impossible without the assistance and efforts of caregivers.

> *"They are making our work much less . . . more lighter . . . Without them we wouldn't be able to reach each and every patient, all our patients."*
>
> \- Mokete Mngwandi, CX nurse

> *"Without [caregivers], we won't win . . . Our work would be unbearable without their support."*
>
> \- Zandile Tladi, DOH employee

> *"Easier, because you would not be able to go out there and reach for communities that are out of reach for the clinic, especially now with scarce resources in terms of human . . . in terms of everything."*
>
> \- Suzan Mchunu, CY nurse

This finding is particularly problematic as it speaks to the general experience that both nurses and caregivers have with the working relationship. The high percentage of caregivers that believe the clinic makes their job harder (a majority of participants) as well as the great disparity between caregivers and nurse/DOH responses, speaks to serious problems within the system. The ultimate goal of any improvement to the HBC programme in South Africa should be to ensure that the answer to this question is ‘easier’ for 100% of respondents on both sides of the formal/informal divide.

The findings described in this chapter reveal a number of significant issues pertaining to the relationship between nurses and caregivers, and by extension the formal and informal health sectors. It is clear that there are major problems with this relationship. Caregivers believe there is a lack of support from both Government and clinics, their understanding of the clinic’s role in the community speaks to a lack of awareness and/or respect, there is a lack of communication (either written or verbal) from both sides, training on the relationship and queuing systems are not being implemented on the ground and referrals are done in a haphazard way. Even the most positive finding, regarding trust, can only be accepted with reservations.

There are two primary ways that these findings might be analysed. The first is to look at the micro-level. In this perspective, the problems at hand can be explained through individual behaviour and actions. For micro-level advocates, the problems experienced within the relationship are a result of negative attitudes from both nurses and caregivers and weak leadership that fails to implement proper systems. In short, it represents the failure of individuals, not something larger.

The ‘micro’ school of thought is by no means wrong. In fact, individual behaviour and actions are an essential part of any working relationship and/or system. There is no way that the problems revealed in this chapter can be separated from the individuals who experience them every day. With that being said, a second level of analysis – one which looks at the macro-level – is more helpful in trying to understand the issues at hand.

The ‘macro’ school of thought is less concerned with individuals and more interested in structural or systemic problems. Here, the failures of individuals are explained *because* of structural or systemic issues, not in spite of them. The reason that caregivers do not feel supported by the local clinic is not because nurses are negative towards them, but because clinics are so under-resourced and understaffed that they are unable to give support. Poor communication is not the result of laziness or a lack of interest, but instead of the fact that there are no systems in place to make communication easy, consistent and effective. The same can be said for queuing, referrals and training. At the structural or macro-level, there are few (if any) mechanisms that make these things understandable and possible for people on the ground. This weak structural foundation leads to poor implementation, weak relationships, disempowered health workers (both formal and informal), frustration, confusion and, ultimately, inferior health and developmental outcomes. The way forward, which will be discussed in more detail in Chapter VII, must attempt to address both the micro- and macro-level issues if real improvements are to be made.

Chapter V
Findings & Analysis – Degrees of Informality

In addition to trying to uncover the factors that influence the relationship between HBC organisations and local clinics, one of the central questions of this research study relates to how degrees of informality influence the experience of caregivers and HBC organisations. As noted in Chapter I and III, the HBC organisations that participated in this study are characterised by different degrees of informality. OA receives no funding or training from the DOH while OB is sponsored by the DOH and its caregivers each receive a monthly stipend from Government for their HBC activities.

This chapter will revisit some of the issues from Chapter IV, as well as introduce several new ones, to explore the impact of degrees of informality. Importantly, the findings will focus not only on those themes where differing degrees of informality translate into divergent experiences, but also on instances where differing degrees of informality have little to no impact on the experience of caregivers in their everyday activities. The chapter will be divided into two sections, the first exploring the impact of informality on the internal operations of the HBC organisations, and the second exploring how informality affects relationships with the clinic and Government.

Internal Operations

In some ways, the internal operations of OA and OB are very similar. Both organisations hold a monthly staff meeting to discuss challenges in the field and organisational issues (e.g., policies and procedures). Both organisations have a constitution and defined organisational structure and keep files on every one of their patients. Caregivers at both organisations submit a written monthly report to the director outlining activities, new patients, issues around adherence, accomplishments, challenges and the like. Both organisations have problems with staff turnover as caregivers find higher paying jobs, become frustrated with the small stipend they do receive or experience burnout. In all of these ways, the degree of informality seems to have little impact on the way the organisations operate. Beyond these similarities, however, there are three crucial differences.

Contracts

Every OB caregiver has a signed contract with the organisation (see Appendix F for a sample of OB's Caregiver Contract). This contract outlines the duration of 'employment' with the organisation and explains that a stipend will only be paid if funds are available. It notes that there are no pension or other benefits, but there is an allotment of sick and annual leave. Finally, the contract binds the caregiver into following the rules and regulations of the organisation. Every caregiver at OB understood the terms of the contract and explained them during the interview process.

By contrast, only 5 of the 7 caregivers at OA have signed contracts. Importantly, these contracts are not with the actual organisation, but instead have been signed with OA's OVC funder. This funder provides a stipend to 5 of the 7 caregivers to implement an OVC after-school programme (these funds are eventually split between all caregivers to ensure everyone gets at least some payment at the end of each month). The caregivers have signed a contract with the funder outlining their duties for the OVC programme and their remuneration. None of the caregivers, except the director, could explain exactly what was stipulated in the contract that they had signed. There is no contract of any sort between the caregivers and OA itself.

Both OA and OB are technically volunteer organisations. For this reason, it would seem that signing any sort of contract would be unnecessary, especially if there is no money involved (as in the case of OA). The literature on the informal sector makes it clear that one of the defining characteristics of informality is a lack of contractual and/or social protection. Without this, informal workers have little leverage or ability to improve their working conditions. In her discussion of strategies for improving inclusion of the informal sector, Tokman (2007) notes the importance of ensuring contracts exist and have at least *some* semblance of protection. The lack of organisational contracts at OA provides no actual link between the caregivers and the organisation itself. In essence, staff members are free to come and go as they please and there are no written expectations and/or requirements in order to remain as part of the organisation.

Training

As noted above, OB receives Government training through their sponsorship while OA does not. This is one of the most obvious consequences of degrees of informality, but its impact is so far-reaching that further elaboration is necessary. Even though a significant minority of caregivers at OB (40.0% - 6/15) have not completed the 69-day HBC training course, these caregivers are constantly exposed to training opportunities. Every caregiver at OB has completed at least two Government training courses that help them to perform their job better. These courses include the 69-day course, basic HIV/AIDS, basic HBC, nutrition, communication, OVC care, bereavement counseling, TB, first aid and rape counseling.

At OA, the situation is drastically different. Only one caregiver has completed the 69-day HBC course. Beyond this, caregivers have very little formal, Government-approved training. Because they are not sponsored by the DOH, OA caregivers only have access to short, non-Government workshops and training sessions (usually 1-2 days). Although most OA caregivers have attended some of these workshops, the amount and quality of training received is inferior to a sponsored organisation like OB. This is not to say that the work OA does is necessarily of low quality, but the skills and capacity to do the job are certainly lower as compared to OB. This obviously has major implications for the impact of informality on organisational effectiveness and the depth of care that patients receive. If caregivers do not receive the necessary training, there is no way that they will be able to provide a fully effective service to PLWHAs and other ill community members. In these cases, the service provided becomes more like 'home visiting' rather than 'home care' (Hunter 2006). Although the social care related to home visiting is unquestionably valuable, the real potential of HBC lies in the combination of social *and* health care, which can only be provided by trained individuals.

Teaching

Another important finding, which is directly linked to the issue of training, relates to how caregivers at both OA and OB describe the services they provide. At the beginning of each interview, caregivers were asked what they do for patients when they visit their homes. Participants generally provided a relatively similar list, which included cleaning and cooking, ensuring patients adhere to their medication schedules and informal counseling. There was, however, one striking difference between the two organisations. Only 14.3% (1/7) of OA caregivers mentioned *teaching* or *educating* their patients about health and disease. At OB, 80.0% (12/15) of caregivers noted that teaching their patients was one of the central services provided.

