Treatment, Care and Support for HIV Positive People in Rural South Africa

A Qualitative Study of the Link between Formal and Informal Healthcare

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Abstract

This study is an explorative investigation of healthcare in a small rural village in Kwazulu-Natal focusing on the situation for healthcare workers providing treatment, care and support to HIV positive people. The theory of social capital has been used to investigate community participation, cooperation in the community and cooperation between the community and the government. Seven organizations were interviewed in semi-structured interviews and data was analyzed using thematic analyses. The results showed a high level of community participation and use of volunteers and informal groups to provide treatment, care and support. Cooperation and "bridging" between organizations was reported as high and was found to increase the quality of healthcare. Factors found to reduce cooperation and "bridging" in the village were lack of coordination and lack of human and material resources. Cooperation between the community and the government was mentioned to be low or non-existent. The study concludes that the level of community participation and "bridging" in the community is increasing social capital while the low level of cooperation and "linking" between community and government is reducing social capital. The study highlights the use of interventions that both facilitate "bridging" and "linking" to support community participation and coordination of healthcare in the village. Interventions to empower and educate healthcare workers in the village to treat patients closer to their homes are recommended.

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Acronyms

AIDS:	Acquired Immunodeficiency Syndrome
ARVs	Antiretrovirals
CBC	Community Based Care
CBO	Community based Organization
CHW	Community Health Worker
DOH	Department of Health
FBO	Faith Based Organizations
HIV	Human Immunodeficiency Virus
HBC	Home Based Care
KZN	KwaZulu-Natal
MSF	Medecins Sans Frontieres
NGO	Nongovernmental Organisation
PLWHA	People Living with HIV/AIDS
TB	Tuberculosis
UNAIDS	United Nations Programme on AIDS
WHO	World Health Organization

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1.1. Introduction

South Africa is the country in the world with most HIV infected people. According to UNAIDS the estimated number of HIV positive people stood at 5.7 million in 2008. HIV/AIDS is the leading cause of death in South Africa and it is estimated that between 270 000 and 420 000 people died from HIV/AIDS in 2007 (UNAIDS, 2008). Still only 28 % of all HIV positive people in South Africa have access to antiretroviral treatment (UNAIDS/WHO, 2008).

The HIV pandemic represents one of the most serious challenges to public health today, according the World Health Organization (WHO/UNAIDS, 2007). An estimated 34.4 million people are infected with HIV and approximately 2 million died from AIDS related illness in 2008 (WHO, 2009). Though the infection rate has increased slightly in some western countries and decreased in Africa, 68 % of all HIV infected people are still living in Sub- Saharan countries (UNAIDS/WHO, 2007). The poorest continent in the world with a history of conflicts, colonialism and famine pays the heaviest price for the worldwide pandemic. The virus is not only killing people in their most active and productive years but it is also leaving behind children, husbands, wives and families without their most significant social support. In some Sub-Saharan countries and cultures where family, friends and community members represent the social and economic security, the death of a close relative can have devastating impacts. Similarly, the AIDS epidemic is putting major pressure on fragile health structures in Africa, often leading to a vicious cycle of weaker health systems and more patients (Benatar, M.B., Ch.B., 2004; Chopra and Ford, 2005).

As many fragile health systems and health facilities in developing countries are struggling to cope with the magnitude of the HIV/AIDS epidemic much of the burden of HIV/AIDS care has fallen on poor communities and families (Russel and Schreider, 2000; Department of Health, 2001). As a consequence Russel and Schreider (2000) argue that health professionals need to understand factors that facilitate community participation, community empowerment and the community's role in improving the conditions for people living with HIV/AIDS (PLWHA). Similarly, Chopra and Ford (2005) argue that the health interventions that

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succeed are based on an understanding of a community and its preferences rather than generalized models of how people or communities should behave and what they want.

This thesis investigates the organization of treatment, care and support for HIV positive community members in a small rural village in KwaZulu- Natal, South Africa. The theoretical framework of social capital is used to investigate healthcare in the village, community participation and cooperation between informal and formal healthcare.

1.2. Background

In 1990 an Antenatal Sera-Prevalence survey reported an infection rate of 0.8 % in South Africa (Schreider and Stein, 2001). Though recognized as a growing health challenge the number was not alarming compared to other countries in the world. Similar numbers were reported in countries like Brazil and Thailand (Achmat and Simcock, 2007).

In 2007 the prevalence rate for South Africa was 18.1 %, 0.6 % for Brazil and 1.4 % for Thailand (UNAIDS, 2008). Why had the prevalence increased so dramatically in South Africa compared to similar countries like Brazil and Thailand? One common explanation is South Africa`s vulnerable healthcare system and societal structures weakened after years of conflicts, colonialism and apartheid. Simultaneously there has been a continuous debate if poor African countries have the infrastructure and facilities necessary to implement interventions and fight pandemics like HIV/ AIDS. There is a consensus among social scientists that the South African HIV/AIDS epidemic is deeply rooted in a history of social inequality, exploitation and oppression with migrant labor and rural labor reservoirs being a driving force in the epidemic (Achmat and Simcock, 2007). Benatar et al. (2004) argues that global economy, and global structures that facilitates poverty, have increased the burden of HIV/AIDS in poor countries and have been the biggest barrier for successful implementation of prevention and treatment plans.

On the other hand the theory linking poverty to AIDS does not explain why many countries in Africa, poorer than South Africa and with a similar history of colonialism, have managed to control the pandemic and even decrease it (e.g. Uganda and Botswana). Neither does it explain why Brazil, with a similar structure of social and economic inequality as South Africa, has managed to keep the prevalence rate below 1% since 1990. Crewe (2000) argues that South

Africa in 1994, despite its turbulent history, was ready to mobilize against the growing AIDS crisis and that the leadership was aware of the structural and social challenges in the country. A National AIDS Plan was drafted in 1994 that was supported by the Minister of Health, cabinet, nongovernmental organizations (NGOs), community organizations and trade unions. South Africa, with an economy and infrastructure superior to all other Sub Saharan countries, was ready for the impact. But something failed. The plan was never implemented and six years later, in 2000, the number of HIV positive South Africans had reached 4 million (Crewe, 2000).

> We knew about AIDS – this was not some new unfolding mystery that we were the first to experience. We had a time lag of infection, the oft-repeated "window of opportunity", a committed government, an excellent plan and the relative wealth and advanced infrastructure to set our response apart from that of the rest of the continent. There was a strong NGO sector committed to partnership. But this was a plan that did not come together, and instead South Africa has been touched in many ways by the vengeance of AIDS (Crewe, 2000, p. 27).

Crewe (2000) is discussing whether the failure to implement the plan, and South Africa's AIDS policy in general, partly stems from a lack of coordinated actions between government, provinces, NGOs and community groups after 1994. In 1994 South Africa was already a diverse and complex society mainly due to a history of colonial nation building, a migrant labor system and the Apartheid policy of separating people into different classes, races and cultural groups. Despite Nelson Mandela's effort to unite the new nation, the political settlement in 1994, dividing the country into nine independent provinces may have created a basis for more diversity (Crewe, 2000). The system made it possible to have ten AIDS policies at the same time, one official government AIDS policy and nine independent provincial AIDS policies, each fighting for their own autonomy. When comparing the prevalence rates for different provinces the dissimilarities are striking. A study on HIV prevalence among antenatal clinic attendees in 2000 showed a national prevalence rate of 25.5 % but only 8.7 % in Western Cape and 11.1 % in Northern Cape. The highest HIV rates were found in the provinces of Kwazulu-Natal (36.2 %) and Mpumalanga (29.7%) (Department of Health, 2010).

In addition to structural differences in the federal system scientists have focused on South Africa's complex mixture of cultures, norms and values as a barrier to a united AIDS- response (Robins, 2004). The complex nature of HIV/AIDS due to its long incubation period and its

relation to sexual behavior, gender roles, stigma, poverty, education, religion and cultural beliefs about medicine and sickness, has been particularly highlighted in the multi-cultural South Africa. An often used example is the case when AIDS activist Gugu Dlamini was beaten to death in a township outside Durban in 1998 after she went public as HIV positive on television (Robins, 2004). Similarly, the AIDS crisis in South Africa created an arena for political debate and controversy not seen in any other country facing the challenges of HIV/AIDS, according to Robins (2004). New AIDS medicines, that continued to improve conditions for HIV positive people in western countries after 1996, were launched during a highly political time in South Africa where the new government sometimes seemed to perceive research on HIV/AIDS, western science and the pharmaceutical industry as an extension of the Apartheid area (Robins, 2004).The South African government`s hostility towards antiretrovirals (ARVs) continued even after the drug companies gave up their drug patents and allowed South Africa to produce cheap ARVs after 2001 (Robins, 2004). This created several conflicts regarding the roll-out of ARVs between government and the NGO Treatment Action Campaign (TAC) (Crewe, 2000). Though South Africa in 2007 had the world's largest ARV program, with over 370 000 people under treatment; this was only approximately 28% of all AIDS patients and much lower than most other countries in Africa. (Botswana 95%, Namibia 71%, Rwanda 72%, Kenya 44%, Malawi 43%, Swaziland 42%, Uganda 41%) (UNAIDS, 2008).

In 2008 a report was published estimating that at least 330 000 people had died in South Africa as a result of inefficient treatment programs in the period between 2000 and 2005 (Chigwedere et al., 2008). In addition the number of new HIV infections had increased dramatically to 5.7 million.

Finally, in March 2007 after years of denial and hesitation the South African government came up with a national and concrete strategic plan for fighting HIV and AIDS (The National Strategic Plan 2007-2011 (NSP 2007-2011). The plan focuses on access to treatment and care for HIV positive individuals and emphasizes strong cooperation between governmental organizations and nongovernmental organizations (NGOs). The NSPs (2007 -2011) main goal is to reduce the number of new HIV- infections by 50% and to give "access to an appropriate package of treatment, care and support to 80% of all people diagnosed with HIV" (NSP, p. 63).

In 2008 a report analyzing the consequences of implementing the plan was published. The study concluded that a rapid growth in ARV provision, as the NSP 2007-2011 suggested, would reduce the number of HIV positive people dying from AIDS by 1.2 million in the five year period (Walensky et al., 2008). A full implementation of the NSP 2007-2011 would prevent the death of over a million South Africans suffering from HIV/AIDS. On the other hand the study concluded that a realization of the plan would mean enormous financial and human cost for the South African society. Analyses have shown that a full HIV treatment coverage by 2010 would cost 16.9-21.4 billion Rand (US$2.54-3.22 billion) and result in 2,932,000 people being simultaneously on treatment in South Africa (Walensky et al., 2008).

A full implementation of the NSP seems unrealistic as the South African health system is suffering from lack of human recourses, poor administration and expanding demands related to the HIV/AIDS crisis (Benatar et al., 2004). Constraints for implementing the health plan is also related to the brain drain as thousands of educated health personnel are leaving the country for better conditions or higher salaries (Kober and Van Damme, 2004). The health personnel working in South Africa face the risk of increased workload and burnout as many of their colleagues travel abroad or become victims of the AIDS pandemic themselves. A survey from 2002 showed a prevalence rate of 35 % among student nurses and 15.7 % for health care workers in general (Achmat and Simcock, 2007).

