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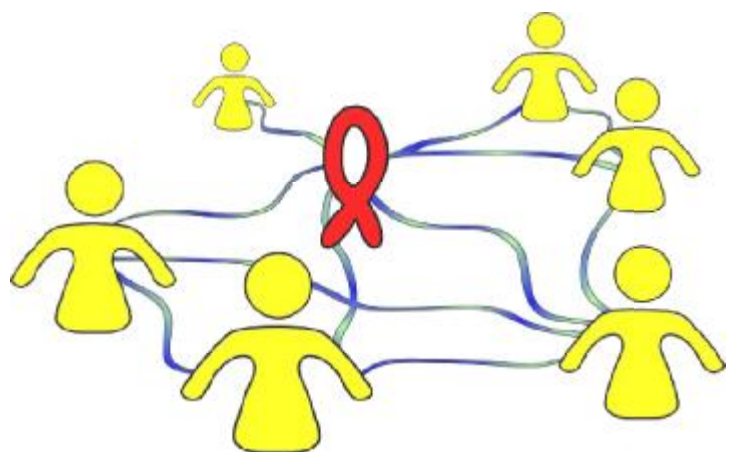
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Formal and Informal Care and Support for People Living with HIV/AIDS in Two Sites in Botswana

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PHD Thesis
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February 2009



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Formal and informal care and support for people living with HIV/AIDS in two sites in Botswana

Daniel Turner
PhD Thesis Summary

The increasing availability of anti-retroviral drugs (ARVs) allows for the possibility of extended lives for the 36.8 million people living with HIV/AIDS (PLWHAs) across the world. Yet the drugs alone do not tackle the psychological and social problems of HIV, needs which are met by large networks of support, which including family, friends, NGOs support groups and government services. This research investigates these networks of social support for PLWHA using qualitative participatory research methods in Botswana, where many structures exist to provide help for PLWHA in a context where ARVs are freely available. Focus groups, participant diaries and interviews with service providers detail a complex landscape of care, which PLWHA utilise to get the help and assistance they need. A special emphasis is placed on the complex role of support groups, shown as a critical source of support which are currently under-researched in the literature. The study also illustrates the problems in networking between a myriad of NGOs, CBOs and government service providers, demonstrating issues of communication, governance and power.



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Glossary

ACHAP	African Comprehensive HIV/AIDS Partnership
ART	Anti-Retroviral Therapy
ARV	Anti-RetroVirals
ASO	AIDS Service Organisation
AIDS	Acquired Immune Deficiency Syndrome
BBCA	Botswana Business Coalition on AIDS
BOCAIP	Botswana Christian AIDS Intervention Programme
BOCONGO	Botswana Council of Non-governmental Organisations
BONASO	Botswana Network of AIDS Service Organisations
BONELA	Botswana Network on Ethics, Law and HIV/AIDS
BONEPWA	Botswana Network of People living With HIV/AIDS
BORNUS	Botswana Retired Nurses Society
BOTUSA	Botswana/USA Partnership in disease research
CBO	Community Based Organisation
CD4	Cluster of Differentiation protein 4: white blood cell marker
CDC	Centre for Disease Control
CEYHOH	The Centre of Youth for Hope
CHBC	Community Home Based Care
COCEPWA	Coping Centre for People With AIDS
DAC	District AIDS Co-ordinator
DMSAC	District Multi-Sectorial AIDS Committee
FBO	Faith Based Organisation
GIPA	Greater Involvement of People with AIDS
HIV	Human Immunodeficiency Virus
ICW	International Community of Women living with HIV/AIDS
INGO	International Non-Governmental Organisation
Masa	Botswana anti-retroviral programme
MoH	Ministry of Health
MoLG	Ministry of Local Government
Motswana	Citizen of Botswana
NAC	National AIDS Council
NACA	National AIDS Co-ordinating Agency
NGO	Non-Governmental Organisation
OVC	Orphans and Vulnerable Children
Pact	Funding NGO of the USA Government
PEPFAR	Presidents Emergency Plan for AIDS Relief
PLWHA	People Living With HIV/AIDS
PMTCT	Prevention of Mother To Child Transmission
Setswana	Dominant language of Botswana
TB	Tuberculosis
Tswana	Dominant ethnic group of Botswana
UN	United Nations
WHO	World Health Organisation
WUSC	World University Service of Canada