> *"I pass on the knowledge I have learned through trainings to teach people what they should do to be healthier . . . A good thing about home-based care is that patients get knowledge from me after I get knowledge from trainings."*
>
> \- Judith Cele, OB caregiver

This finding does not provide grounds for arguing that OA caregivers do not pass knowledge onto their patients. HBC has an inherent educational component that exists whether one makes a concerted effort to teach patients or not. The important thing here is that OB caregivers, who have access to a substantial training network, identify educating their patients as a central part of their job. Rather than something that just 'happens,' teaching and passing on knowledge becomes an important component of their HBC activity and something in which caregivers take pride. The worth of this fact cannot be overstated. Uys (2003) notes that the ability to teach is one of the most important skills that a caregiver can possess. Padarath, Searle and Esu-Williams (2006) stress the importance of educating people in their homes because "face-to-face education predominantly takes place at health centres and accrues to people already within the broader health system, as opposed to reaching people who are not accessing services" (51). For HBC to fulfill its potential, it is essential that knowledge and capacity-building does not stop with caregivers. Instead, it needs to be passed on to others throughout the community (both those suffering from illnesses and healthy members) in order to improve overall health outcomes.

Informality and Relations with Clinics and Government

The consequences of being unsponsored, and therefore more informal, are many for an organisation like OA. Some of these consequences are quite obvious:

- There is less communication between caregivers and nurses at the clinic;
- There is no frequent, direct contact with the DOH (except through NGO Forum meetings, which a representative from OA attends);
- Clinics rarely (if ever) refer patients to the organisation (only one of 7 OA caregivers noted ever receiving a referral from CX);
- A lower percentage of caregivers receive training on how to work with the clinic (14.3% or 1/7 of OA caregivers versus 66.7% or 10/15 of OB caregivers); and
- A lower percentage of caregivers describe the relationship with the clinic in fully positive terms (20.0% or 1/5 of OA caregivers versus 46.7 % or 7/15 of OB caregivers).

Generally, unsponsored HBC organisations work in greater isolation than their sponsored counterparts, providing services with little formal health sector support. In some ways, this is a natural phenomenon, as it is more difficult to 'stay in touch' and build linkages when one falls outside of official channels. The study revealed that the decision not to work with unsponsored organisations, in some cases, is a deliberate decision by both the DOH and clinics.

Government Perception and Support of HBC

DOH employees were asked how they utilised unsponsored HBC organisations in their health activities throughout the region. There was consensus that the use of unsponsored organisations should be limited to community awareness campaigns. During these campaigns, caregivers can help to distribute information, visit houses and provide support in other ways. Participants also noted this was a good opportunity to provide caregivers who do not receive a Government stipend with money because campaign volunteers are usually given a small allowance for their work.

Beyond awareness campaigns, DOH employees saw little opportunity for working with unsponsored organisations. There were several reasons for their reluctance to do so:

1) Sponsored organisations receive more training, so when the DOH needs to deal with medical issues, it does not want to risk working with untrained caregivers.
2) There is a greater level of control – a greater ability to ensure that instructions are followed – with sponsored organisations because they receive Government funding.
3) There are so many NGOs – a "mushrooming" as one DOH employee called it – that it is easier to work with officially sponsored ones so it is known exactly who is being dealt with.
4) Sponsored organisations perform better because they have more skills and are motivated by the stipend they receive (all four DOH employees did agree that the stipend was too low).

> *"Yeah I can say [sponsored organisations] perform better because you know that motivation is there. They are motivated because they know that something is coming . . . The [caregivers] that don't have the stipend and they're not trained, you know, that confidence it's not there so much, although, yes, they are willing to learn, but, you know, there is a difference."*
>
> - Jeanette van der Merwe, DOH employee

> *"There's a great difference . . . Where there's money it's like the petrol in your car. Without petrol in your car, you can't move . . . [Sponsored organisations] feel they're part of the Government."*
>
> - Ntsako Msimango, DOH employee

This last quote makes perhaps the crucial distinction between sponsored and unsponsored HBC organisations in regards to their relationship with Government. Very simply, sponsored caregivers feel that they are "part of the Government" – a point which is reinforced by OB's mission statement found in Chapter III – while unsponsored caregivers do not. Degrees of informality have a powerful impact on caregivers' connection to the healthcare system as a whole, with obvious consequences for their ability to work effectively.

Clinic Perception and Support of HBC

As noted in Chapter IV, the Government has recently implemented a new strategy that sees caregivers placed within the actual clinic. The caregivers remain as staff members (or volunteers) of their HBC organisation, but they spend up to three hours each day at the clinic in order to provide assistance with TB treatment or VCT (these caregivers are called "TB DOT Supporters" or "VCT Counselors" at the clinic). After their duties at the clinic are complete, they go out into the community and do home visits and other traditional HBC activities.

Both participating clinics had DOT Supporters and VCT Counselors. At CX, the caregivers based at the clinic were not from OA. Instead, they came from a separate HBC organisation that was sponsored by the DOH. Two caregivers from this organisation rotate into the clinic each day to perform their TB- and HIV/AIDS-related duties. At CY, the DOT Supporters are caregivers from OB (there are 2 of them) and the VCT Counselor is a caregiver from another DOH-sponsored HBC organisation. The OB caregivers do not rotate like at CX, but instead the same two caregivers come to the clinic each day to assist with DOT-ing patients.

There is a generally optimistic view of this new system from all stakeholders. DOH employees, nurses and caregivers all noted that having caregivers based part-time at the clinics was helpful in improving communication and the working relationship between clinics and HBC organisations. The system is still very new, and the true impact will only be measurable in the longer-term, but it does seem to be regarded as a step in the right direction. The system is also an example of how degrees of informality affect HBC organisations.

As a sponsored organisation, OB has been provided with a direct link to the clinic – a stable connection between the formal and informal health sectors. This not only helps to build the organisation's capacity – both DOT Supporters noted that they had learned many new things since being based at the clinic and were consistently exposed to informal training – but also strengthens their feeling of being part of the healthcare system. By contrast, an organisation like OA gains nothing from the new system, and is in fact hurt by it.

Rendall-Mkosi and Phohole (2005) note that the link between the formal and informal health sectors can be damaged by competition between HBC organisations. During interviews, several OA caregivers discussed their feelings that the organisation based at the clinic was benefiting from favouritism and that, in essence, OA was being discriminated against. OA's relationship with the clinic, which was already extremely weak, had now become non-existent. This was reinforced by one of the nurses at CX, who stated that she had no relationship with any HBC organisations in the community (outside of the one based at the clinic).

Here again, we see the impact of degrees of informality. The implementation of a new system – basing caregivers at clinics – has a strongly positive effect for sponsored organisations and a decidedly negative effect on unsponsored organisations. The question, therefore, is whether or not the benefits accrued by sponsored organisations outweigh the costs for others. In a community like L2, the benefits may outweigh the costs due to the small number of organisations, most of which are sponsored. In L1, however, there is a larger number of HBC organisations – as many as 10 according to the director of OA – so the exclusivity of the new system may actually cause more damage than good.

Degrees of informality undoubtedly have a profound effect on the operation of different HBC organisations. One of the unexpected findings from the study, however, was that the experiences of sponsored and unsponsored organisations was quite similar in relation to some of the key factors identified as impacting the links across the formal/informal divide.

Introductions

As noted in Chapter IV, being introduced to your partners or colleagues is a key first step towards building a strong working relationship. The study revealed that whether or not one worked for a sponsored or unsponsored HBC organisation, only a small minority of caregivers had had a formal introduction to clinic staff. Only 14.3% (1/7) of OA caregivers had been formally introduced to CX clinic staff (the director noted that getting such an introduction scheduled has been difficult due to the bias shown by the clinic towards the organisation already based there). Similarly, only 14.3% (2/14) of OB caregivers had been formally introduced to nurses at CY. This despite the fact that some of their fellow caregivers are actually based at the clinic and caregivers and nurses come into contact with each other on a daily basis.