As a result of the overwhelming pressure the AIDS crisis has placed on the formal healthcare system, the South African government has highlighted the need for home based care (HBC) and community based care (CBC) to use the limited health care resources in the country as optimally as possible (Department of Health, 2001). The South African government released a national guideline for HBC/CBC in 2001 where reasons for promoting HBC/CBC were given; 1) shortage of hospital beds, 2) inadequate number of health professionals in the public sector, 3) lack of resources for treatment and drugs, 4) cost of institutional care and crowded hospitals not able to give adequate care to people who are dying from terminal or long term diseases (DOH, 2001). For a successful implementation of HBC/CBC the government guideline also highlighted the support of education programs, social development, local government, traditional healers,

faith-based organizations (FBOs), nongovernmental organizations (NGOs) and community based organizations (CBOs) (DOH, 2001).

According to the national guidelines on HBC/CBC the informal organizations (NGOs, CBOs, FBOs, traditional healers) are intended to play an important role in South Africa`s healthcare provision and are necessary for: 1) identifying community needs (including financial needs) 2) coordination, planning and cooperation 3) monitoring and evaluation of quality of care, 4) lobbying for services and resources, and 5) negotiating with other sectors and advising formal systems (DOH, 2001).

1.3. South Africa`s Healthcare System

The South African healthcare system is similar to many other developing countries in Africa with a mixture of formal and informal healthcare structures (Benatar et al., 2004). Though there are different definitions of formal healthcare it can be defined as healthcare that is governed and supported by government and is working in accordance with the national healthcare plans (WHO, 2000). This could include hospitals, clinics and home based carers working for and being paid by the government. Informal healthcare can be defined as healthcare that is operating outside the rule of the healthcare system and is working independently from government administration with no economic support from government. This could include nongovernmental organizations (NGOs), community based organizations (CBO,) faith based organizations (FBOs), volunteers, family members and home based carers (HBCs) who work independently and without any support from government (WHO, 2000).

WHO defines home based care (HBC) as the provision of health services by formal and informal caregivers in the home in order to promote, restore and maintain a person`s maximum level of comfort, function and health including care towards a dignified death (DOH, 2001). The Department of Health (2001) defines community based care (CBC) as the care that the consumer can access nearest to home, which encourages participation by people, responds to the needs of people, encourages traditional community life and creates responsibilities.

A study from KwaZulu-Natal revealed that the most common tasks for home based carers were spiritual and moral support, basic nursing care, turning bedridden patients, monitoring drug

adherence, helping the patients with feeding, bathing, going to the toilet, shopping, cooking and transportation (Akintola, 2006). Uys (2003) argues that the introduction of home based care in developing countries is an adequate strategy to improve the illness and death experience for HIV positive patients when no cure is available. Her 2003 study showed that deaths in homes connected to long term illness were more often reported as "good" deaths compared to patients dying in hospital facilities. Uys (2003) concludes that the relationship between dying at home and having a "good" death can be the result of proximity to family and friends, who often cannot afford hospital visits, and love and personal care from family and friends not always found in crowded hospitals.

Though the use of HBC in marginalized communities is supported by government, most home based carers in South Africa are family members and volunteers who receive little or no support and who work under tough physical and psychological conditions (Campell and Foulis, 2004; Russel and Schreider, 2000). Akintola (2006) argues that the hidden physical and psychological costs of people doing home based care are often underestimated by the government and the cost analytics. Akintola`s 2006 study about home based care in townships in KwaZulu-Natal revealed that the burden of home based care often falls on people who are marginalized and troubled in the first place such as women, poor, unemployed, and HIV positive individuals. Some are also questioning the government's hypotheses; that home based care necessarily is more cost-effective and cheaper then hospitalization (Russel and Schreider, 2000). Russel and Screider (2000) argue that home based care should not be used as a substitute for hospital care to reduce hospital admissions but in coordination with other health facilities.

The introduction of HBC/CBC as a national healthcare strategy came in the challenging period of reconstruction and rebuilding in South Africa after apartheid (Benatar et al., 2004). The new democratic South Africa inherited one of the least equal healthcare systems in the world, according to Braa and Hedberg (2002), with 60 % of the resources in private hands, serving only 20 % of the population. To make the healthcare system more equal and directed towards the public the new government launched the Reconstruction and Development plan (RDP) and a National Health Plan based on a more decentralized health system and increased independence for provinces and districts (Braa and Hedberg, 2002).

The achievements of the RDP and the new government have been many. They have provided water, accommodation, electricity and telephone connections to millions of people, created hundreds of primary health care clinics, launched free health care for expectant mothers and children under five years and organized food programs for 5 million children (Benatar et al., 2004). The transformation of the health system included a national redistribution of resources away from tertiary care and hospital funding to long neglected primary care with a focus on strengthening community based care and traditional African healing practices (Benatar et al., 2004). However, Benatar et al. (2004) argues that the development of a healthcare system that resembles the systems in most developed countries, with a well-balanced division between primary, secondary and tertiary facilities, has been slow in South Africa. According to Benatar et al. (2004) the transmission created a heavy pressure on primary care leading to inadequate facilities and shortage of personnel and basic medicines in the primary care sector. Simultaneously, the reconstruction reduced availability to the tertiary care sector and hindered effective interactions between the different health sectors (Benatar et al., 2004).

The transformations and reconstructions of the healthcare system in South Africa had implications for how the new democracy was equipped to deal with the AIDS epidemic in the country, according to Habib (2005). He argues that the transformation particularly affected the interaction between governmental and nongovernmental organizations (NGOs). Habib and Taylor (1999) argue that the NGO sector became weaker after 1994 as personnel and skilled members found their way to the new state-run institutions. At the same time the NGO sector lost much of its independence as the financial support from abroad, which previously had been distributed directly to private organizations during the Apartheid period, now were given to the South African government (Habib, 2005).

In 1998 there were 98 920 civic organizations in South Africa and 53% of these were CBOs operating in poor and marginalized communities (Habib, 2005). The more formal NGOs were in minority even thought they received the largest portion of aid support from the government and foreign donors. Another study showed that the majority of community based organizations (CBO), who worked in poor communities, were entirely dependent on a few key

supporters to uphold the organizations (Ballard, Habib, Valondia and Zuern, 2005). The studies reveal a gap between the government and the majority of CBOs in South Africa.

The majority of home based carers and CBOs work under adverse conditions with little or no help and support from the government, according to Campell and Foulis (2004). Efforts have been made to strengthen formal health structures for those working with HBC/CBC but the structures are often fragile and still in their infancy (Campell and Foulis, 2004). They highlight three challenges connected to the use of HBC/CBC as a substitute or reinforcement of the formal healthcare system: 1) Challenges connected to providing adequate and effective care. 2) Challenges connected to providing home based carers, and their patients, with sufficient resources and equipment. 3) Challenges connected to empowerment and strengthening of communities to give them greater resilience against the HIV/AIDS epidemic and future epidemics. In addition they recommend a better linkage between the formal health sector and informal healthcare to increase the flow of resources and information, to improve the condition for home based carers and to increase the quality of treatment, care and support for HIV positive people in South Africa.

1.4. Social Capital

Amongst health researchers there has been a growing interest in the relationship between community building, health, and social capital in recent years. The recent interest in social capital is often attributed to *Pierre Bourdieu, James Coleman and Robert Putman* (Hawe and Shiell, 2000). Bourdieu, who is claimed to be the first to use the term, has mainly focused on the individual aspect of social capital and how the individual can gain access to resources through his/her relationship with others. Most health researchers on the other hand are using James Coleman and Robert Putnam's definition of social capital as a collective attribute, and focus on how cooperation, trust and norms in a society can create social capital. Putnam (1995) defines social capital as "the features of social organizations, such as networks, norms and social trust that facilitate coordination and cooperation for mutual benefit" (p. 66).

Though Bourdieu, Coleman and Putnam are using social capital in different ways all three seem to agree on a definition of social capital as resources created through relations between people or groups (Derose and Varda, 2009). This relationship is often analyzed and

distinguished into three different forms of social capital, namely *"bonding"*, *"bridging"* and *"linking"*. (Derose and Varda, 2009). "Bonding" represents the intragroup relationship between people who have similar background and status and how those individuals support one another for mutual benefit (Derose and Varda, 2009). "Bridging" social capital refers to how different groups relate and cooperate with each other on a horizontal level. "Linking" social capital refers to the vertical relationship between people or groups who cooperate and interact with each other across formal or institutionalized levels in the society (e. g between formal health workers and poor marginalized community members) (Derose and Varda, 2009).

Derose and Varda (2009) suggest that the "bonding", "bridging" and "linking" aspect of social capital can be understood and analyzed using three different dimensions of social capital; *cognitive, behavioral and structural*. The cognitive dimension focus on the levels of trust and norms in a society, in accordance with Putnam`s definition. The behavioral dimension analyzes the behavior of people or groups and their level of participation and volunteering. The structural dimension of social capital refers to the numbers of networks, relationships and the quality of these relationships and cooperation in a society.

While Bourdieu`s definition of social capital is useful for investigation of the individual`s relationship with its networks on a micro-level, Putnam's definition works better to understand relationships at a macro level and the "state-society connections, or the extent to which there is synergy between the state`s actions and the interests of its populace." according to Hawe and Shiell (2000, p. 873). Similarly Hawe and Shiell (2000) highlight community-building as a way to connect the micro and macro dimensions of social capital.

The use of social capital as a way to increase community participation can also be seen as a reaction to the failure of many information based health education programs in poor marginalized communities (Campell, 2005). Chopra and Ford (2005) argue that information based programs often fail to acknowledge that health related behavior not only is determined by rational choices and access to information but also by contextual factors that facilitate such behavior. As a result of the limited success of early interventions, using experts, posters and television to educate a passive target audience, there has been paradigm shift in health promotion toward community empowerment and community participation (Campell, 2005). According to

Campell (2005) this realization brings new challenges to the field of health promotion. Firstly, health researchers have to take into account contextual factors that facilitate or hinder care and support when planning their interventions. Secondly, they have to find tools to measure what kind of factors leads to a health-enabling community. The growing interest in social capital, and Putnam's hypothesis that a community with a high level of social capital will also show high levels of health, can be seen as a result of this realization (Campell, 2005).

Putnam`s idea that a healthy society is measured through its civic participation and trust, norms and cooperation between networks and formal institutions has won the interest of many leaders and decision makers (Campell, 2005). Some critics have questioned the motive of leaders supporting social capital as a way to eliminate health disadvantages connected to poverty and inequality. They argue that the support of social capital could be a way for political leaders to run away from their responsibility and to justify cuts in welfare spending (Campell, 2005). Others relate the growing enthusiasm for social capital to the fact that promoting social capital and telling community members to increase their participation is a cheaper and more convenient solution for politicians than to remove poverty and inequality in the first place (Campell, 2005).

Foley and Edwards (1999) argue that Putnam's definition of social capital is limited since it mainly focuses on behavior and responsibility of community members without analyzing their context and the resources available. In a survey about community-based HIV/AIDS care and support in South Africa Russel and Schreider (2000) revealed that though many communities were willing to mobilize they were unable to do this as they were lacking resources, skills and basic necessities like water and food. On the other hand Foley and Edwards argue that social capital is a useful concept when taking into account "the many ways in which social resources are made available to individuals and groups for individual or group benefit…" (1999, p. 141) They recommend the use of a context dependent definition of social capital as "access plus resources" (Foley and Edward, 1999, p. 141).