Chapter One

Introduction

1.1 Finding support

Who are the first people we ask for help when we are sick? Are doctors and nurses the first source of help, or do most people turn to friends, family and co-workers before seeking medical attention? If we are sick for a long time, what do we need apart from medical treatment? Advice? Someone to do the housework? Or just love and support? To understand ill-health, an approach is needed that looks beyond the medical factors to the social and psychological needs of the long term sick. This thesis aims use an innovative approach to looking at social support for people infected with the Human Immunodeficiency Virus (HIV), a treatable but incurable pathogen which is estimated to infect some 33 million people across the world (UNAIDS 2008). Recent drops in the price of the drugs to treat HIV mean that millions more people are able to afford life saving drugs, but is this all they need? When living with an incurable stigmatising disease, people may not be able to just take the medication and live normal lives, there are many complex social issues which can prevent people from moving on and becoming ordinary parents, workers and active members of the community.

This thesis will attempt to answer some of these questions in the context of the HIV/AIDS epidemic in Botswana, looking at how people living with HIV/AIDS cope with their illness, and where they get support from. Uniquely the research will look at both formal and informal sources of support, suggesting that individuals exist in multiple-overlapping spheres of support that include friends, family, peers and professional services. A new approach to this field will be adopted that visualises the support system as an interconnected network of individuals and organisations who provide not just formal services such as counselling, but also a multitude of informal acts of support from friends and family, which is essential to the well-being of People Living With HIV/AIDS (PLWHA). To investigate this issue, a multi-method strategy will be outlined that provides insight into all levels of support, and attempts to show some of the problems and bottlenecks in providing effective assistance to PLWHA.

1.2 Social support for PLWHA

“Society is a network” (Borgatti and Everett 1992, p17), a huge interconnected network of people, business, organisations, family, processes and most importantly, relationships. Millions of interactions between people have reciprocal and knock-on effects that make

and shape communities and society.

HIV is a sexually transmitted virus which infects some 2.5 million people a year, making it one of the most rapidly growing global epidemics (UNAIDS 2008). HIV weakens the immune system, leaving people vulnerable to other infections that may prove fatal. There is currently no cure for the fatal disease the HIV virus causes, called Acquired-Immunodeficiency Syndrome (AIDS). However, anti-retroviral drugs can be used to stop the progression of the disease, and may give an extra 15 years of life (Badri et al. 2006). As these drugs become increasingly available across the world, the emphasis of research will shift from the medical, to the social needs of people living long lives with the virus. The treatments are not without drawbacks, they must be taken frequently and can have many side-effects. In addition, HIV is still an extremely stigmatised condition: there is still no cure for the social problems of the disease, which may lead to people being irrationally excluded from social life and work. So while the virus itself is becoming easier to manage, the same cannot be said for the wider health and well-being of HIV sufferers.

Nowhere is this situation more acute than in sub-Saharan Africa, which has the largest HIV epidemic, and where PLWHA can expect to find "deepening poverty, isolation, an inability to satisfy basic needs such as food and shelter, and rejection in communities and formal services and fear for their children." (Russel and Schneider 2000, p3). The situation is compounded by the low income levels in many countries, which mean that individuals and governments cannot afford to pay for the treatment or health infrastructure to contain and manage the epidemic. International bodies are attempting to rally support for increasing the number of people across the world who have access to anti-retroviral (ARV) treatment, with limited success (Van Damme et al 2006), but even if they succeed, social problems still remain.

While most countries in sub-Saharan Africa still have a long way to go in rolling out treatment for PLWHA, Botswana has an advanced national treatment programme which since 2001 has been providing free anti-retroviral drugs to any citizen who needs them (ACHAP 2004). This provides an example to the rest of Africa, and also an opportunity to assess the long-term needs of people on ARV drugs. One day, hopefully every HIV positive person will have access to treatment, and the new challenge will be to provide long-term social support for them. This study hopes to contribute to an emerging literature on meeting the psychological and social needs of PLWHA on anti-retroviral treatment in resource limited settings. When these lessons are combined with advances in medical treatment, millions of people with HIV will be returned to full health, and can again contribute fully to society, averting a huge loss of life and human capital which could have a destructive impact on the economy, food security and political stability of the African continent (Fourie and Schönsteich 2001). Providing this support is important not just for the rehabilitation into society of PLWHA who have previously been ostracised; providing social support actually has other indirect benefits which strengthen the case for studying supportive mechanisms. For example, it can help with prevention efforts, as HIV ceases to be a hidden problem, and PLWHA themselves can become involved in warning the public of the dangers of HIV. When they are too afraid to admit they have HIV, and are shunned in public, these interactions are impossible. Also, numerous studies have shown that when people feel supported and loved, they actually become healthier, and have measurably stronger immune systems (Uchino et al. 1996)