Queuing

The fact that they were forced to queue with patients at the clinic was a source of major frustration for caregivers at both OA and OB. 0.0% of caregivers at *either* organisation (0/5 at OA and 0/14 at OB) reported that they were able to skip the queue (except in some cases where patients were extremely ill). The degree of informality does not translate into any sort of different system or working procedure for OB caregivers as compared to OA caregivers. Both are forced to, in effect, waste many of their working hours standing in a queue rather than visiting the homes of patients.

Trust

Trust is the foundation of any positive working relationship. It would be expected that, given closer contact and more direct linkages, caregivers at OB would express a greater level of trust for nurses than caregivers at OA. The study did reveal this to be true, but the difference in levels of trust is minimal. 60.0% (3/5) of OA caregivers noted that they trusted clinic staff as compared to 66.7% (10/15) of OB caregivers. In other words, at least 40% of the staff at *both* organisations does not fully trust clinic staff. Degrees of informality, it seems, has little bearing on this fundamental building block of the formal/informal connection.

Easier or Harder

Perhaps the most startling finding from the study relates to the question of if the clinic made the caregivers' jobs easier or harder. Quite surprisingly, a *greater* percentage of OA caregivers reported that the clinic made their job easier than OB caregivers. Although both were in the minority within their organisations, 40.0% (3/5) of OA caregivers believe the clinic makes their job easier as compared to only 35.7% (5/14) of OB caregivers. OB is sponsored by the DOH, has DOT Supporters based at the clinic, has access to more training, is staffed by caregivers with more skills and capacity, is considered by at least one DOH employee as "part of the Government" and receives more overall support from both Government and the clinic. Despite all of these advantages, *OB caregivers as a whole find the clinic harder to work with than OA caregivers*. Having a higher degree of informality – in other words being *more* informal – has little (and possibly a positive impact) on caregivers' perception of the clinic and its role in making their job easier.

It is clear that degrees of informality have a distinct impact on the operation and experiences of HBC organisations. This is, in many ways, an obvious point. This study's findings confirm that unsponsored HBC organisations are less connected and work in greater isolation to the formal health system than their sponsored counterparts. This is to be expected. What is unexpected, however, is the relative *lack* of impact that degrees of informality have on the experiences of sponsored and unsponsored HBC organisations in many ways. Once again, the findings point to major problems with the HBC system in South Africa as a whole.

Despite the greater isolation of OA, its experience with many of the key micro-level issues discussed in Chapter IV are the same (or at least similar) to that of OB. Both organisations report a lack of communication, frustration with queuing and a generally negative outlook of the relationship with the clinic. The similarity of the responses from OA and OB make the discrepancy between caregiver and nurse responses even more striking. Why are caregivers (for the most part) having similar experiences and feelings while caregiver and nurse perceptions are so dramatically far apart? There is, of course, no 'correct' answer to this question, but part of the problem is certainly linked to the structural, macro-level challenges identified earlier.

Successful systems are not reliant on individual personalities and decisions. Individual actions are certainly necessary for any system to work properly, but the key to success is mechanisms, procedures and structural arrangements. The similarities in the experiences of OA and OB reveal a lack of these key factors in South Africa's HBC system. If sponsored organisations were experiencing few problems in their relationship with local clinics, while unsponsored organisations were having a wide variety of challenges, this would point to the fact that degrees of informality were the primary factor in explaining the effectiveness or ineffectiveness of different HBC organisations. In other words, the structural foundation would be in place, and the main challenge would be to bring unsponsored organisations further into the fold. The relatively similar experiences of OA and OB (especially in regards to the fact that a majority of both organisations believe the clinic makes their job harder) reveals something very different. The findings from the study suggest that the degree of informality is *not* the primary factor in explaining the experiences of HBC organisations. Instead, it seems that the essential aspect is the foundation itself. Structural problems – representated in a lack of systems, highly divergent perceptions across the informal/formal divide and struggling health workers – are creating widespread difficulties. In this environment, a higher degree of informality is certainly a burden on an HBC organisation such as OA, but the central challenge is the system's fundamentals, not the simple matter of receiving Government funds and support.

Chapter VI
Discussion

The findings of this study provide a considerable amount of information about the relationship between the participating clinics and HBC organisations. The findings also create many questions about the state of this relationship. This chapter will attempt to elaborate on the findings and analysis thus far. It will do so by linking the data to some of the themes discussed in Chapter II, as well as using the three original research questions as a guide.

The Nature of the Relationship between Clinics and HBC Organisations

As noted in Chapter II, there is an undeniable level of co-dependency between the formal and informal economic and/or health sectors. This co-dependency can be described in two primary ways: benign or exploitative.

The findings from the study tend towards the exploitative. Caregivers provide by all accounts an essential service for the clinics and the public health sector as a whole. They visit patients in their homes, providing valuable follow-up that directly leads to greater medication adherence, lower defaulter rates and further ‘reach’ for the South African healthcare system. This service simultaneously alleviates the burden on the admittedly overstretched public health system by reducing unnecessary clinic and/or hospital visits. In addition, many caregivers are actually based at clinics, providing formal health care services (like VCT and DOT). These caregivers are, with the exception of pay and benefits, fulfilling the role of a DOH employee.

All of these services and benefits are accrued by the state nearly free of charge. Unsponsored HBC organisations do not receive any funding (even though they are registered and allowed to operate by the Government). Sponsored organisations receive minimal funding to operate, which leads to lack of protective equipment, supplies and transport. Even caregivers who are supposed to receive a monthly stipend sometimes go months with no pay, reducing them to pure, Government volunteers with no social protection. Furthermore, they operate in the most difficult parts of the country, with weak infrastructure, poor health and education services, high HIV/AIDS and TB burdens and a host of other social problems. The situation clearly reflects Meagher’s (1995) analysis of informal-formal linkages as “an attempt by [the] formal sector . . . acting with the complicity of the state, to reduce wage costs and enhance flexibility by making use of unprotected workers in the informal sector” (260). Similarly, it demonstrates Hunter’s (2006) argument that Government is shifting the burden of care to communities without shifting the necessary financial resources.

The findings of the study provide further support for an exploitative analysis of the clinic-HBC relationship. While actors within the formal health sector are overwhelmingly positive about the relationship, caregivers are largely negative. Nurses and DOH employees note that their jobs would be near impossible without the assistance of caregivers, whereas the majority of the caregivers believe their work is made harder by the clinics. Furthermore, there is a distinct desire by caregivers to become formal Government employees. 33.3% (5/15) of OB caregivers specifically noted that they should become DOH employees, with full salaries and benefits, while the remaining caregivers at least alluded to this desire.

> *"[Government] must employ home-based caregivers because obviously it needs us and we do need to work with the patients but we can't if we're also hungry."*
>
> - Refiloe Mothabela, OB caregiver

> *"If the Government cared for [caregivers], they are not supposed to get stipends, they're supposed to get salary."*
>
> - Dimakatso Selebe, OB caregiver

66.6% (4/6) of clinic nurses agreed with this sentiment, believing that employing caregivers would be a step in the right direction (the remaining nurses only noted that the stipend was too low, but did not go as far as to suggest full employment). None of the DOH employees believed employment was feasible, although all of them noted that the stipend level was too low and generally unfair.

Undoubtedly, there is a case to be made that the relationship between the clinics and HBC organisations is an exploitative one. Looking a bit deeper below the surface, however, reveals that there are also benign aspects to this formal/informal partnership. The dependence of the formal sector on the informal is undeniable – clinics' reliance on caregivers to provide adequate services and increase effectiveness was noted repeatedly by nurses and DOH employees. The question, therefore, is if caregivers accrue any benefits from their interaction with the formal health sector.

The answer, it seems, is that they do. A number of caregivers – both from OA and OB – noted the importance of the clinics in their work. Nurses at the clinic are the closest health professionals in the community, and they are called upon often for assistance. During emergencies, caregivers rush patients to the clinic before being referred to hospital. Essential medication for patients is provided by the formal health sector (sometimes directly to patients and sometimes through HBC organisations). Nurses and caregivers work closely together during community awareness campaigns. In a few cases, caregivers even noted that they went to nurses for advice and support during difficult challenges.