Derose and Varda (2009) see social capital as a useful way of investigating health care access, and the availability of health services in poor marginalized communities, through its concepts of "bridging" and "linking". Marginalized and underserved communities can organize health care groups and health care centers in their communities through strong civic participation

and "bridging" between different agents in the community. Similarly, the relationship and "linking" between formal health care institutions and underserved communities can facilitate and strengthen the level of health care service, health education and information across vertical structures (Derose and Varda, 2009). In accordance with Foley and Edwards's definition of social capital (1999) the "bridging" and civic participation can be seen as a facilitator for community members access to health care, and the linkage between formal health care and communities as a facilitator for access to resources. Health interventions that both facilitate "bridging" and "linking" in a community will therefore increase the levels of social capital and health according to Foley and Edward (1999).

The linkage between formal health care and underserved communities can also facilitate trust and closer relationships that could increase marginalized community members willingness to use the formal healthcare, according to Derose and Varda (2009). However, they argue that scientists using social capital need to develop universally accepted definitions and measures of the concept to make it more robust and sustainable in current academic research. To make social capital a useful framework for studying public health and health delivery, scientists have to focus on relations and the horizontal and vertical ties through " bonding", " bridging" and " linking", instead of cognitive constructs, according to Derose and Varda (2009). This is also in congruence with Foley and Edwards (1999) recommendations, who after reviewing 45 articles on social capital, argue that the structural dimensions of social capital, and research on networks, relations and cooperation, seem to be better measures for health care access then the cognitive constructs.

Derose and Varda (2009) highlight three ways that social capital can be used to explore health and healthcare delivery: A) Examine the sources of connections between community members and groups. B) Explore what kind of resources that are transmitted through the connections can be of interest to health and health care. C) Understand how one can facilitate or change the connections to improve health and health care delivery. Similarly, Campell (2005) emphasizes the need for more studies on community level and community networks and argues that "social capital forms a fruitful starting point for filling the current gap in our understanding of community-level determinants of health (Campell, 2005, p. 189).

1.5. Aim of the Study

As the South African government highlights the support of communities and home based carers to assist in the implementation of the National Strategic Plan (NSP 2007-2011) it is important to map out which organizations are operating in isolated and marginalized communities and how they work. The NSP 2007-2011 focuses on improved access to treatment and care for HIV positive individuals and emphasizes a strong cooperation between government organizations and nongovernment organizations (NGOs). Two years into the plan it is necessary to investigate how the current situation is for AIDS affected communities and health workers who are trying to implement the plan. It is also important to find out whether the recommended cooperation between government and NGOs/CBOs is working in accordance with the plan. This investigation can give organizations that are working with HIV/AIDS an opportunity to express their opinions about the current situation and provide reflections on what kind of aid or support would improve their work and the conditions for those affected by HIV/AIDS. This bottom-up information can give useful feedback and corrections back to the leaders and organizers of the NSP 2007-2011.

Though many health scientists have drawn attention to the role of social capital as a way to illuminate the quality of healthcare in communities there is yet little current research on the topic (Campell, 2005). This thesis investigates the role of social capital in promoting treatment, care, and support for HIV/AIDS affected people in a poor marginalized community by examining the levels of participation and cooperation between formal and informal healthcare structures in the community. In accordance with Derose and Varda`s (2009) and Foley and Edward`s (1999) recommendations for the use of social capital in academic research the thesis will not focus on cognitive dimensions of social capital but on structural aspects and how participation and cooperation between horizontal and vertical structures in a society can facilitate social capital and health.

Research questions:

1) In which ways do formal and informal organizations provide treatment, care and support to HIV positive people in the village?
2) How do the organizations cooperate and coordinate their work?

3) To what degree do organizations working in the community cooperate and communicate with formal structures of the government?

4) What are the main constraints for providing efficient treatment, care and support for HIV positive people in the village?

2. Method

2.1. Qualitative Method and Semi-Structured Interviews

A qualitative method was used in order to get an in-depth and first-hand experience of the research topic. I found the method appropriate to the explorative nature of the research objectives and the bottom-up approach as it enabled HIV/AIDS workers in the community to tell their stories in rich detail. The national AIDS plan (NSP (2007-2011) is a normative approach to what the government wants to achieve in connection with HIV/AIDS in a five year period, but does not say anything about the actual treatment, care and support situation for HIV positive people in any particular area, including the research area. I decided to use a bottom-up approach to let community members, working with HIV/AIDS in the village, voice their own opinion on how treatment, care and support for HIV positive individuals is organized in the community.

In accordance with this approach I found it most useful to conduct qualitative semi-structured interviews with significant people working directly with HIV/AIDS. I used an interview guide covering different topics, selected on the basis of my research objectives and a literature review, and conducted semi-structured interviews in accordance with Kvale`s (1996) definition: "It has a sequence of themes to be covered, as well as suggested questions. Yet at the same time there is an openness to changes or sequence and forms of questions in order to follow up the answers given and the stories told by the subjects." (Kvale, 1996, p.124).

The main themes in the interview guide were: 1) organizational work, number of members and main goal of the organization 2) cooperation between the organization and other, formal and informal, organizations 3) relationship with the government and 4) support from the government that could improve the conditions for health workers and HIV positive people in the research area.

All the themes were covered during the interviews but the respondents chose what kind of stories or answers they would give in relation to the themes. The conversations during the interviews therefore varied a lot from organization to organization depending on the respondent's interest and wish to speak. However, through following the interview guide and covering main themes during the interviews most of the data became valid in relation to the research questions.

2.2. Study Site

The interviews were conducted in a rural village in the eThekwini Municipality in KwaZulu-Natal. KwaZulu -Natal is the most populated province in South Africa with about 10 million inhabitants (StatsOnline, 2007a). The province has the highest HIV prevalence in the country with 19.2 % of the population being HIV positive (UNAIDS, 2008). 57.7 % of all deaths in KwaZulu-Natal were related to HIV/AIDS in 2009 and with no change in the situation the percentage would reach 71.6 % in 2010 (Health System Trust, 2010a). In 2006 there were 67 public hospitals providing 23 833 beds and 32 private hospitals providing 3 827 beds in the province (HST, 2010b). The unemployment rate is the highest in the country with officially 30 % of the labor staff being without work (StatsOnline, 2007b). 71. 5 % of the population in KwaZulu-Natal use electricity for lighting and 79.4 % have access to piped water, which is approximately 10 % lower, than the national average (StatsOnline, 2007a). In 2001 54 % of the population in KwaZulu- Natal lived in rural areas similar to the research area (HST, 2010c).

The area of investigation is a village in a rural and hilly area with approximately 10 000 inhabitants (Statistics South Africa, 2004). There is little infrastructure with only one main road going through the village. Driving or walking in the hilly landscape outside the main road might sometimes be challenging. Most of the houses are small and built of soil and metal. According to a community survey on health/HIV and social capital from 2008, 21 % of the community members were employed (Dageid, 2010). The average household income for community members was between R400-3200 and 30 % reported no income at all. 40 % got their income from grants. In the health survey from 2008, with a sample of 969 people, (318 males and 649 females) a quarter reported poor health and half of the sample reported good health. Approximately half of the sample reported that life quality had decreased since 2004 and the reasons most frequently stated were unemployment, inaccessible health services and lack of

clean water. 51% of the sample reported the overall health service provision in the community as poor or fair (Dageid, 2010).

2.3. Informants and Procedure

The interviews were conducted over a period of four weeks from 2009-10-06 to 2009-11-05. As part of the research I travelled regularly to the field for two months with a team from University of KwaZulu-Natal (UKZN) who were conducting interviews and research in the area. The purpose of these trips was to get used to the area, the culture and the atmosphere, and to map out which organizations were working in connection to HIV/AIDS. In this period I also did intensive literature reviews on HIV/AIDS by reading articles and surveys on the issue as well as documentaries by contemporary South African writers.

The mapping process was conducted in three stages: First, during my four weeks in the field as an observer I noted what kind of organizations the research group was interviewing, what kind of work the organizations did and how many times a particular organization was mentioned in connection with HIV/AIDS work. Secondly, I searched the internet for organizations that were operating in the area and checked whether they were providing treatment, care or support for HIV/AIDS affected people. All the organizations I found on the internet were organizations I had been in contact with or noticed in the field during my time as an observer. The internet investigating was done to check the significance of organizations I had found in the community and the validity of my field observations. The third method was snowball sampling: I asked the organization I interviewed if they were working with any other organization or if they knew other organization working in connection to HIV/AIDS in the area. If an organization was mentioned by several of the other organizations interviewed I decided to contact them. Three organizations were finally recruited through the snowball-sampling.

The Seven Organizations Interviewed:

Organization 1: *"The Volunteers"*: Informal volunteer home based care group in the village.

Organization 2: Informal *faith based organization (FBO)* outside the village with a 23 bed unit.

Organization 3: Informal *community based organization (CBO)* inside the village.

Organization 4: Informal group of *traditional healers* in the village.

Organization 5: *"Community health workers":* Formal home based care group in the village.

Organization 6: Formal *clinic* in the village.

Organization 7: Formal *district hospital* outside the village.

Before I arranged the interviews I phoned the contact person listed for each organization. This person was either the leader of the organization or I was referred to the leader of the organization to conduct the actual interview. Though this sample representation happened by default I found it useful because many of my questions were relatively technical questions regarding the structure, cooperation, funding and goals of the organization designed for a person with a good overall view of the organizational work.

When interviewing the CBO inside the village I interviewed both the leader and the counselor in two separate interviews. The interview with the traditional healers was conducted with both the leader and members at the same time as a focus group interview. All the other interviews were conducted with the leader of the organization only. My main objective was to investigate the structure and the cooperation between organizations in the area and I found that interviewing the leaders of the organizations was appropriate to meet these objectives.

I gave the respondent the opportunity to choose the time and location for the interviews and to decide what language they preferred to use. Seven of the eight interviews were conducted at the organization`s facilities and one in the home of the respondent (the interview with the leader of "the community health workers"). Six of the interviews were conducted in English. The interview with the traditional healers and "the community health workers" were conducted in isiZulu where the questions and answers were translated to me by a field-assistant from UKZN speaking isiZulu as his first language. Seven of the respondents were women and one was male (the leader of the district hospital). The interviews lasted from 30 minutes to one hour with an average of 45 minutes. The interviews were audio taped and transcribed by the interviewer into 76 pages of written text. The two interviews conducted in isiZulu were transcribed by the interviewer using the English translations. Some details in those interviews may therefore have been lost during interpretation and translation. All the interviews were transcribed as they

appeared phonetically from the tape recorder. Small grammatical and linguistic changes were made to make the text more suitable for reading.

2.4. Ethical Considerations

The study has been approved by REK, Research Office Westville Campus and Norsk samfunnvitenskapelig datatjeneste (NSD). Information and a consent form to protect the respondents confidentiality was signed by the respondent and the interviewer before each interview. As an interviewer I tried to be sensitive to every respondent and tried to conduct the interview in accordance with the serious nature of the topic. In lack of any fixed set of rules or gold standard on how to conduct an interview in the field I hope that my ethical consideration and preparations for the topic helped me conduct interviews that were fruitful for both researcher and respondent. " The absence of prescribed sets of rules creates an open-ended field of opportunity for the interviewer's skills, knowledge, and intuition. Interviewing is a craft that is closer to art than to standardized social science methods." (Kvale, 1996, p. 84).