But what exactly constitutes social support, and where does it come from? To answer

these questions, the thesis will adopt a unique social networking approach, which will attempt for the first time in such a setting to examine the complete network of support. This will draw from key literatures on social support and social networks (eg Cohen and Syme 1984, Gottlieb 1981), and ideas of social capital proposed by Putnam (1995) and others. Previous studies have looked at formal service provision, such as counselling services, and others have looked at informal support from families and caregivers using similar theoretical approaches. Yet in this vast network of society, most people can be expected to get support of some sort from a variety of sources, for example they may have formal counselling, but also a chat with friends and family. Are these not both important sources of support? Thus the research will look at both formal and informal support mechanisms together, bringing them together by examining them all as networked systems offering support to PLWHA.

There is another gap in the literature that needs to be filled, the role played by 'support groups' in resource limited settings, a term often used by the WHO for areas where there is a deficiency of service provision, caused by a insufficiency of funding, human capital or infrastructure. These are small organisations run by PLWHA for PLWHA, peer support mechanisms that provides information, counselling, care, and even food and a source of income. There are hundreds of these groups across Africa, supporting thousands of people with HIV/AIDS, but few studies on their role for PLWHA in African settings. The research shows that in resource limited settings, support groups not only provide much needed psychological support, but also practical and material services for members, including regular cooked meals and income generation projects. They provide information about HIV and treatment options to PLWHA, and also provide adherence counselling, ensuring that medication is taken regularly. They are also important in educating the wider public about HIV/AIDS, and hence assisting community HIV prevention efforts, a discovery which may be new to the literature.

1.3 Influences and approaches

This thesis draws from several disciplines, drawing on a wide range of different literature. There is much influence from Geography, especially Health Geography literature, which has long history of innovating research into HIV/AIDS, from classic studies showing the spatial spread of the epidemic, to newer research which focuses on the experience of space by individuals with HIV (Wilton 1996). In addition, the research acknowledges attempts to emphasise the difference of experience of health and illness between places (Smith and Easterlow 2005), especially between urban and rural, and the developed and developing world. Feminist geography also influences much of the research, especially the participatory methods which attempt to address power issues, and engage with the reflexivity of the researcher (WGSG 1997). Drawing on development literature is also crucial in conceptualising the role of states and civil society in tackling the epidemic in emerging areas (Zaidi 1999), as well as the problems in providing health services. There is a vast array of literature on HIV/AIDS, including both medical and social investigations, however there is still a tendency for it to focus on prevention efforts in developing areas (Patterson 2005), especially compared to the onus placed on care and treatment for people already infected in Western countries. This project will draw considerably from research set in developed nations, as it represents decades of experience in providing social support, the function of support groups. The needs of PLWHA may vary in different contexts, but there is still a commonality of experience from which much can be learnt, and adopting a human rights based approach to health emphasises a universal definition of full health, not differences in culture and

wealth. Social support and network analysis have literatures of their own, as well as the fertile area where they overlap and examine social support as a function of a networked society (Cohen and Syme 1984) and this will prove an important framework for the thesis

The four main objectives of this thesis are to.

- 1 Identify the main sources and forms of support for people with HIV/AIDS in the study areas
- 2 Examine the current role and functions offered by support groups, how users experience them, and how support networks are evolving
- 3 Explore the needs of persons on ARV treatment, and how these needs are met by formal and informal methods of support
- 4 Explain the variance in objectives 1-3 along lines of social difference, e.g. gender and location, from which appropriate support strategies for people on ARV treatment can be formulated.