Beyond this day-to-day support, there are other advantages that caregivers receive from the formal sector. The first is recognition. Although caregivers are not considered health professionals and attempts to organise them (and other informal workers for that matter) have been notoriously difficult (see Munakamwe 2008), caregivers are recognised by nearly all stakeholders as an integral part of the South African healthcare system. Despite the existence of negative attitudes and experiences, few would argue that the contributions of HBC organisations around the country are not extremely valuable. Unlike informal economic actors – which are often looked down upon and treated with suspicion – caregivers hold a relatively exalted place in the healthcare community.

Second, although caregivers are, by definition, informal health workers, their links with the formal health sector accord them with some degree of formalisation. Both sponsored and unsponsored organisations are officially registered entities with the Government, which provides at least the opportunity to access funding (either from Government or through applications to independent funders). In addition, sponsored organisations have access to Government-approved trainings, which provide caregivers with more formal health-related skills (unsponsored organisations do not benefit in this way).

Finally, one of the central benefits is the Government stipend. For sponsored organisations, access to a stipend not only helps in provision of better quality care to PLWHAs and other patients, but it also improves the livelihoods of caregivers and their families. Although it represents a much less significant benefit, even unsponsored organisations sometimes receive Government support through volunteer work as part of awareness campaigns in their communities.

It is beyond the scope of this study to make any pronouncements on the nature of the relationship between nurses and caregivers, or the formal and informal health sectors as a whole. In fact, it would be nearly impossible to make any sort of definitive statement in this regard. As the findings reveal, there are benign and exploitative aspects of the relationship, which influence both effectiveness and impact. The more important questions, however, are related to the key factors of the HBC-clinic relationship, the impact of the degrees of informality on this relationship and the best way forward to improve the HBC system in South Africa. These are the questions with which this research is primarily concerned.

What are the primary factors that influence the relationship between HBC organisations and local clinics?

The findings of the study reveal a number of key factors that have a strong influence on the relationship between HBC organisations and clinics. Although by no means an exhaustive list, these key factors are trust, training, communication, systems and cost.

Trust

For a working relationship – or any relationship for that matter – to work, trust must be in place. All stakeholders within the relationship must trust that not only are their counterparts a necessary contributor to the task at hand, but also that they will execute their duties in an effective and professional way. Despite many of the problems identified between nurses and caregivers in their relationship, there is general consensus that one side does trust the other to perform their duties. With the exception of a few concerns regarding confidentiality and monitoring, the vast majority of actors on both sides of the formal/informal divide trust that patients are being cared for in the best way possible given the situation and limited-resources.

As noted in Chapter IV, however, the study's findings around trust should be handled with a degree of skepticism. The data related to feelings of trust between caregivers and nurses is quite anomalous in comparison to the rest of the research. Trust between stakeholders may very well be strong (if this is the case, it is very encouraging), but the findings from this study alone are not enough to say so conclusively.

Training

As noted in Chapter II, the DOH (2004) asserts that "when properly trained and supported, [caregivers] can play a major role in closing the gap between professional services and patients" (8). This statement is certainly true, but the facts on the ground point to two major problems. First, although caregivers are receiving a great deal of training, this training is divided in a highly unequal manner. Unsponsored organisations are operating with little to no formal training, and more importantly they have almost no access to this training.

The second problem also relates to who is not receiving training. Great focus and energy is put towards training home-based caregivers in many of the skills necessary to provide services to the community. At the same time, caregivers are told to collaborate and work closely with clinics in their areas of operation. The positive impact of these efforts, however, is greatly reduced because formal health sector employees are largely left out of the equation. A majority of participating caregivers have received training on how they are supposed to work with clinics and nurses, but only one nurse received training on the same topic. It is no coincidence that the caregivers who have received this training all reported that what they learned does not translate into practice on the ground. If only one half of a working partnership is taught how the partnership is supposed to work, there is little chance for success. The untrained partner will not only fail to implement the appropriate system, but they will not even know that this is the system meant to be in place.

Communication

When asked what they believed was the biggest challenge regarding their relationship with the clinic, a number of caregivers from both OA and OB answered "communication." Similarly, a majority of the nurses at CY noted that communication was their biggest challenge. Communication problems can be placed into two broad categories: attitude and structural.

Attitude seems to be a problem on all sides of the formal/informal divide. Friedman et al (2007) report that a positive view of HBC by formal clinic staff has a beneficial impact on the efficacy of programmes. In this study, caregivers, nurses and DOH employees all noted that attitudes had a negative impact on the working relationship and the success of HBC. One DOH employee even noted that this was *the* biggest problem related to the programme. Negative attitudes are expressed in all directions. Caregivers feel that nurses do not give them the proper respect and vice versa; DOH employees must deal with personnel and communication problems from both sides. Negative attitudes, unsurprisingly, poison the relationship between clinics and HBC organisations. As one DOH employee put it, “you’ll find that there’s that silent war between the [HBC organisation] and the clinic.” Communication between these two stakeholders is already generally weak, and negative attitudes only create further deterioration.

Communication problems that fall within the structural category refer to the lack of regular, formal communication between clinics and HBC organisations. Nurses and caregivers are tasked to work together to improve health outcomes for PLWHAs and other ill people in the community. Despite the closeness of their working relationship in theory, there is no form of required communication between the partners. There are no written reports providing the relevant activities, accomplishments, statistics and challenges relating to their work together. There is also no requirement to hold regular meetings – either between the facility managers and HBC directors or full staff meetings – to discuss these issues. Any meetings or communication that does occur is informal and based on the individual choices of actors, not structured communication channels and/or systems. All of this stands in stark contrast to the communication and reporting that occurs between HBC organisations or clinics and the DOH. Both are required to send multiple reports and have, at minimum, monthly communication with the Government. The working relationship between HBC organisations and clinics is unlikely to develop positively if there are no directives or systems from Government to ensure they communicate regularly.

Systems

In addition to inadequate communication, the relationship between HBC organisations and clinics is characterised by an almost complete lack of systems. This is evident in many ways – not the least of which is communication – but two other problem areas are queuing and referrals. On the surface, the need for caregivers to queue with their patients seems a harmless requirement. Despite this, the most frequent response for caregivers as to what is the biggest challenge with the clinic was being forced to queue. This problem was made even more severe by the fact that a number of caregivers had received training that explicitly stated they were *not* required to queue. Whether they are purely volunteering or receiving a small stipend, caregivers are also doing a job in which they feel a great sense of pride. When they are forced to use a large portion of their time waiting in a queue with their patients, they feel less effective and efficient and become frustrated. Ultimately, this may lead to stronger feelings of exploitation and disempowerment.

The issue of queuing is also directly related to training and communication. As noted in Chapters IV and V, 100% of caregivers said they were required to queue while all but one of the nurses confirmed this. The remaining 5 nurses all asserted that caregivers were allowed to skip the queue in order to save valuable time. Obviously, there is a communication and training gap in this regard. Somewhere along the line, the proper messages and instructions are not being funneled down to the right people. This is not a failure of individuals, but is instead a failure of systems. Well-functioning systems have not been developed to ensure that programmes and policy are properly implemented on the ground.

The lack of a unified or structured referral system is another serious problem, especially given the focus placed on it by countless scholars and Government. Any multi-tiered healthcare system relies on referrals to help facilitate patients' movement. It is an essential mode of communication and information sharing. Despite the proclamations about the centrality of referrals to the HBC programme, there is an almost complete lack of implementation on the ground. Referral forms are rarely, if ever, used by both sides of the formal/informal divide. Within organisations, the variety of referral experiences is staggering. The fragmented, informal nature of referrals leads to confusion, duplication and wasted time and energy for all stakeholders. This fact was recognised by nearly every participant, noting that a standardised referral system, with standardised forms, would help to improve their work greatly. Once again, this is not an individual issue, but a larger, structural one. It is not enough for people to implement efficient referral systems in isolated pockets. Broader, systematic efforts are needed to create a well-functioning system that is implemented across the national (or provincial) spectrum.

Cost

When one takes a look at the relationship between HBC organisations and clinics, as well as the HBC programme in general, cost is clearly one of the most important influencing factors. Nearly every issue identified by participants in this study can be connected – either directly or indirectly – to cost. Stipends, supplies, systems, training, communication – all of these have cost implications.