There are many potential ethical dilemmas and considerations for a researcher operating in a poor community desperately needing resources and help. It can create illusory beliefs in the community that the researcher is coming to fix their problems, or create hostility from other groups who perceive the researcher to be an agent for the government. Though I was aware of this potential problem before I started the interviews I sometimes ended up in situations during interviews which I found challenging. During some of the interviews the respondent asked me if I could help them or if I could contact others for help. The challenge was to give a balanced answer that did not give the respondent a false hope and at the same time not ruin optimistic beliefs about the future and give the impression that the time and energy spent on the interview was completely wasted. There are no fixed rules to follow in those situations but I always tried to be aware of my position and ethical responsibility as a researcher when giving answers and interacting with the respondents.

2.5. Analyses

The method of thematic analysis was chosen to analyze the data. Thematic analysis is a method that organizes the data into themes and at the same time seeks to describe the data in rich detail (Braun & Clarke, 2006). Thematic analysis is recommended for researchers early in their

research career because it does not require detailed knowledge of the research area and because it is a flexible method that can be used within different theoretical frameworks, according to Braun and Clarke (2006). I found thematic analysis to be an adequate method for investigating my research objectives because I had an explorative approach and little previous knowledge about the research area. I analyzed my data in six steps as recommended by Braun and Clarke`s step-by –step guide (2006).

First I read through the transcripts of the semi-structured interviews several times, took notes and familiarized myself with the data. As the questions in the semi-structured interviews were designed to get information related to my research objectives I read the interviews in the same way. At the same time I tried to look for new knowledge and information in the dataset that could be of interest when analyzing and discussing the data later. After reading and getting familiarized with the text I highlighted every quote in the text that could be meaningfully interpreted and summarized the interpretation into a short sentence or a code. After going through all eight interviews I ended up with approximately 250 codes and small sentences that were reflecting my interpretation of the meaning and answers given during the interviews. I copied the codes into a different document and started grouping similar codes together. I thereafter divided the codes into different themes and categories. Many of the categories came naturally as a result of my research questions e.g. *community participation in HIV treatment, care and support. cooperation in the community and constraints for cooperation,* while themes within the categories such as *stigma*, *lack of human resources*, *access to transport* etc. came as a result of similar and repeating pattern of answers after grouping the codes. Some themes were excluded because they were not part of my research questions. This was done to narrow the data in accordance with my research objectives. In accordance with the bottom-up approach I conducted the analyses using a realistic method and treated the respondent's answers as factual information without looking for constructivist explanations or underlying latent information.

3. Results

When interviewing the organizations working in connection to HIV/AIDS I was interested in how the organizations were working and how they were providing treatment, care and support to HIV positive people in the community. Three of the organizations were licensed

to provide formal medical care, as well as other forms of health care, and four of the organizations were mainly focusing on providing care and support. The results are categorist and presented under the themes: *3.1. Healthcare in the Community*, *3.2. Cooperation in the Community*, *3.3. Cooperation between Healthcare in the Community and Formal Healthcare* and *3.4. Constraints for Efficient Healthcare in the Community.*

3.1. Healthcare in the Community

When analyzing data related to the explorative investigation of the healthcare structure in the community I found both informal and formal community organizations working to provide treatment, care and support. The informal organizations were categorized under the theme; *3.1.1. Community Participation in HIV/AIDS Treatment, Care and Support*, while the formal organizations are described under the theme; *3.1.2. Formal Structures in the Community*. Though I was aware that separating the community organizations into two different themes was a simplification of a complex interaction it was done to clarify the differences and relations between formal and informal health care.

3.1.1. Community Participation in HIV/AIDS Treatment, Care and Support. When driving through the village conducting research or carrying out appointments with the organizations it was not obvious that this was a community suffering from a severe HIV/AIDS epidemic as well as other serious health conditions. Though most people lived in simple houses and the village seemed to have a problem getting rid of garbage, people looked healthy and relaxed and met us in a friendly manner without mentioning problems connected to HIV/AIDS. It was only through reading the HIV/AIDS statistics from the area and doing in depth interviews with the organizations that the extent of the AIDS crisis and its impact on the community became clear.

> There are also some children; I would presume that they are born positive. There are also some very young children that are infected and some quite young girls that are infected. I'm not quite sure if that is through sexual relationships? We have high school learners who are infected. So it is affecting every level. We have babies, young girls, teenage girls, mothers, to older mothers, grannies, everyone. (Leader CBO, inside the village).

I found three organizations inside the village and one organization outside the village which I defined as informal groups because they were working independently from formal healthcare and did not receive any funding from the government. The organizations located inside the village were a group of home based carers called "the volunteers", a community based organization (CBO) and a group of traditional healers. The organization located outside the village was a faith based organization (FBO) that was working in the area close to the village.

"The volunteers" is a group of 30 members. They have been working without pay since 1996, except a R500 stipend provided monthly by the government from 2007. The organization was started in 1996 as an initiative from the leader who wanted to help her community. The members are doing house visits in the village and are caring for people who are sick, especially people who are sick from HIV/AIDS according the leader. She told me that they are often helping elderly people who are taking care of orphans and patients who are locked inside the houses. When asked how many people they were caring for the leader told me that they had visited 586 patients last month. Divided by 30 that would be approximately 20 patients per home based carer each month. The patients are spread out in a fairly big area, the landscape is hilly and rocky and the volunteers have to do their home visits by foot because there is a lack of roads and transport vehicles.

The community based organization (CBO) was started in 1994 as an outreach from a church based organization outside the village. They were at first working as a soup kitchen feeding the hungry and poor in the village before the organization formalized in 2000. According to the leader of the organization they realized that there were other challenges in the community that needed to be taken care of. One of the problems was that HIV positive people and families with orphans, who had the rights to receive health grants, did not know how to apply or what procedures they had to follow. The CBO is counselling HIV positive people, giving them information about testing and treatment and helping them to apply for and receive their grants. The CBO is also helping orphans who have lost parents due to HIV/ AIDS and are providing them with school material. In addition they are helping HIV positive people with food parcels and teaching them how to grow their own vegetables. The councillor told me that the majority of the people that are coming to the organization are coming in connection to HIV/AIDS.

The traditional healers is a group of traditional South Africans healers called the sangomas who provide traditional medicine to the community as well as provide care and support to the sick. Traditional medicine is often the primary and only accessible healthcare option for many people living in Sub-Saharan Africa according to UNAIDS (2007). The South African government has focused on traditional healers in the fight against HIV/AIDS because of the important role they play in the communities (DOH, 2001). The traditional healers in the village are using their traditional healing skills to treat physical and psychological conditions as well as referring patients with HIV symptoms or other serious conditions to the nearest clinics. They grow and produce the traditional herbs used for the traditional medicine in the village but when it comes to formal healthcare equipments such as gloves and bandages, according to the leader they lack the most basic necessities.

The faith based organization (FBO) started as a volunteer church based organization in 1990 and formalized in 1996. The leader told me that they are caring for the community around HIV/AIDS in a way that empowers and uplifts rather than one that moralizes. They are governing a center outside the village where they provide information and education, testing, CD4 counts and refer HIV positive patients to ARV sites. They are administrating a home based care group working in the surrounding area and a 23 bed hospice opened in 2008. AIDS sick patients from the area are cared for by 5 nurses and 41 health workers. In addition approximately 50 volunteers are working for the organization. The leader told me that independence and sustainability is very important for the organization and that they are getting income from a garden project, a handcraft project and from private donors.

All the leaders of the informal organizations reported that the wish to help the community was the main motivation for building the organizations. The members of the organizations have various backgrounds and educations and range from nurses, administrative leaders to volunteers with no formal education. None of the members receive any salaries or funding from government except "the volunteers" who receive a minimal stipend of R500 per member per month according the leader. The other members are either working as volunteers without pay or are receiving salaries funded by private donors or private income projects.

3.2.1. Formal Structures in the Community. When exploring the area I was also interested in investigating what kinds of formal healthcare structures existed inside the village or in connection to the village. As mentioned in the introduction I chose to define formal healthcare as healthcare that is governed and funded by government and is working in accordance with the national healthcare plans. Three organizations were found to provide formal healthcare in the area: *"The community health workers" (CHWs), the clinic* and *the district hospital.*

"The community health workers" (CHWs) is a group of 28 health workers stationed in the village conducting home based care. They are working for and receive salaries from the government. However, the leader told me that they have minimal contact with the government and are mainly connecting and reporting to the clinic. Nevertheless I chose to define them as a formal group because they are supported by government and are working closely with the clinic which is under government responsibility. The group was started in 1981 to help poor people in the community who were suffering from malnutrition and diarrhea. The leader told me that their work now mainly revolves around caring for people who are suffering from HIV/AIDS and TB in their houses.

The clinic in the village is the only port to formal medical care inside the village. The clinic is operating without doctors or pharmacies and patients are taken care of by nurses and health workers. There are 13 staff members working in the clinic and 5 of those are professional nurses. The clinic is the first port of help for 9887 people in the area and serves an average number of 2200 patients every month according to the leader. When I asked what kind of work they do, the clinic leader told me that they are mainly treating chronic illnesses and HIV positive people who are not ready for ARVs or who have opportunistic infections. The nurses in the clinic are helping people with both physical and psychological problems but for more serious conditions they are referring patients to the nearest hospitals. The clinic performs HIV testing and CD4 counts of patients but to start on an ARV program the HIV positive people would have to travel outside the village to surrounding hospitals or initiatives sites. Some 90 patients who are already enrolled in an ARV program get their ARVs sent to the clinic.

The district hospital manager told me that approximately 80 %, of their patients are coming in connection to HIV/AIDS. In addition to serving people from the village and

surrounding areas the hospital is the biggest hospital in the area of approximately 750 000 people. One third of that population, approximately 250 000 people, are HIV positive according the statistics. 10% of those, nearly 25 000 people, have advanced HIV infections and would need medical treatment according the district hospital leader. The hospital has 200 beds and is treating 4000 HIV positive people with ARVs. That would be approximately 20 % of all HIV positive people in the area surrounding the village who need treatment. In addition, 3000 HIV positive people are getting treatment from other government facilities, according to the leader of the district hospital. That brings the number of HIV positive people in the area, who receive ARV treatment, close to the national estimate of 28%.

3.2. Cooperation in the community

When analyzing the interviews I was interested in how the organizations, both formal and informal, were cooperating with each other in the provision of treatment, care and support. Codes for cooperation between organizations in the community were divided into two themes: *3.2.1. Cooperation between Organizations in the Community* and *3.2.2. Constraints for Cooperation in the Community.*

3. 2.1. Cooperation between Organizations in the Community. When asking the organizations what kind of groups they were cooperating with in the community most organizations mentioned at least two or three of the other organizations I interviewed. There seemed to be a general high level of cooperation in the community for both formal and informal groups. The clinic leader told me that they are cooperating with both the "volunteers" and the CHWs and are meeting them monthly at the clinic to share problems and ideas.

> Yes. We got home based careers ("the volunteers") and community health workers ("the CHWs"), we cooperate with them. Whenever we don't see a person coming to us we keep registers. You look at the address of the person you know who is located for that area, and then you ask he or she to visit (Leader, Clinic).

The clinic is also cooperating with and referring patients to the district hospital. The clinic leader told me that the CBO in the village is assisting them and helping patients with feeding schemes. There is a high degree of poverty and malnutrition in the village and the CBO

is providing people with food and putting them on feeding schemes, especially sick people who need a healthy diet according the clinic leader.