Choosing a methodological framework that can integrate all the different types and sources of support is a challenge, so the project incorporated a series of methods that can be brought together and analysed concurrently to answer these key questions. To investigate support groups a group data collection technique would be appropriate, so focus groups discussions were used that echo the multiple voices and opinions of support group members. An ethnographic approach was also used, with the researcher volunteering with support groups for several months, gaining trust and an insight into the day-to-day running of the groups. To get an individual take on what support people were receiving, participants kept diaries for several weeks, showing a multitude of individual instances of support from neighbours, family and formal services. To get a perception of support from service providers, semi-structured interviews were conducted with officials from government, donors and civil society organisations. Looking at support at three scales of investigation, at the individual, community and institutional levels allows for the construction of a picture of the complete landscape of care for PLWHA in the research areas of Botswana. In addition, two workshops allowed participants to give feedback on the research, which in turn validated previous findings, and allowed for new insights.

Studying support as a network is a fertile approach, because most people will get different kinds of support from different sources, so examining only one source, for example community based organisations, leads to an incomplete picture. Secondly, the network approach suggests that support is a bi-directional flow: actors in the network will not just be receivers or providers, but both in different amounts. The same should be true for organisations, as even donors need reports and feedback from organisations they work with, so it is important to build a mutually respectful relationship. Thus the landscape of support should be shown as a multiplicity of networked flows of support, information and resources.

1.4 Structure of the thesis

Chapter Two introduces the background to the study, the global HIV epidemic threatening millions of lives, and details how social and biological factors have allowed its proliferation, especially in sub-Saharan Africa. The chapter will move on to show how anti-retroviral treatment has improved the life quality for PLWHA, and discuss factors that are hindering a rollout across the continent. It will also explore the social

effects the disease has on individuals, communities and nations, hence showing how critical it is to provide comprehensive medical and social interventions. Then the specific context of Botswana will be described, including the factors of governance and economics that facilitated the development of one of the best HIV/AIDS programmes in the world

In Chapter Three, the epistemology underpinning the thesis will be built up, engaging with theories of social support and network analysis that provide the framework on which fieldwork was designed to answer the key research questions. It shows the importance of social support for PLWHA, and society in general, and how trust and relationships are conduits for getting assistance and information when an individual is in need. Key terms such as 'support' and 'social networks' are defined and debated together with alternative theories such as social capital and actor-network theory. The chapter will show interconnections between local and international society in the epidemic, and how networks of support at all levels interact to provide a landscape of care in which individuals receive assistance. This landscape includes many different formal structures and civil society organisations, which will be shown as essential, but also problematic sources of support, necessitating an approach that can describe what issues are restricting their ability to provide services.

Chapter Four introduces a methodology which can investigate multiple levels of support in a resource limited setting. The benefits and limitations of particular methods will be debated, such as focus groups, interviews and participant diaries, as well as an engagement with theories of knowledge creation, and how best to create accurate and impartial research. This will necessitate engaging with the literature on reflexivity and positionality, and the role of the researcher's voice in research. The realities and problems of conducting fieldwork in emerging areas will also be discussed, in an attempt to ensure that there is a partnership between the researcher and participants, and to ensure that the research is beneficial to the researched, and can feedback to the community. The chapter concludes with overview of the fieldwork period and various issues encountered during data collection.

Chapter Five introduces results from the research starting with the important role that peer support groups play for PLWHA, using the opinions of both formal service providers, and the individuals involved in the groups. Detailed case studies and focus groups with four groups will provide the backbone of the analysis, combined with contributions from support groups across the country, and the perceptions of the donor organisations that fund them. It will show how they can provide a wide range of practical and psychological help for people with few other reliable sources of support, but also how the wider organisational network is restricting their ability to provide services. Much of the chapter is spent describing the function and format of the groups, an important focus since there is currently very little empirical research into support groups in sub-Saharan Africa.

Chapter Six focuses in on the individual and community levels, letting the voices of PLWHA tell the story of support networks in Botswana. Starting with self as the first step of support, and moving up to friends, family and the community, the research shows the vast variety of experience of support, and how the stigmatised nature of the condition makes certain individuals rely on certain sources of support. The importance of God and the church in providing support and encouragement to PLWHA is also shown to be very significant for participants of faith. Lastly, support group members describe the importance of support from community organisations, for both individuals

and the support groups themselves. This chapter will also show how support must be seen as a networked two-way flow, as most participants act as both providers and receivers of support.