The cost of HBC programmes has been debated in scholarly circles. One school of thought argues that HBC is much cheaper than formal healthcare, which is precisely why it is so attractive to resource-constrained Governments. Hunter (2006) claims that HBC is a cost-effective alternative for care of PLWHAs, while Kganakga (2003) asserts that HBC can cost as little as R50 per day. These arguments are challenged by another group, which argues that HBC is actually not as cheap as advertised. Hansen et al (1998) studied the cost-efficiency and effectiveness of HBC in Zimbabwe and found that 78-90% of spending went towards personnel and transport and 56-75% of spending did not directly benefit patients. The same study found that a home visit in Zimbabwe and Zambia cost the same as one to 3.5 days of inpatient care through hospitalisation. These latter findings suggest that HBC may not be as cost-effective as some scholars (and Governments) believe. There is at least some evidence to suggest that HBC is either just as, or perhaps more expensive than tertiary care, and that these costs are not utilised in the most efficient way possible.

Regardless of the actual costs of HBC, one fact remains clear. Inadequately funded HBC programmes will have limited impact and success (Friedman 2005; Friedman et al 2007). Government must recognise that for HBC to fulfill its potential, it needs to receive adequate resources and funds. This does not necessarily mean funding every HBC organisation in the country, but more creative strategies must be employed to ensure as many organisations as possible – whether sponsored or not – have access to training and supplies that will help them perform. More funding must also be allocated to developing systems and mechanisms to strengthen HBC in the country. This increased spending will not only improve the system as a whole, but will help to reduce the impact of degrees of informality on different HBC organisations.

How does the degree of informality of HBC organisations affect the formal/informal relationship?

The findings of this study reveal that degrees of informality do not impact the formal/informal relationship across the board. Many of the internal operations of the organisations do not differ greatly and the services that these organisations provide are more or less the same. Perhaps most surprisingly, the experience of some of the key factors identified above is not drastically different for sponsored and unsponsored organisations. The majority of caregivers at both OA and OB were never introduced to clinic staff (an important first step in building channels of communication), all caregivers in both organisations are required to queue with their patients at the clinic and there are similar levels of trust displayed towards nurses for both OA and OB caregivers. As noted, the majority of caregivers at both organisations believe that the clinic makes their jobs harder at the end of the day as well.

Despite these similarities, the ways in which the degree of informality *does* have an impact on the relationship are also crucial. As noted in Chapter V, some of these are obvious. There is less communication, weaker (or non-existent) referral systems, less training and greater isolation. Caregivers at OA are less likely to report that teaching their patients about health and healthy living is a central part of their work. The study also found that in most cases, Government makes a conscious decision *not* to utilise unsponsored HBC organisations except for activities like awareness campaigns. This decision is made due to concerns over control, monitoring, skills and capacity. At the ground level, a higher degree of informality leads to a relationship with the clinic that borders on non-existent. Both caregivers and nurses confirmed that there is minimal contact between OA and CY, even more so now that caregivers from another HBC organisation are placed at the clinic.

In the final analysis, a higher degree of informality has a negative impact on the ability of an HBC organisation (and its caregivers) to provide services to the community. This is not to say that the available services are ineffective or deficient, but the greater isolation experienced by unsponsored organisations undoubtedly has a negative impact. The issue moving forward, therefore, is how to close the gap between sponsored and unsponsored organisations. How can more informal organisations be brought closer to Government, even if making them fully sponsored is not possible?

The literature on the linkages between the informal and formal economic sectors provides some guidance. First, there must be recognition that the two sectors can benefit from each other. This is a central tenet of the benign school of thought. Throughout the literature, there are constant reminders of the ways in which informal and formal activities can bolster and support one another (e.g., Henry 1987; Nugent and Swaminathan 2006; Gaughn & Ferman 1987; Lomnitz 1988; Hart 2005). Second, creative strategies for inclusion need to be designed. In their recommendations for inclusion of the informal sector, Guha-Khasnobis, Kanbur and Ostrom (2006) argue that one of the key steps is to place formal structures (in this case the clinic) as close as possible to informal structures (HBC organisations), both institutionally and geographically. In his recommendations for the same purpose, Tokman (2007) stresses the importance of clearly defining the obligations of all parties. Perhaps most importantly, stakeholders on both sides of the formal/informal divide need to be capacitated to understand the relevant policy and implement it.

These recommendations can be implemented and achieved (at least partly) through training, systems development, better communication and the building of trust. Most importantly (in relation to degrees of informality), *none* of these steps is overly expensive and all of them can be designed with and applied to unsponsored and sponsored HBC organisations alike. The relationship between HBC organisations and the Government and/or clinics does not need to be financial in order to be strong. As a first step, Government can make a greater effort in bringing unsponsored organisations to the table when designing interventions or changes to the system. Of course, funding is ‘first prize’ for any HBC organisation, but by simply including unsponsored organisations in the decision-making and negotiation process, great improvements can be made. For organisations like OA, there is deep sense of being discriminated against by Government. They perform a vital service to the community – and thus to the country – but still remain excluded from nearly all activities or communication.

If Government and the clinics make a concerted effort to include unsponsored organisations more fully, this would have a great impact on the overall effectiveness of HBC in South Africa. With a relatively minimal increase in funding (mostly for added training costs), the DOH could drastically improve their reach and coverage. At the same time, they could be confident that the care being provided by *all* HBC organisations was of a certain minimum quality. Finally, this would increase overall cohesion and participation in the healthcare system by bringing a greater number of informal actors (i.e., caregivers) under the Government umbrella.

There is one crucial caveat. The integration of unsponsored HBC organisations will only be successful and effective if the HBC system as a whole is successful and effective. In order to make this a reality, the structural challenges to the system must be confronted, along with building off of practices that are already working effectively.

What are the challenges and the most effective practices related to the partnership between HBC organisations and clinics?

It is clear that there are a number of problems concerning the HBC programme in South Africa, as well as its connections to the formal healthcare system. A number of these problems can be considered ‘micro-problems,’ as they concern the intricacies of how the relationship between HBC organisations and clinics actually ‘work.’ These micro-problems can be found within the 5 key influencing factors identified earlier in this chapter. Outside of these issues, however, are a number of ‘macro-level’ problems that are of concern. These larger issues speak to weaknesses in the foundation of the system, not the specific activities and tactics employed to implement the HBC programme.

One macro-problem concerns collaboration and integration. The importance of collaboration and integration between HBC and the formal healthcare system is unquestionable. There is no doubt that informal health strategies like HBC can only be successful if they are integrated into the larger healthcare system. Likewise, given the limited resources available to the South African health sector, informal activities like HBC are vital in ‘filling the gaps’ left by formal structures. Despite these facts, there seems to be very little collaboration, partnership and integration *actually* happening.

In their book on community care in the United Kingdom, Means and Smith (1994) note that "‘exhortations to organisations, professionals and other producer interests to work together more closely and effectively litter the policy landscape’ yet the reality is ‘all too often a jumble of services fractionalised by professional, cultural and organisational boundaries and by tiers of governance" (139-140, quoting Webb 1991). In similar fashion, Campbell and Foulis (2004) state the following about HBC in sub-Saharan Africa:

> The most striking example . . . in the literature on HBC is the frequency with which authors refer to the importance of partnerships between local communities and other actors and agencies . . . However, there is little attention . . . given to the complexities of implementing collaborative partnerships between constituencies who may have very different needs and interests. (10)

Finally, Campbell et al (2008) write that there are three aspects of the environment that impact the ability of communities to respond to the HIV/AIDS epidemic. The first two, the material and symbolic contexts, have been studied at length. The third is the institutional context, which "refers to the extent to which public sector, private sector and civil society networks are supportive of people with AIDS and the quality of collaboration amongst these networks to enhance the cumulative effect of their individual efforts to promote effective AIDS-management" (508). This aspect has been the focus of very little academic research.