> And there is also ...(CBO). They also provide HIV positive people, though they don't might not know if they are HIV positive. They look at the weight of the person. They provide them with the food. So they relieve us with the bedding, because sometimes we do run short of beds, porridges... (Leader, Clinic).

In addition to cooperating with the clinic, the leader of the CBO told me that nurses from the FBO outside the village are coming to the CBO to assist them with HIV testing. The leader of the CHWs mentioned the CBO inside the village and the clinic as two of the organizations they were cooperating closest with. The leader of the CBO highlighted cooperation with the CHWs as a way to empower the community and to save time and resources connected to their home based care work.

> So the last years or so we had a quite good relationship with the social workers (CHWs), where we can finally see that… we do know all the families here …they can just come to us and say: " where is this family?" We can show them, we can tell them. Everything we know that can help them with their investigation… Sometimes they come down here, they only come once a month, they don't know where the families are or... They are wasting a lot of their time. So now they are working with us (Leader, CBO).

According to the organizations it seemed that even the organizations that were quite similar and which provided the same kind of care and support to the community, like the CBO/ FBO and the home based care groups, were cooperating and supporting each other. The leader of the CBO highlighted cooperation among the organizations as an important factor to hinder duplication of work.

> And there are different resources. So now there are other organizations with food, so what is important is that we are not all doing the same. Like if that family is getting food from them they shouldn't be getting from us. Or, at least, it they are getting from us, then we should know what the others are doing and that's why the networking it is quite important (Leader, CBO).

The most surprising finding was that even the clinic and the traditional healers seemed to have a close cooperation despite representing two very different healing paradigms. The traditional healers told me that they were referring patients to the clinics and the leader of the clinic told me that she was working with the traditional healers to gain their trust.

> Yes. I even attend their meetings, because I should to gain their confidence. I even attend their meetings, if they do have meetings. Otherwise, if I don't attend, there would be friction. (Leader, clinic).

3.2.2. Constraints for Cooperation in the Community. The organizations were mainly focusing on the positive effects of the interactions with one another and only a few of the organizations mentioned problems related to cooperation and communication. However, the leader of the CBO and the leader of the district hospital both told of constraints for cooperation connected to competition for resources and misunderstandings in the community related to what kind of role the different organizations play and what kind of resources they provide.

> Yes I think there is a bit of competition out there. With the community they kind of compare, "I go to ...(CBO) for that but I go to them for that" or "they gave me this but they didn't". I suppose it is just lack of understanding of a community. Sometimes a community expects something and then we can't provide it. Or they can say: "why did they get it and not us?" That because we don't have never ending resources. So yes there are those challenges (Leader, CBO).

The district hospital leader also described how the limited resources facilitate competition instead of cooperation among the organizations.

> Yes and remember at the end of the day it is a dog eat dog world out there and there is a final amount of resources and we are all scrambling for a piece of the pie (Leader, District Hospital).

The leader of the district hospital told me that he had the impression that there seemed to be a general lack of a coherent response to the AIDS crisis in the province. He argued that the lack of coordination and the lack of sustainability connected to the provision of treatment, care

and support in the communities is the biggest obstacle for efficient cooperation between the different organizations.

> There are a lot of structures that are supposed to be there, clinic, committees and community health forums, and all those sort of things that just are not. And even when they do get created they are very fluent. Because different people see them as opportunities for political power and the community structures are continuously changing. So you never really know who you are dealing with, what sort of mandate they got and if they have a personal access to grant or if they are genuinely interested in health? It is a very tough place to work; in community structures in South Africa (Leader, District hospital).

The leader of the CBO also highlighted the problem connected to lack of common criteria when it comes to doing community healthcare work. Because there is no common coordination strategy in the community to synchronize work, all the organizations have to meet each other on a regular basis and there is not enough time to do this according the leader.

> Each one has their own criteria. So we might decide that this granny needs… but another organization might decide that that granny doesn't need. So it's just depending on your criteria and your resources at the time and you can't actually have a meeting every time, every organization to make a decision (Leader, CBO).

3.3. Cooperation between Healthcare in the Community and Formal Healthcare

Codes related to cooperation between healthcare in community and formal healthcare, both formal healthcare inside the village and governmental healthcare outside the village, were grouped into two different themes: *3.3.1. Provision of Care and Support* and *3.3.2. Provision of ARV Treatment.*

3.3.1. Provision of Care and Support. While the cooperation between organizations working in the community, both informal and formal, generally were reported as good none of the informal organizations providing care and support reported working closely with the government. When interviewing the organizations many of them are focusing on the lack of coordination and communication between government and the community. Some reported that their relationship with the government was very unreliable and that they received some sort of

support one year but not the next year. There seemed be a wish among the community organizations to have a more reliable and reciprocal connection with the government.

> Before we got it. Department of Health they gave us the home based care life skills, counseling. Now this year: No money to the Department of Health. So there is no training (Leader, "The volunteers").

The district hospital leader also emphasized the need for more stability and better coordination between the government and different community organizations.

> There are a lot of people out there that do need food. But you can't do it the way the government do it. They got money, so "I give you food now reliably for three or four months" and then: "-I don't give it to you for six months". Then you can just as well not give it (Leader, District hospital).

Both the CBO and the FBO reported that the lack of cooperation with the government partly stemmed from a wish to remain independent and that they don't trust the government as a sustainable funder. Even the CHWs, who are working in the village but are funded by the government, report that they have little connections with the government.

> We are cooperating with the government and get information from the clinic but there is no information given in regards to HIV. Government is going to put out buses on the world AIDS day 1st of December but they are not going to address the issue of AIDS. It is only on that particular day. Otherwise there is no intervention (Leader, CHWs).

All the informal organizations in the village cooperate and report to the government funded clinic but this cooperation seemed to be created as an initiative inside the community between the clinic and the informal organizations to fill the gap in healthcare provision.

> It is better than it was but there are always gaps you know. If they were doing their job (Government) then we wouldn't have… we wouldn't be needed. But you know the extent of the epidemic is so large … (Leader, the FBO).

The councillor of the CBO expressed a wish that the government would work closer with the community to help them in the provision of care and support. She argued that there is a gap between the people and the ministers and that people in the community have the impression that they are not allowed to speak directly to the leaders. Therefore the ministers would have to take an initiative to make contact and bridge the gap, according to the councillor.

> And I think another thing is that government needs to avail themselves to the community, because you can see that if I want to communicate with the minister. Other people don't know how to, and they think that you are not allowed to communicate with the minister (Councillor, CBO).

Both the councillor of the CBO and the leader of the CHWs told me that they wished the government could come to the village to see with their own eyes the extent of the epidemic and the conditions the health workers are operating under. According to the two organizations the government need to have a bottom up approach and work closer with the community to know what has to be done and what needs to be addressed.

> Yes if the government can come and visit the ...(CBO), like you are here today, then say: "take me to one of the families that are struggling". Then for you to visit that family and see exactly what is happening on ground. And so the government could take the steps. Because if I am reporting it is not like when I am at that family facing the sick people laying down with the old granny, maybe the mother with a four year old child sitting next to the mother who is between dead and alive... (Councillor, CBO).

> But we as the care givers we know what is happening but the government would not respond to that. So it sends out people to do thing which the government doesn't know about (Leader, CHWs).

3.3.2. Provision of ARV Treatment. As already mentioned in the introduction many have questioned whether ARVs can be successfully distributed in poor marginalized communities in Sub Saharan countries. When interviewing the organizations and asking them what kind of changes or formal interventions that have been most important for HIV positive people in the village a substantial part of them are focusing on the provision of ARVs. The clinic in the village cannot initiative ARV treatment and only 90 patients get their ARVs sent to the clinic. However, the clinic leader still highlighted the positive effects of ARVs in the area. She

told me that before ARVs became available there were few HIV positive people who came to the clinic and nurses were uncertain about how to consult and support a patient who tested positive.

> Those years they were very difficult. And by that time there were no ARVs except in private organizations. So if was just like telling a person...giving a person a death-sentence if you are saying a person is HIV positive. You don't know how to help him or her (Leader, Clinic).

Many of the organizations are mentioning how the introduction of ARVs made it easier for people to come forward and disclose because there was treatment available.

> Well it has brought hope into this situation, in some cases it is starting to reduce stigma. I am not so sure about behaviour change. Now in a consultation a patient is more likely to say up-front: "I am HIV positive, I know, and my last CD4 count was 350 or... " . So you are getting more of those sorts of consultations where people are more open about it (Leader, District hospital).

However the district hospital and the FBO also highlighted the structural challenges connected to implementing the ARV roll outs and how the ARVs have distorted and extended the pressure on the health sector.

> Well there is treatment available now and the AIDS movements. It is improving. It is more ARV roll-out. The roll-out in some cases is becoming more efficient. In some cases they just become overloaded and they can't cope. So their quality of care is going down. It just depends (Leader, FBO).

> It has brought huge challenges in terms of it is a fairly technical intervention and it has distorted health care funding and it has distorted this hospitals operation (Leader, District hospital).

The general impression from interviewing the organizations is that the governmental administrated ARV roll outs have brought hope into the situation for HIV positive people in the village and have made people come forward for testing because they know there is treatment available. While some organizations are mentioning increased workload as a negative effect of

the ARV intervention the hospital also focused on how the introduction of ARVs had freed resources in the hospitals.

> The one advantage it has given is that there are people out there that would have been using a big chunk of other resources and then dying who are now well and out of the system (Leader, District hospital).

3.4. Constraints for Efficient Healthcare in the Community

When analyzing the interviews conducted with both the formal and informal organizations several constraints for efficient provision of treatment, care and support emerged. The constraints mentioned most frequently were 3.4.1. *Lack of Human Resources*, 3.4.2. *Lack of Material Resources,* 3.4.3. *Access to Transport,* and 3.4.4. *Stigma.*

3.4.1. Lack of Human Resources. The problem most often mentioned by the organizations was lack of human resources to provide care and support, provide home based care and administrate extended ARV roll outs. When interviewing the different organizations a substantial part of them were focusing on the acute need for home based care and other kinds of care and support in the community.

> There is just not enough hospital bed in South Africa for the number of sick patients that are coming. So that is a reality. So those patients have to be attended to by home based carers or by their families with no support from home based carers...(Leader, district hospital).

According to the leader of "the volunteers" they are 30 members caring for approximately 586 patients in the village. With the 28 member of the CHWs added too that would be 58 home based carers to care for more than 500 people in a fairly big area.

> We need support because the community they need us. They need us too much. Even the home based carers that did not come. -They phone to me: "I didn't see you lady today! Where is she?" I most phone to her, go to that house. They need you (Leader, "the volunteers").

The district hospital also mentioned the lack of human resources in the South African health system as a barrier for implementing the NSP and its intention to provide 80% of all people diagnosed with HIV access to treatment, care and support. Although only approximately 25-30 % of all HIV positive individuals who need medical treatment in the area have access to ARVs the district hospital leader told me that this is the maximum number of patients that the hospital is capable of attending to with its current staff and resources.

> So we are all overwhelmed! And there is no way if you look at the resources available to the sub district at the moment the physical and the personnel that we can cope with the theoretical number of patients that need treatment. It is sad, but in some ways it is actually good that they are not all coming knocking at our door. Cause we wouldn't be able to attend to them. (Leader, District hospital).

The FBO was also mentioning the lack of staff as a barrier for implementing the NSP and how the pressure on the understaffed healthcare system leads to burnouts and brain drain. She told of an ARV rollout in the area where the number of patients raised from 100 to 6000 patients without increasing the numbers of staff.

> ...But that is the biggest problem, -they got this lovely plan but they have not increased staff. And so that is why it is not working (Leader, the FBO).

According to the clinic leader they do not only need more staff but also qualified health personnel to treat serious conditions and initiate ARV treatment.

> ...Because we are not accredited to initiate so even in other clinics they refer to initiative sides, the accredited sides. Because it should be a doctor, pharmacists, occupation therapist and social workers so here we don't have those people (Leader, Clinic).

3.4.2. Lack of Material Resources. The lack of human resources is related to the more general lack of material resources in the community. Most organizations spoke of the lack of overall service delivery as a major barrier for providing treatment, care and support.

You may be willing to help but the main problem is that we don't have the necessary resources to do our support to this people. So if it's beyond our power we don't do anything (Leader, traditional healers).

When asked what kind of resources they needed to be able to carry on with their work both "the volunteers" and the traditional healers said they would like to have a house or a unit where they could provide care to the sick in the community.

So let's say… because we haven't got resources, so they need resources because we want to take them to stay at our place, in the morning, afternoon we must take them to their house. Now we haven't got nothing for the time being. We need help (Leader, "The volunteers").

Both the CBO, who received help to build a house from private donors in the village, and the FBO who built a respite unit in 2008 focused on how the new facilities improved the quality of healthcare significantly. The leader of the CBO told me that they realized that there was a need for treatment and care in a communal setting when they saw more and more people who were left in their houses dying alone and not cared for because other family members were dead. In addition they saw that children were taken out of school to care for sick family members.

So admitting people into a controlled environment where you are giving them love. You are giving them a bed, you giving them three meals a day and giving them whatever medicine they need. They take it regularly. It is incredible. What happened is: In that first year; from February to December 53 patients that was actually admitted to die got up and went home and they are still doing well. What we realized then is that there is a place for respite care (Leader, FBO).

The councillor of the CBO and the leader of the district hospital leader also highlighted the need for restructuring the clinic in the village and give it more resources to help the community.

The first thing I would make sure….-because it is not easy to build a hospital. I can make sure that the clinic has all the things that is needed by the community (Councillor, CBO).

… The district hospital should be a resource for the district ok. But the people should be treated closer to their homes. In other words there is no reason (District Hospital) should

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be treating all 25 000 people. There should be government ARV initiation sites started throughout our sub district...(Leader, District Hospital).

3.4.3. Access to Transport. Transport appeared to be a big problem in the community as a result of inefficient roads, steep and hilly landscape and the long distances to surrounding hospitals and clinics. The problem is also connected to the lack of public transport and lack of money to pay for mini-taxis that are the only way of transport for the majority of people in the village.

> We got big challenges in the communities. Because they others are too far. There are no roads, we are just going this small places. So it is too much challenges (Leader, "The volunteers").

> Remember the trip to a hospital for some people is a big issue, it cost them a lot of money. And some might prefer to die at home actually. If some of the issues around stigma and other things can be addressed or can be looked after (Leader, District hospital).

The councillor of the CBO told me that if somebody becomes sick and is not able to travel to hospital for whatever reason it can take days before an ambulance arrives. In addition the leader of the CBO said that they started giving HIV positive people money for transport because the organization experienced that people were defaulting treatment because they did not have money to pay for the mini-taxis. When asking what was the biggest constraint for providing treatment, care and support for HIV positive people in the area, the leader of the FBO answered transport because many of their patients defaulted treatment after they had left the unit.

> ...We then get them into ARVs and they do very well. Their CD4 then gets over 200 –the government takes their disability grant away ok. Because they are well now, they can work. But they are unemployed and they can't get work. So what happens is without that thousand rand they have no money to get to clinic. They have no bus–fee. So they default on treatment. They end up back in the unit. They developed resistance and they die. And that we are seeing a lot of. (Leader, FBO).

3.4.4. Stigma. Most of the organisations talked of the stigma and shame connected to disclosure as a barrier to access treatment, care and support for HIV positive people. Even after education programs, awareness campaigns and the introduction of ARVs stigma still seemed to be a major problem in the community. The CBO emphasized stigma as a factor that could explain why many people were reluctant to go for treatment and testing in the village clinic.

> Well it seems like the clinic is supposed to be the first step, but a lot of people would miss that step, because of community, I think. Because it is a small community. People that live here they have lived here their whole life and they all know each other and just about all are related. And I think the stigma... and maybe there has been some gossip or whatever. So some people would prefer to go out for an initial test (Leader, CBO).

The clinic on the other hand was the only organization I interviewed who argued that stigma is a fading problem and that HIV positive people would come to the clinic if only the ARVs were accessible.

> The challenges are those who still fear to go forward. Even if they suspect they might…there are those who still fear. But with persistent consoling and telling them that there is ARV that does work. You better test early. Because if you start ARV when your CD4 is very low you are likely to become very sick (Leader, Clinic).

The community organizations that are providing care and support to people in their houses generally reported stigma to be a bigger problem in the community than the leader of the clinic did. The CHWs told me that stigma is serious problem for them because patients do not want to reveal what kind of condition they are suffering from when they are going from house to house. In addition the leader of "the volunteers" said that people often are hidden in their houses because families do not want to be associated with having an AIDS sick person in the house.

> It is difficult with AIDS because many people do not like to disclose their status. So the only way you get treated, get medical attention, is when you disclose. The ...(CHWs) take you to the clinic and they check your CD4-counts. In many cases when they find your status it is below 200 because many people do not disclose their status. They keep quiet and by the time when they decide to disclose their CD4 counts have already dropped (Leader, "CHWs").

When HIV positive people finally are coming for treatment either by their own initiative or by the help of the home based carers or family it is often too late to start efficient treatment. This point is also mentioned by the district hospital leader.

> Although I am still concerned about stigma and all the barriers for people to get care because we still get people who present CD4 counts that are less than 50. They are coming very late in the disease. And there are multiple reasons for that, but it is concerning (Leader, District hospital).

In sum: The overall results indicate a fundamental lack of staff, qualified health personnel and resources inside the community to carry out the tasks that are necessary for implementing the NSP and reach the targets when it comes to treatment, care and support. The organizations highlighted the need to upgrade the infrastructures in the village and to increase the quality of treatment for PLWHA. Building more healthcare units and upgrading the clinic with staff and resources were some of the suggestions to achieve this.

Transport, money constraints and lack of staff at hospitals and clinics were mentioned as the major constraints for getting efficient treatment, care and support outside the village. Lack of resources and stigma were seen as the most serious challenges connected to providing HIV positive people with treatment, care and support inside the village. There was a tendency toward lack of coordination and confusion in the community related to what role the different organizations play and what kind of care and support they provide. The level of community participation and cooperation between organizations in the community, both formal and informal, seemed to be high and were generally reported as good. Cooperation and communication between the community and the government was generally reported as poor or non-existing with the exception of cooperation with the governmental funded clinic and the "community health workers".

4. Discussion

This chapter is divided into four themes where the results are discussed in relation to the research questions and the theory of social capital. The four themes are; *4.1. Participation, Volunteering and Healthcare in the Community*, 4.*2. Cooperation and "Bridging" in the*

Community, 4.3. Cooperation and "Linking" between Formal and Informal Healthcare and *4.4.*
Constraints for Efficient Healthcare in the Community. Implications of findings and
recommendations for interventions will be discussed throughout the chapter and summed up in
the theme; 4.5. *Overall Implications and Recommendations.*

4.1 Participation, Volunteering and Healthcare in the Community

The levels of participation and volunteering connected to HIV/AIDS in the village seems
to be high with several organizations helping people with access to grants, healthcare access,
testing, feeding schemes, orphan care and home based care. Most of the organizations which
provide care and support to HIV positive people in the village are volunteer or informal groups
who work with no economic or other tangible support from the government. The results are
similar to those found in a study by Russel and Schreider (2000) who analyzed 20 different
communities and support projects in South Africa and concluded that the majority of them were
functioning with no or little external support. Only a few were supported by provincial or local
governments. The most common tasks for the community groups were funding and support,
facilitation of welfare services, education, counseling, income generation and home based care.
The tasks of the community groups found in the 20 communities resemble what I found in the
investigation of community participation in my study. The congruence could indicate that the
results found in the research area related to community participation and healthcare structure
might be similar in other poor marginalized communities in South Africa.

Many have suggested that South Africa`s inefficient reaction to the HIV crisis and the
slow roll out of ARVs in the country is a result of the existing burden on the health structures
and the lack of fiscal resources available (Chopra et al., 2009; Benatar et al., 2004). According to
this view a government focus on home based care and community based care in poor
marginalized communities is an adequate strategy to cope with the epidemic (Uys, 2003; DOH,
2001). The use of home based care allows patients to be treated in their homes surrounded by
family and loved ones and frees resources for transport and hospital admissions (Uys, 2003).

Several of the organizations I interviewed spoke of the need for home based care in the
community and the important role the home based carers play when it comes to providing care
and support to the sick. The results indicate that the levels of community participation and home

based care in the community are necessary for patients who have fallen through the gap in the healthcare system. This is in accordance with the social capital theory and the proposition that increased levels of civic participation in a society also will increase the levels of health (Putnam, 1995).

However, the home based carers report that they are exhausted from the heavy workloads and the long distances they have to walk. A majority of the organizations underline the need to have a house or a unit where they could treat their patients. They argue that a healthcare unit would solve some of the problems connected to transport and long distances and would assure that patients are supervised and cared for at all times. Their argument is in accordance with Chopra et al. (2009) who recommend a stronger focus on district models of care, to bring care closer to the communities, and a more equal distribution of resources between primary community care and tertiary-level hospital care. Achmat and Simcock (2007) also suggest that community care workers must be given more resources and training to ensure higher levels of specialization and responsibility at the primary care level. Increased mobilization of communities and the scale-up of mid-level workers could be one way to solve the bottlenecks in the health system and increase healthcare provision in poor marginalized communities according to Chopra et al. (2009).

Findings from my study show that many of the informal organizations are governed by only a few community members and that the organizations were created on the initiative of one person, or a small group, to help the community. All the informal and volunteer organizations are nonprofit organizations created to help the community and to fill the gap in the governmental healthcare, as reported by the FBO leader. There is no indication of motivation for personal gain or profit for the founders of the organizations except the wish to help fellow community members. At the same I am aware that it is difficult to reveal underlying motives in my kind of study and that there is always the danger of getting socially acceptable answers when interviewing respondents. In their study of the 20 communities Russel and Shreider (2000) found that the willingness to participate and to volunteer varied a lot from community to community. The programs that had managed to successfully recruit and incorporate volunteers were those

who targeted respected community members such as leaders and church members and who used incentives like stipends or uniforms.

The results could indicate that a high level of participation and volunteering is not enough to provide efficient care and support if the organizations intended to do this are not supported from the outside. This is in line with Foley and Edwards (1999) who argue that social capital has to be defined as access plus resources and that increased social capital in a community has to be built both "internally", through increased participation and volunteering, as well as "externally" through resources, support and coordination of healthcare programs.