The three statements above speak to the lack of attention given to actually making collaboration, partnership and integration ‘work’ (not only in the developing world, but the developed one as well). Instead, fluffy statements – whether policy or otherwise – are released insisting that these things are necessary and vital, with little action or strategy to back them up. This pattern is clearly evident in relation to HBC. Nearly every document one can read about HBC discusses the importance of integration and cooperation between different stakeholders, especially informal caregivers and formal staff like clinic nurses. This has frequently failed to translate in practice. Instead, as this study has revealed, the South African HBC programme is characterised by a *lack* of collaboration and integration between the informal and formal health sectors. There are examples of good *individual* relationships, but these are overshadowed by the fragmentation and ineffectiveness of weak, poorly implemented systems. Much more time, effort and funding must be put towards building the necessary structures to make HBC effective in South Africa.

First, this means identifying the barriers to integration and partnership. Means and Smith (1994) list 6 key factors that predispose organisations to collaborate. These are homogeneity between organisations, the ability to agree on roles and responsibilities, network awareness, the existence of mutual benefits, the absence of alternative resources and trust. In the case of HBC in South Africa, some of these factors are already present. The mutual benefits for all stakeholders are obvious, alternative strategies are unlikely given limited resources and trust may be relatively strong. Without neglecting these factors, greater attention should be paid to the first three. There are commonalities between HBC organisations and clinics, not the least of which is the commitment to improve community health outcomes, but more places to 'build bridges' must be located. Greater clarity on roles and responsibilities would also be welcome, especially in regards to the thousands of unsponsored HBC organisations in the country. How do they 'fit' into the system and how can they be used and benefit the most? Lastly, much work remains on building network awareness and maximising the ability of all stakeholders to utilise existing health networks effectively.

Second, this means designing new incentive strategies. Padarath, Searle and Esu-Williams (2006) contend that there are few incentives for the formal and informal health sectors to work together. Professional health employees do not gain anything tangible from working with caregivers. Their job may become easier, and the statistics submitted by the clinic may improve, but these things may not be concrete enough to encourage real collaboration and partnership. Instead, Government could look at the possibility of introducing both negative and positive incentives. Negative incentives would include punishment or censure for not holding required monthly meetings with HBC directors, not allowing caregivers to skip the queue (if this is agreed upon) and the like. Positive incentives could include public recognition for clinics that work exceptionally closely with local caregivers (both sponsored and unsponsored) *and* perform well. In some cases, these accomplishments could even be linked to bonuses or other job-related rewards.

Third and finally, this means bringing all stakeholders around the same table, not only to design interventions and plans, but also to implement them. Policies and strategies do not translate into successful action by themselves. It takes rigorous planning and training, as well as hard work. In this regard, *all* HBC stakeholders still have a long way to go.

Another macro-problem related to the HBC programme is a lack of capacity. It has been well-documented that South Africa has an overburdened public healthcare system. Campbell et al (2008) note that clinics are overcrowded, understaffed and lacking skills, while Padarath, Searle and Esu-Williams (2006) assert that there are serious human resource shortages at *all* levels of the healthcare system. This is confirmed by Schneider, Barron and Fonn (2007) who claim that there was a shortage of approximately 46,000 trained health personnel in 2005. Finally, Steinberg (2008) provides a clear description of the challenges facing under-resourced clinics in his book about ART and HIV/AIDS in Lusikisiki, Eastern Cape.

In this context, it is not helpful to blame the problems of the HBC system on attitudes. Although negative attitudes on both sides of the divide certainly have an impact, this answer is simply too easy. The key issue is *why* attitudes are so bad. In addition to all of the micro- and macro-problems listed here, understaffing and poor working conditions are a central factor as well.

These human resource problems were evident at participating clinics and HBC organisations in this study, regardless of how big or small they were. All participants were overworked and overburdened, tasked with completing difficult, draining work without the necessary resources or support. It goes without saying that if the system does not have the appropriate human resources to do the job, even the most well-designed systems and policies will fail to bring about the desired outcomes. Fully capacitated staff – whether informal home-based caregivers, formal nurses or any other role player – must form the foundation and backbone of any healthcare system. South Africa is no exception.

The issue of payment to caregivers and provision of supplies is another macro-problem related to capacity. Both the informal and formal health sectors suffer from understaffing and lack of capacity. In the case of caregivers, weak human capacity is made far worse by late or delayed payments. Sponsored HBC organisations are required to perform certain tasks in order to receive their funding, but the payment system is designed in such a way that even if these tasks are performed correctly and on-time, funding is not guaranteed to come as it should. This overly bureaucratised payment system is a structural issue. It is crucial that it is made more efficient and effective in order to maintain morale among the caregiver force, thus strengthening the HBC system as a whole.

The issue of supplies affects both caregivers and nurses alike. Both HBC organisations and clinics are poorly supplied with medicine and equipment. The combination of weak human resources and under-supply of vital materials is a deadly one – both literally and figuratively – for the entire healthcare system. Even if staff numbers were sufficient and all the necessary systems were working, lack of supplies would hamper positive health outcomes. The consistent, adequate provision of supplies is both a cost and a structural issue. More funding needs to be allocated, but there must also be a focus on building supply chain systems that can ensure both clinics and HBC organisations have the materials they need. This will not only improve healthcare functioning in the country, but will also reduce tension between clinics and HBC organisations as they fight over and protect their scarce resources.

A final macro-problem is directly connected to the effective practices related to HBC and the formal healthcare system (discussed below). This is the ‘individualisation’ of the programme. Friedman et al (2007) assert that Government support is not built into the HBC system in South Africa. Instead, success is overly dependent on individual action and what the authors call “champions.” Although the ‘champions’ Friedman et al refer to are HBC directors and programme managers, the same could be said for facility managers or nurses who work with HBC organisations. Those that build strong partnerships with caregivers and put well-functioning systems in place do so not because it is built into the Government's HBC policy or because they receive instructions, but instead because they personally realise the benefits of this relationship and therefore do their best to capitalise on it. This strategy may work in isolated cases, but it is certainly not the best way to build a coherent, national system of integrated HBC.

The problems related to individualisation are made even more acute due to the frequent rotation of nurses at some clinics. If the entire clinic staff changes every year or two (as it does in CY), even the most effective practices implemented by a given facility manager or nurse are by definition temporary. When the new staff enters, new systems, policies and strategies (around communication, meeting, queuing, etc.) must be built. By contrast, if systems were permanently in place, staff would simply be responsible for implementing the system, rather than re-inventing it with each new cycle.

This study revealed very few effective practices, even of the individualised kind. This is not to say that the relationships between participating caregivers and nurses were completely ineffective or futile, simply that the relationships studied were characterised by high degrees of fragmentation and confusion. In most cases, it seemed that both caregivers and nurses were 'going it alone,' attempting to navigate their way through the partnership on a personal level, rather than an organisational or structural one. This was most clearly demonstrated in experiences with referrals, but could be seen throughout the study.

There are, however, a few places where attempts are being made to implement practices that may have the potential to improve the working relationship between clinics and HBC organisations. The first is the monthly NGO Forum meeting between the DOH and HBC organisations (and other NGOs) within a given area. This is a valuable space for stakeholders from Government and the informal health sector to discuss challenges and issues related to their work. The missing ingredient, of course, is clinic staff. If clinic staff participated in these NGO forum meetings (each clinic could have a designated representative), it would be an ideal place to start bridging the communication gap between caregivers and nurses.

The second effective practice is the decision by the DOH to place caregivers at clinics (although the jury is still out because the system is very new). Both OB caregivers who were based at CY claimed that their relationship with the clinic was very good. In addition, they both received informal training and felt valued by the clinic staff. It seems likely that this new strategy will not only improve communication between clinics and HBC organisations, but will also help to build a stronger relationship between the two in general. There are, however, two challenges. First, strategies need to be designed and implemented to ensure that the positive experiences of caregivers based at the clinic 'trickle down' to other caregivers at the organisation. One way may be to rotate the clinic-based caregivers, a strategy that is being employed at CX (although one nurse complained that this leads to a lack of stability and consistency). Second, the DOH must ensure that placing organisations at the clinic does not lead to the exclusion of other, unsponsored caregivers. It is important that all HBC organisations in a catchment area have access to and a relationship with the clinic, even if they do not receive Government funding.