If the government wants to facilitate volunteering and participation in the communities, to relieve some of the pressure on the formal healthcare system and to achieve the targets in the NSP, it seems crucial that they respond to private initiatives in the communities and support them to make the organizations sustainable. Increased support and stipends to volunteers and informal groups, and help to build healthcare facilities inside the village, are interventions recommended by some of the organizations. This would mean increased spending for the government to the private community groups providing healthcare in the village. On the other hand it would probably be cheaper than spending money on formal healthcare workers who otherwise would have to provide home based care in the village from distant hospitals and clinics. A study from 2002 analyzing the cost of home based terminal care for people with AIDS in South Africa showed that the cost of terminal home based care was R 2 840 per patient per year compared to hospital costs of R 2 522, and the primary clinic care cost of R 1 154 per year. The study concluded that the higher cost of terminal home based care, and the lowest cost of primary clinic care, was related to the extended training of health care workers and the cost of vehicles required for staff transport in rural areas (Uys and Hensher, 2002).

One reason for the lack of support to private initiatives taken in the community could be that the government is unaware of what is going on in the community and that there are no structures in the current healthcare system to channel this kind of information. If this is the case then the creation of programs to map out informal groups in marginalized communities and to investigate how these groups could be supported would be one way to uphold and sustain the

important level of civic participation found in this study and in studies conducted in other South African communities (Russel and Schreider, 2000; Campbell, Nair, Maimane and Sibiya, 2005).

4.2. Cooperation and "Bridging" in the Community

Cooperation and communication among organizations in the community, both formal and informal, are apparently functioning with minor constraints while the organizations highlight the need for a better cooperation with formal healthcare outside the village. The results show that the cooperation between organizations follows a horizontal level of groups and people who are similar in background and status, while there seemed to be a lack of cooperation between groups or people across vertical structures in the healthcare system. According to the social capital theory the results indicate a high level of "bridging" in the village and a similar low level of "linking" between the village and governmental structures (Derose and Varda, 2009).

All the organizations located in the village reported that they were cooperating and communicating with each other to increase the level of healthcare in the community. The clinic leader reported that she gets help from home based carers to trace patients who miss appointments at the clinic. In addition she pinpointed the importance of cooperation with the CBO who provide patients and other community members with food and feeding schemes. The CBO highlight their cooperation and communication with the "CHWs" as a tool to make the home based care work in the village more efficient. In congruence with the social capital theory the reported high level of "bridging" seems to contribute positively to the level of healthcare access in the community (Derose and Varda, 2009).

However, the organizations reported that they were lacking resources to work efficiently and to coordinate their work. According to the leader of the CBO and the district hospital leader there seemed to be some cooperation problems connected to lack of coordination and some misunderstanding in the community related to what kind of work the different organizations were doing. Whether the CBO and the district hospital are the only organizations that have experienced difficulties related to cooperation and communication or if the other organizations are unwilling to discuss this issue with an outsider is an open question. In any circumstance the challenges connected to cooperation mentioned by the CBO and district hospital leader have

been found in other studies on community health care work in South Africa (Russel and Schreider, 2000; Campell et al., 2005).

Problems related to coordination of healthcare work were found in a majority of the 20 communities that Russel and Schreider (2000) investigated. When interviewing HIV positive individuals they found that many had difficulties applying for disability and welfare grants. HIV positive people did not know how or where to apply for grants and there seemed to be little or no standard criteria in the communities regarding who was qualified for healthcare. Coordination of the community work was often found to be a problem leading to lack of standardization, monitoring and possible duplication of work and activities (Russel and Schreider, 2000). The provision of support and stipends from the government varied a great deal between the different volunteer groups. The struggle for resources and the potential conflicts, envy and misunderstanding that can be created because of this was also something that was highlighted by several of the organizations I interviewed. Better coordination and communication and more knowledge in the community on how the resources are distributed would probably reduce many of those problems (Russel and Schreider, 2000). Interventions to help the community with coordination of work, either by educating the organizations in administrative work or by hiring persons from the outside to help coordinate, could be ways to increase "bridging" in the community and thus increase the level of social capital.

4.3. Cooperation and "Linking" between Formal and Informal Healthcare

The results indicate a lack of communication and cooperation between the community and governmental institutions. Many of the organizations I interviewed (e.g. "the volunteers", "the CHWs" and the traditional healers) reported that their distant or irregular relationship with government was an obstacle to working efficiently in the village. According to the social capital theory the lack of cooperation across different horizontal structures in a society can hinder efficient healthcare and decrease social capital in a community (Putnam, 1995).

The results also revealed resistance from some of the organizations to working more closely with the government. The CBO and the FBO were both focusing on how they wish to remain independent from government policy and how they do not trust the government as a sustainable funder. The wish from some informal organizations to have a sustainable

organization and to work independently from government is understandable, especially after the government's recent controversial stands on HIV/AIDS and its many shifts in HIV/AIDS strategy. Yet, according to Chopra et al. (2009) a better cooperation and coordination of healthcare between formal and informal organizations would be necessary to implement the NSP and to improve conditions for HIV positive people in South Africa. To achieve this, the government would need to give independent HIV/AIDS organizations, working in isolated communities, more responsibility and resources to sustain their work according to Chopra et al. (2009).

Governmental support and increased responsibility to informal organizations have been reported to be factors in Uganda's successful HIV/AIDS policy (Parkhurst and Lush, 2004). Uganda and South Africa are often compared because both countries have a history of political upheaval in the 80's and 90's, and because both countries experienced a catastrophic increase in HIV cases in this period. While South Africa today is the country in the world with most HIV positive people, Uganda is often used as an example of how a poor, developing country in Africa can change a catastrophic HIV/AIDS situation for the better (Parkhurst and Lush, 2004). Parkhurst and Lush (2004) argue that Uganda and South Africa chose different strategies with regard to the use of NGOs and CBOs in the countries. They discuss whether Uganda's success in reducing its HIV prevalence was related to its close cooperation with NGOs, religious organizations, donors and self help groups in the country. Since Uganda lacked a strong management and a national bureaucracy, much of the responsibility for HIV and AIDS work was transferred to NGOs and local groups. These groups got economic and political support from the government but were otherwise working independently (Parkhurst and Lush, 2004).

The AIDS policy in South Africa however had little connection with the NGOs and CBOs in the country, according to Schneider and Stein (2001). The AIDS interventions were based on the old health systems where doctors and hospitals were the focus areas. The system weakened the autonomy and influence of clinics, NGOs, nurses, and other health personnel at the same time as the growing AIDS crisis increased the need for a broader response, according to Schneider and Stein (2001). The pressure on hospitals and expertise created bottle-necks in the

South African healthcare system as the numbers of sick people increased (Schneider and Stein 2001; Benatar et al., 2004).

The lack of hospital beds, health personnel and ARV treatment, and the gap in the healthcare system as a result of this, is also something that is emphasized by the organizations that were interviewed in the research area. The high level of participation and volunteering in the village seem to fill some of the gap but still the organizations interviewed report that there is a need for human resources and qualified healthcare personnel to treat serious conditions and to provide treatment, care and support in the village. The clinic inside the village reported that they were unable to initiative ARV treatment because the clinic lacked doctors, pharmacists, occupational therapists and social workers.

As the formal healthcare sector is suffering from heavy workloads connected to HIV/AIDS, brain drain and the high prevalence of HIV among health personnel, a broad recruiting of other healthcare workers in South Africa seems necessary (Benatar et. al., 2004; Chopra and Ford, 2005). If the cooperation and linking level between community and government could be increased then programs to empower and educate volunteers and healthcare workers in the communities could be one way to meet the increased demands of more qualified healthcare personnel in the communities according to Campell et al. (2005). They argue that there has been too much focus on medically trained personnel such as doctors and nurses in South Africa when it comes to human resources necessary for implementing the treatment plans and rolls out of ARVs. Campell et al. (2005) highlight the role of grassroots community representatives to help in the implementation of treatment, care and support to bridge the gap found between poor marginalized communities and formal health services.

4.4. Constraints for Efficient Healthcare in the Community

The four major constraints for efficient healthcare in the village were found to be lack of human resources, lack of material resources, limited access to transport, and stigma. Most of the problems connected to providing efficient treatment, care and support to HIV positive people in the village were connected to the lack of staff and human resources. This was also found in a study from 2004, which analyzed access to treatment in southern Africa (Malawi, Mozambique, Swaziland and South Africa). It concluded that human resources were the single most important

factor for successful implementation of the countries HIV and AIDS plans (Kober and Van Damme, 2004). In addition, Achmat and Simcock (2007) draw attention to the problem that nurses and healthcare workers, intended to play an important role in the fight against AIDS and in the implementation of NSP, are two of the professions in South Africa with the highest rates of HIV infection (Achmat and Simcock, 2007).

The leader of the FBO reported that they had experienced that many patients were left in their homes and not cared for because other family members had died. In addition many patients could not adhere to their treatment because there was no one to accompany them to the hospital or the clinic. As a consequence the FBO built a respite unit where patients were given love, care, food and help to take their medicines at regular times. According to the leader of the FBO this strategy has shown great results and she reported that many patients who actually were admitted to die had got up and gone home. She highlighted the need of home based care in a controlled setting because ARVs were becoming increasingly more accessible while at the same time there were less people to care for the sick in their own houses. The combination of giving treatment and home based care in a controlled setting has shown similar successful results in community projects by Medecins Sans Frontieres (MSF) in rural areas of Western and Eastern Cape (Coetzee et al., 2004; Achmat and Simcock, 2007).

Many of the organizations also spoke of the lack of skilled healthcare workers to initiate ARV treatment and the long distance to hospitals and initiate sites as constraints for providing adequate healthcare in the village. The problem often discussed in relation to the question of extended ARV roll out in South Africa is the financial cost and the challenges of distributing medicines in poor marginalized communities with little infrastructure. In 2001 the head of USAid Andrew Natsios infamously remarked: "[Africans] do not know what watches and clocks are. They do not use western means for telling time. They use the sun" (Avert, 2009). The remarks came in a debate regarding the possibilities of starting to rollout ARVs in rural areas in Africa and the importance of patient adherence to strict medicine regimes. Others have argued that if it is possible to distribute Coca Cola and beers to every little remote corner of Africa the same should be the case for medications. This view is congruent with my observation from the field where I saw at least three liquor shops inside the village, each one with a varied selection of

drink and foreign labels, but only one clinic were 90 patients received ARVs from distant initiative sites. If the HIV prevalence in the village is the same as the provincial average (which is probably a small estimate) then 2 000 of the 10 000 inhabitants are HIV positive and would need treatment, care and support at some stage. As only 90 patients receive ARV treatment from the clinic the others would have to travel long distances to the nearest hospital or other initiative sites to get treatment. Achmat and Simcock (2007) are discussing whether extended ARV roll outs actually will be cost effective because the medicines give HIV positive people, that otherwise would have stayed sick for a long period and been an economic burden for families and health facilities, an opportunity to live a relatively long and healthy life. This point is also stressed by the district hospital leader though he at the same time highlighted the need for more ARV initiative sites spread around the district to relieve some of the pressure put on the district hospital. Studies from Brazil, which already in 1996 started producing cheap generics of ARVs and granted free treatment to all HIV positive people in Brazil, is supporting the theory that extended ARV roll-outs can be cost effective (UNAIDS, 2005).

However, the results indicate that limited access to transport could be a factor that could be a potential obstacle for efficient up scaling of ARVs in South Africa. The majority of the organizations interviewed report that patients would have to travel long distances to collect their ARVs outside the village and that they often lack money to pay for the mini-taxis which is the only means of public transport. The leader of the FBO tells that many of the patients, who they have successfully managed to admit to a treatment program, later develop resistance and die because they lack money to go for their treatment appointments. This was also found in a similar study in KwaZulu-Natal where Campell et al. (2005) conducted 60 in-depth interviews and focus group interviews with different local residents who either were HIV positive or healthcare workers.

The results also indicate that stigma remains a constraint in the village. Though the clinic leader reported stigma to be a fading problem her impression is possible based on conversations with HIV positive people who are coming to the clinic and who are open in the first place. The home based care groups on the other hand reported stigma to be a major problem in the village and that many of their patients still refuse to disclose or are hidden in their houses. The study by

Campell et al. (2005) in KwaZulu-Natal revealed that stigma remained a serious constraint for providing treatment, care and support in the area. Many people would not talk openly about their status and health workers were unaware of what conditions the patients were suffering from. This point was also pinpointed by the leader of the "community health workers" in my study.

Russel and Schreider`s 2000 study sheds light on the problem related to stigma and the fine but significant distinction between confidentiality and secrecy when it comes to the issue of HIV/AIDS. Many felt that confidentiality was doing more harm than good and that secrecy around HIV/AIDS in the communities was "killing" people instead of protecting them (Russel and Shcreider (2000). Community health workers and people conducting home based care often reported that they had to lie about why they were visiting people and as a result people in the communities often were unaware of the problems connected to HIV/AIDS and the fact that there was help available (Russel and Shreider, 2000).

Yet, a substantial number of the organizations I interviewed were talking about how ARVs have been an important tool in the fight against stigma. According the clinic leader disclosure seemed to be easier for many HIV positive people when AIDS was not longer regarded a death sentence. Several of the organizations mentioned that people were more motivated to go for testing when they knew there was treatment and care available. The findings is in accordance with Derose and Varda`s (2009) who suggest a better "linking" between formal health care and underserved communities can facilitate trust and increase marginalized community members willingness to use the formal healthcare.

On the other hand some of the organizations interviewed are focusing on the tendency that many people seek help outside the village because they are afraid of gossip and the chance of meeting people they know at the clinic. Increased access to ARV from the clinic, as many of the organizations recommended, will not be efficient if people still travel long distances to the nearest hospitals to remain hidden. Interventions to educate and empower nurses and healthcare workers to initiate ARVs at the clinic would therefore need to go hand in hand with programs to fight stigma and promote acceptance in the community. The combination of educating and empowering nurses and healthcare workers and promoting openness and acceptance around

HIV/AIDS is also found to be the most significant factor for the successful interventions by MSF in Western and Eastern Cape (Achmat and Simcock, 2007; Coetzee et al., 2004).

The project by MSF in the poor community of Lusikisiki in Eastern Cape showed greater access and adherence rates in primary care clinics than in secondary care clinics (Achmat and Simcock, 2007). Achmat and Simcock (2007) are discussing whether this could be related to the lower levels of cost and travel time for patients using the primary care facilities. This factor was also highlighted in a study about the MSF project in Khayelitsha, a township near Cape Town, where Coetzee et al. (2004) concluded that the high adherence rate found in the study could be related to services being situated close to the patient's homes and family environment. Coetzee et al. (2004) concluded that a firsthand knowledge about each patient is important due to the complex nature of ARV treatment. As a consequence he recommended small health facilities spread out in the districts with a manageable number of patients rather than having a few big initiative sites and hospitals where patients often were lost and disappeared in the system. The MSF projects showed no difference in treatment provision and adherence rates in the clinics mainly staffed by nurses compared to hospitals or clinics with doctors (Achmat and Simcock, 2007). All the professional nurses in the poor marginalized community of Lusikisiki were trained to initiate and monitor ARV treatment similarly as community based health workers were used as HIV/AIDS educators and adherence counselors (Achmat and Simcock 2007).

The success in Lusikisiki and Khayelitsha, after giving nurses increased responsibility to initiate ARV treatment in primary care clinics, and the high access and adherences rates after using community health workers as councilors, could indicate that it is possible to empower a community to tackle the challenges connected to HIV/AIDS despite constraints like stigma, lack of professional healthcare workers and limited access to transport. However, to make this happen a broad recruitment of community healthcare workers to participate in the provision of healthcare seems necessary. At the same time those healthcare workers would need to be supported from the outside with education, guiding and resources. Coordination of work and cooperation between the community and the government would be essential to recruit and

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empower volunteers and other healthcare workers to meet the needs of PLWHA in marginalized communities (Chopra et al., 2009).

The studies of the MSF projects in Lusikisiki and Khayelitsha could be interpreted as a support of the social capital theory and the postulate that increased community participation, "bridging" and "linking" would lead to higher levels of healthcare and health in a community. On the other hand the studies could also be read as an indication that community participation, "bridging" and "linking" would need to go hand in hand with external support and coordinative strategies to empower the community.

4.5. Overall Implications and Recommendations

To solve the problems connected to providing efficient healthcare to HIV positive people in the village some overall suggestions for implementations follow:

1) Increase support and stipends to volunteers and healthcare workers participating in the provision of care and support to HIV positive people and help them build healthcare facilities inside the village. This could motivate and sustain community participation in the village which is important for the promotion of social capital and healthcare in the community. Building more healthcare facilities in the village could give groups providing care and support an opportunity to treat patients under controlled conditions and at the same time save money, time and energy spent on walking or transport.

2) Empowering and educating nurses and healthcare personnel at the clinic to initiate ARV treatment in the village. This could solve the problems connected to lack of human resources and the lack of professional staff in the village. At the same time it would solve some of the problems connected to lack of transport to distant hospitals and initiatives sites.

3) Develop programs to fight stigma and promote acceptance and disclosure in order to facilitate testing, treatment and access to care and support in the village.

4) Develop programs to coordinate healthcare work in the village and increased communication between those involved in community healthcare work and governmental healthcare plans. This could be a way to increase the flow of resources and information between the different vertical structures in the healthcare system and bridge the gap between marginalized communities and the government that has been found in many studies (e.g. Russsel and Schreider , 2000; Campell et al., 2005; including mine).

5. Limitations of the Study

This study was a qualitative investigation of a particular research area and findings should not be generalized to other areas without further investigations. As a bottom-up approach was used representatives from the governmental healthcare system were not interviewed and their views only presented through public statements by the Department of Health and the NSP (2007-2011). Additional information from people representing the government or answers to critics of the current healthcare policy has therefore not been included in the results. There is also the possibility that there exist other groups in the community with different views than the organizations I interviewed. The method of snowball sampling to recruit organizations may have contributed to the high level of networking and cooperation reported in the community. Interpretations of information and answers given in the field may have been biased or influenced by my different cultural background. There is always a possibility that a researcher who is coming to a community as an outsider will get different kinds of answers and information than a researcher who knows the community. These are some of the advantages and disadvantages connected to doing qualitative research.

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7. Appendix

7.1. Interview Guide

1.   When and how was your organization started?

   a, How many members are working in your organization?

   b, What kind of work do you do?

2.   How is the leadership of the organization organized?

3.   What is the purpose and goal of your organization?

4.   Does your organization cooperate with other government or nongovernment organizations working with HIV/AIDS?

5.   How would you describe your organizations relationship with other organizations working with HIV and AIDS?

6.   Which organizations do you work mostly with?

7.   What is your opinion on the work that the Government and the health department do in connection to HIV/AIDS in your community?

8.   Does your organization get any economic support from the government?

9.   Does your organization get any guidelines from the government on your work with HIV/AIDS?

10.   What kind of support from the government do you think would be most helpful for the people affected by HIV/AIDS in your community?

7.2. Extract of Analyzing Process

So admitting people into a controlled environment where you are giving them love. You are giving them a bed, you giving them three meals a day and giving them whatever medicine they need. They take it regularly. It is incredible. What happened is: In that first year; from February to December 53 patients that was actually admitted to die got up and went home and they are still doing well. What we realized then is that there is a place for respite care (Leader, FBO*). (8, 9, 10, 11.)*

8. From HBC to controlled setting, 9. Volunteering, 10. Many on ARV got up and went home, 11. Respite Care.

Yes. I even attend their meetings, because I should to gain their confidence. I even attend their meetings, if they do have meetings. Otherwise, if I don't attend, there would be friction. (Leader, clinic). *(69, 70.)*

69. Clinic has positive relationship with traditional healers, 70. Clinic work with traditional healers to build trust and avoid friction.

And I think another thing is that government needs to avail themselves to the community, because you can see that if I want to communicate with the minister. Other people don't know how to, and they think that you are not allowed to communicate with the minister (Councillor, CBO). *(105, 106.)*

105. Government needs to avail themselves to the community, 106. People don't think they are allowed to communicate with the ministers.

Extract of Codes:

1) Challenges come about
2) Home Based Care project
3) Respite Unit
4) No person at home to care for the sick
5) More people on ARV
6) Get those (patients) on treatment so they can live a long life
7) HBC in controlled setting
8) From HBC to controlled setting
9) Volunteering
10) Many on ARV got up and went home
11) Respite care

60) Much networking in the community
61) Transferring patients from clinic to hospital because clinic got no doctor
62) Clinic getting support from government
63) Not enough budget for clinic
64) ARV treatment makes people come to the clinic
65) Previously people thought AIDS was witchcraft
66) People don't think AIDS is witchcraft anymore
67) Important to build trust with the HIV positive people
68) Clinic doing education
69) Clinic has positive relationship with traditional healers
70) Clinic work with traditional healers to build trust and avoid friction

105) Government needs to avail themselves to the community
106) People don't think they are allowed to communicate with the ministers
107) Words need to come from the mouths of one in the department
108) Government need to come to the community and see what is happening
109) Church based organization
110) Started feeding the community
111) Political change
112) Social problems
113) Helping getting grants
114) Helping orphans
115) Orphans often extra burden for extended families

7.3. Request for Participation in the Research Project

Informed consent:

Research Project; Understanding care and support in relation to HIV/AIDS

This project looks at how people are experiencing the organizations of treatment care and support in relation to HIV/AIDS in the community you are living in. The research is conducted by University of Kwa-Zulu Natal in cooperation with the University of Oslo, Norway and all the people that may ask you questions have been trained by the Universities. Your name and the information you provide will not be known by anyone and your name will not be filled in on any forms. All informed will be safely stored within the university premises and kept under lock and key and will only be disposed of after five years. All the information you provide will be kept anonymously. It will take about an hour to answer all the questions. Your answers will help us to understand issues relating to treatment, care and support in your community. We hope that the results of the study will inform ways in which care and support for people with HIV/AIDS can be increased. If you have any doubts or concerns you can speak directly to the researcher Staale Vaage at 0761552724, project leader Prof. Yvonne Sliep directly at 082-4989343 or to an independent person in the research office Ms. Phumela Ximba at 031-2603587. Please ask any questions if you want more clarification. If you are willing to participate in the study please sign the document. You can refuse to participate in the study or withdraw from the project at any time you wish to do so.

I…………………………………………………………………(full names of participant) understand the contents of this document and the nature of the research project, and I consent to participating in the research project.

SIGNATURE OF PARTICIPANT   DATE

………………………………………………………………………………………………………

7.4. Statements of Approval