Although this study found few entrenched effective practices, it did reveal a strong commitment on the part of Government to improve the HBC programme. All four DOH employees who participated in the study were open about the limitations and weaknesses of the present HBC strategy, but all of them were also full of ideas and energy about how to change this. These interviews revealed a real sense that Government is learning from its mistakes and moving in the right direction. This, combined with the obvious desire of both caregivers and nurses to get their relationship working right, is highly encouraging.

Chapter VII
Recommendations & Conclusion

HBC has been shown to reduce hospitalisation rates, lessen the burden on the PHC system, decrease health-related costs to poor families, reduce stigma, increase awareness, improve treatment adherence and strengthen monitoring of patients. In short, the benefits of HBC and its potential to strengthen the South African healthcare system are clear.

The ways in which HBC should and can be successfully integrated into the formal healthcare system, however, are less clear. This is the great challenge that now lies before the Government and communities. It is made even more urgent by the continued problems associated with health in South Africa. Since 1994, despite the unification of the healthcare system and the renewed focus on PHC, many of the same difficulties remain. A brief chronological analysis clearly demonstrates this fact:

- From 1996-2003, the number of doctors and nurses in South African provincial health structures (such as clinics) declined by 24% and 16%, respectively (Schnedier, Barron & Fonn 2007);
- In 2000, South Africa ranked 175th out of 191 countries in healthcare system performance (*Ibid* 2007);
- In 2003, 62% of health spending was in the private sector, reaching only 20% of the population (McIntyre et al 2006); and
- In 2004, 59% of total health expenditure was spent in the private sector, benefiting only 16% of the population (Schneider, Barron & Fonn 2007).

This persistent inequality, lack of capacity and underperformance must be seen within the context of HIV/AIDS. According to Shisana (2002), public health facilities are groaning under the weight of HIV/AIDS. The number of HIV/AIDS-related admissions is increasing at every level of the healthcare system, non-HIV/AIDS patients are being “crowded out” by those infected, average bed occupancy rates are around 90% for district and public hospitals (compared to 50% for their private counterparts) and nearly 80% of health facilities studied expressed a need for additional staff to cope with HIV/AIDS. At the same time, multi-drug resistant and extreme-drug resistant TB are spreading, further complicating the treatment of both diseases. Services like HBC, it seems, are needed now as never before.

This study has revealed that despite its central role in South Africa’s healthcare system, HBC’s integration with formal facilities like clinics is far from complete. There is still a yawning divide between the informal and formal sectors, even as they continue to work closely on a daily basis. A number of key factors that would help to strengthen relations between caregivers and clinic staff have been identified. Trust, training, communication, systems development and cost are all central to the success of HBC and its working relationship with the formal health sector.

Unfortunately, the study also revealed that success seems widespread in only one of these key categories – trust – and even this finding must be treated with a degree of skepticism.

Further below the surface, degrees of informality also have a profound impact on the performance and contributions of HBC organisations. Within the informal health sector, there are two distinct categories (one might even call them classes). Whereas a large number of HBC organisations are sponsored by the DOH, perhaps an even larger number operate with no Government funding or support. These unsponsored organisations provide essential home-based services to PLWHAs and other ill people, especially in poor communities, but they do so largely in isolation. Their near total disengagement from the formal health sector is troubling for two reasons. First, they are largely unregulated and unmonitored. Their caregivers receive less training; their activities and contributions go largely unrecorded. Second, the interaction of unsponsored HBC organisations and clinics are just as problematic and frustrating as their sponsored counterparts. Both groups report a lack of communication, weak referral systems, an inordinate amount of time waiting in queues and a generally difficult relationship. Despite all the benefits sponsored organisations receive, these do not translate into a better clinic-HBC partnership.

Finally, the entire clinic-HBC relationship (whether regarding sponsored or unsponsored organisations) is characterised by a lack of systems that would allow it to operate smoothly. Payment and supply structures are failing to deliver. Individual caregivers and nurses have their own procedures and arrangements with each other, designed and implemented on the job with little or no official instruction from the DOH. There is much talk about coordination, cooperation and collaboration, but a striking lack of systematic efforts to make this happen in practice. With some exceptions, HBC organisations and clinics are working together in what can only be described as a haphazard fashion.

This study, however, should not be viewed as one of pessimism and condemnation. Its primary objective is not to attack the shortcomings of HBC in South Africa, but instead to provide constructive criticism that can point the framers of policy design and implementation in a more productive direction. The first step in any improvement project is to identify the gaps and weaknesses within existing circumstances. It is irresponsible to stop there. One must move beyond the relatively easy task of pointing out problems towards the more challenging undertaking of putting forth recommendations.

Through the findings of this study, a number of key recommendations can be put forth. These recommendations fall into three general categories: Research, Bridging the Divide and Getting Systems Right.

Research

The following recommendations refer to possible next steps for further research (either academic or policy) into this topic:

- As noted in Chapter III, the primary limitation of this study is its scope. By studying only two HBC organisations and two clinics, the wider applicability of the findings is far from assured. More research of this kind should be carried out reaching a greater number of stakeholders. This research should focus on both urban and rural HBC-clinic relationships, as well as a varying mixture of sponsored and unsponsored HBC organisations. This will provide invaluable information on the dynamics of this potentially powerful partnership in a wide variety of contexts, therefore strengthening the ability of policymakers and practitioners to devise more effective strategies.
- Another identified weakness of the study was the choice not to include the voices of PLWHAs and TB sufferers. Widening the scope of research to discover and understand the opinions of patients would be a positive development. Who would patients rather work with – nurses or caregivers? Why? How do HBC and/or PHC interact with stigma at the community level? Are both services seen by patients as essential to their well-being and health? How does the failure of clinics and HBC organisations to work together in a systematic manner affect quality of care, if at all? These are just some of the questions that need to be answered in order to gain a better understanding of the system.

Bridging the Divide

There are two meanings to ‘Bridging the Divide’ in this context. First, the gap between sponsored and unsponsored HBC organisations should be narrowed; second, the divide between the formal and informal health sectors must be bridged.

Greater efforts to bring unsponsored HBC organisations ‘into the fold’ must be made. Allowing these organisations to operate in isolation from the formal health sector is not advisable. Limited resources for healthcare in South Africa are and always will be a major constraint, but creative, cost-effective strategies *are* possible.

- It makes little sense for Government to register HBC organisations and approve their operation (through the DoSD), but then provide them with no training to do the job as effectively as possible. Even if it is not feasible for Government to sponsor every HBC organisation, greater effort needs to be put towards ensuring that unsponsored organisations at the very least have access to Government trainings. This will not only help them do their jobs better, but will also make them feel more a “part of Government.” It will increase HBC capacity, quality of care in communities and reduce feelings of discrimination.
- Unsponsored organisations should be included fully in HBC policy design. They need to be brought to the table as a primary stakeholder throughout this process. Even if they do not

receive Government funding, they continue to perform services in communities. They have valuable information and a unique perspective on the country's HBC system. This experience and expertise should be tapped by Government to improve policy design and implementation.

- Unsponsored organisations must have a relationship with their local clinic. This will require greater coordination between the DoSD (which registers HBC organisations) and the DOH (which runs the clinics), but it is absolutely necessary. Clinics should be provided with a list of all registered HBC organisations in their catchment area – whether sponsored or unsponsored. Likewise, all registered HBC organisations should receive a joint letter of introduction from the DoSD and DOH to the local health facility with their registration certificate. This letter can then open the door to the facility to establish a relationship from the very beginning of operation.
- Even if there are sponsored caregivers based at a given clinic, space must be made for unsponsored caregivers to operate as well. This does note mean they too would be based at the clinic, but instead that they would be given the same privileges (e.g., skipping the queue, submitting a monthly report, attending regular meetings, etc.). At the very least, all caregivers should be known by the clinic staff so that they can operate publicly.

Bridging the divide between the formal and informal health sectors in general will be more complicated and, admittedly, more expensive. Still, given some of the negative sentiments expressed by caregivers throughout this study, greater strides should be made towards increasing recognition and protection for these workers.

- Making caregivers full Government employees may be fiscally unrealistic at this time. Short of this, Government should look instead into increasing social protection. This might include providing unemployment insurance for caregivers who no longer are able to work due to sickness or burn-out. Health and/or life insurance might also be provided. Caregivers generally work in some of the most difficult and dangerous environments in the country. Not only are they constantly exposed to potentially fatal diseases, but stigma and the public nature of their work often combine to create a threat of physical violence as well. Providing caregivers with insurance to cover them if the worst should happen would send a strong message that Government was doing what it could. Standardised contracts and job descriptions for both sponsored and unsponsored organisations (even if they provide the most minimal protection) would also help to make caregivers feel more recognised and valued in their work.
- There needs to be more potential for career advancement for caregivers. Several nurses and DOH employees noted that many caregivers (although not all) show great potential to become qualified health professionals. In a country with severe health personnel shortages, it seems that providing caregivers with opportunities to study further and become nurses (or even

doctors) would be a natural decision. Caregivers that are identified as having potential might be provided with bursaries to attend nursing colleges or other medical schools part-time while continuing to perform their duties. (Crucially, the identification and recruitment of these caregivers would be easier through closer relations between HBC organisations and clinics.)

- Each clinic should have a designated HBC contact person. In both participating clinics, caregivers worked closely with several nurses. Although this is acceptable, there should be one main point of contact between the facility and the organisation. This contact might be the facility manager, but given their other duties, a senior nurse could be given the responsibility. This contact person would be responsible for setting regular meetings, ensuring reporting is consistent and clear, dealing with personnel conflicts and challenges and guaranteeing that HBC policy is being implemented at the clinic.
- A representative from the clinic (ideally the contact person described above), should regularly attend NGO Forum meetings within their area of operation. Relying on the DOH to forward messages between HBC organisations and clinics is not the most efficient or effective way of ensuring all stakeholders are on the same page. If representatives from both sides of the formal/informal divide met in a shared, neutral space on a regular basis, communication and relationships would undoubtedly improve.
- The DOH at the district level should have an HBC coordinator. Currently, clinic coordinators at the department work with both clinic staff and caregivers. They meet with both regularly and in most cases act as a 'go-between.' Although all participating DOH employees showed a passion and appreciation for HBC organisations, it is clear that their primary responsibility is coordinating clinics. This is a full-time job in itself. Ensuring that 10-15 clinics are fully equipped and staff is fully trained is a demanding and time consuming affair. Given these demands, there is less time for representing the interests of HBC organisations, or communicating these interests at appropriate levels of the system. If each office had an HBC coordinator who worked alongside the HIV/AIDS and TB clinic coordinators, information would likely flow more freely through the system.
- Finally, the power of small changes should not be overlooked. A simple step, such giving caregivers access to clinic phones to call an ambulance in the case of an emergency, is both easy and possible. Small steps like this would go a long way in building a feeling of teamwork and collaboration across the formal/informal divide.

Getting Systems Right

Further research and bridging the divides within and between the informal and formal health sectors are necessary and urgent tasks. Given the right decisions and actions, there may eventually be no difference between the operation of sponsored and unsponsored organisations. Similarly, at some point all HBC organisations may enjoy greater social protection and opportunity. But if the actual system that brings stakeholders from both sides of the formal/informal divide together is malfunctioning, these improvements may very well fail to translate into better health outcomes. Great effort must be put towards getting integration and collaboration between HBC organisations and clinics working 'right.'

- Training is key. HBC training must be standardised and freely available to all caregivers. More importantly, training on how HBC is supposed to work in the country must be provided to all stakeholders. The tendency of Government to link the idea of HBC training exclusively to caregivers is problematic and must be revisited[30]. Caregivers *and* nurses should be required to attend comprehensive training on HBC policy and how this must translate into practice on the ground. This training should include modules on communication (e.g., introductions, meetings and reporting), referrals, queuing and attitude. Ideally, caregivers and nurses should attend together. In addition, these trainings should put extra emphasis on the importance of leadership. Facility managers and HBC directors must take more responsibility for ensuring HBC policy is being implemented correctly.
- The new HBC policy must include *directives* on how certain aspects of the HBC-clinic relationship will work. It is not enough to write a policy and hope that it will be put into practice on the ground. Both HBC organisations and clinics must be *required* to follow guidelines and approved practices and should be reprimanded if they do not. This should include an approved referral system (using approved referral forms), regular communication (at least monthly meetings and reports) and an agreement around queuing. It is difficult to overstate the impact that this would have on the system. Nearly every participant in this study provided one if not multiple complaints in relation to these three factors. If there was mutual understanding and cooperation here, the working relationship would be vastly improved.
- The Government must commit to increasing expenditure on HBC. Even with limited resources, it is possible to up spending substantially. This increased funding must be targeted in the following ways:
    - Increased supplies and protective equipment for HBC organisations. Although the DOH currently provides each sponsored organisation with a budget for the purchase of supplies, this is not a very cost-effective measure. Government benefits from economies of scale through its purchase of medical supplies and equipment for large numbers of clinics and hospitals. HBC organisations should be included in this purchasing. Beyond this, creative delivery systems must be designed. Delivering through clinics is a distinct possibility (although several nurses noted that this might be overly complicated).

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[30] One DOH employee did note that the Government is working on providing integrated training on the relationship with nurses and caregivers, but this is not happening yet.

  - Increasing the number of caregivers in each catchment area is important. It may be less complicated to only fund one HBC organisation per catchment area, but this does not mean that sponsored organisations cannot have a larger number of caregivers. In the informal settlements and other poor communities of South Africa, there are literally thousands of sick people suffering from diseases like HIV/AIDS and TB. Yet the DOH only sponsors a small number of caregivers (usually between 10-25). Even if each of these caregivers reaches 15 houses a week, the number of patients contacted is far less than the number of patients left untouched by HBC services (and probably formal health services as well).
  - Increasing the stipend would go a long way towards improving the relationship between the informal and formal health sectors. It would help caregivers to feel more valued, but more importantly it would help them to improve their own lives and well-being, thus allowing them to perform at a higher level. As many participating caregivers noted, it is difficult to do a good job when you are hungry. Increasing the stipend would have far-reaching impact.
  - Short of increasing the stipend, urgent attention needs to be given to the inconsistent payment of stipends. Whether HBC organisations or Government is at fault, it is a major source of frustration for caregivers. Systems need to be designed and implemented to ensure that the minimal amount received by caregivers comes each and every month (as long as requirements are fulfilled).
- There needs to be more attention paid to monitoring and evaluation of the HBC programme. This includes monitoring the actual quality of care provided by HBC organisations, but equally important it involves monitoring the relationship between clinics and these organisations. DOH employees must make frequent trips to both clinics and HBC headquarters to ensure that systems are being implemented properly and consistently.

As with any list of recommendations, these are easier said than done. Improving the HBC system in South Africa will surely take sustained, concerted commitment and effort. Perhaps most encouragingly, however, is the fact that many of the recommendations put forward are not overly expensive (with the exception of a few). Improving referral systems, strengthening communication channels and broadening the reach of training programmes are by no means free. But unlike very costly undertakings such as mass recruitment and hiring to fill staffing shortfalls at clinics and hospitals, they do not require ‘breaking the bank.’ Cost and budget will always be a (if not the) primary concern and/or obstacle, but limited resources are not and cannot be an excuse for inaction.

For the foreseeable future, the South African healthcare system will continue to battle with a number of difficult challenges. Inequality of health spending, health personnel shortages at multiple levels and limited budgets will take generations to put right. Similarly, the HIV/AIDS epidemic –

running alongside the scourge of TB – will continue to decimate the population for decades. In this environment, the importance and potential of HBC is undeniable. It has the ability not only to lessen the burden on the formal healthcare system, but also to improve the well-being of PLWHAs and other patients in its own right. In turn, this will lead to better developmental outcomes for the country as a whole.

In his recent book on HIV/AIDS in South Africa, Steinberg (2008) describes the importance of clinic staff and caregivers in fighting the disease. He writes that "a plague as pervasive as southern Africa's AIDS epidemic [must] either be fought by nurses and laypeople or not at all" (92). It is at the primary interface between the formal and informal health sectors – the clinics in the country's poorest communities – where this battle is most ferocious. Ensuring that home-based care is fully integrated into primary healthcare structures is a vital step in helping to bring about a victory.