Chapter Seven brings the focus further out again to the institutional and network level, showing the interactions and interdependency between community, national and international organisations. The importance of communication and trust in the networks is demonstrated again, and using discussion collected from a rare workshop involving both donor and recipient organisations, a worrying picture is drawn of networks falling apart due to mistrust and funding deficiencies. The approach used in the thesis of showing support as an interconnected network is validated, but with evidence collected from participant observation showing the damage that occurs when these networks collapse. The direct impact of this on providing support to PLWHA is illustrated, and participants come to understand the importance of good networking, and pledge to improve this in the future.

The last chapter concludes the thesis with a summary of results, and an attempt to look forward, suggesting avenues for further study that view support for PLWHA as a multi-level network, and also a recognition of the limitations of the research. It also examines the contribution that the research has made to filling gaps in the literature on support, especially the value of integrating formal and informal support sources, and showing the important role of support groups. The thesis finishes with a discussion of how applicable the results and approaches adopted here can be to other areas of investigation, and an expression of hope that one day all PLWHA will be able to live long full lives, by having comprehensive support for both their medical and social needs

Chapter Two

The HIV/AIDS Epidemic in Africa

2.1 Introduction

This chapter will lay the groundwork for the thesis by introducing the HIV/AIDS epidemic and the medical and social factors behind it. It will then focus on the epidemic in sub-Saharan Africa, and note some of the reasons that it has had such a huge impact on the continent. The discussion will then shift to look at the social impacts of the epidemic, and introduce the treatment options which are allowing people to live long, productive lives with HIV/AIDS. Botswana is one country that has successfully rolled out a treatment programme for HIV/AIDS, and this will be introduced as an interesting location to study the social needs of people living with HIV/AIDS (PLWHA), an example which other countries may be able to follow. Providing the anti-retroviral drugs (ARVs) to treat HIV/AIDS is critical because it allows people to relatively live normal lives free from the symptoms of AIDS, and greatly postpones death from the disease. This allows them to be full members of their communities, and critically to be able to provide peer support to other people with HIV/AIDS.

This chapter will detail both the medical and social aspects of the disease. It can be demonstrated that as much as the epidemic has roots in biological and societal elements, treatment must consider both facets. The World Health Organisation (WHO) definition of health states that:

“Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” (WHO 1946)

So to provide complete health, strategies for PLWHA must understand that as well as medical assistance, which provides physical well-being, there must be an attempt to restore mental and social well-being. Social support is an excellent mechanism for achieving this, but if support is to be provided by the community, the right environment must be in place, with social and political conditions that foster assistance for PLWHA. Considering how highly stigmatised HIV is in many communities, this is not an easy task. Yet this chapter will also demonstrate that the effectiveness of medical treatment often rests on social problems: if people are too scared to test for HIV, scared to be seen taking the medication, or are being shunned by their families and community, the

effectiveness of medical support is drastically reduced. The chapter starts with a detailed and very medicalised overview of the HIV epidemic, because many of the technical details have critical social ramifications. For example, understanding the physical transmission of the virus is necessary to explain how the epidemic spreads in different groups of people, and the high rate of mutation of the virus explains why drug regimens are so expensive and complicated: these are medical factors that have a direct social impact.

2.2 The Global Picture

For several reasons, sub-Saharan Africa is the region most affected by HIV/AIDS. It has been estimated that there are as many as 22 million people living with HIV in the region, representing some 5% of the region's total population and contributing to 1.5 million deaths in 2007 (UNAIDS 2008). This clearly has a huge impact, not just on the lives of those affected, but also on the social and financial security of the continent. Compared with other epidemics in Africa, such as malaria that kills 900,000 a year (RBM 2005) and tuberculosis (TB) which accounts for 639,000 deaths a year (WHO 2008), HIV/AIDS may be a bigger killer, but it also has much more wide reaching social impacts especially the stigma that surrounds the disease and its ability to fatally infect all sections of the population. Malaria on the other hand poses the greatest threat to children and older people, especially where effective treatment is unavailable, and in Africa appears to only prove fatal in 0.4% of cases (Snow et al. 1999).

Region	Adults and children living with HIV middle estimates	Adult prevalence (%)	Estimated Adult and child deaths from AIDS in 2007
North America	1,200,000	0.6	23,000
Caribbean	230,000	1.1	14,000
Latin America	1,700,000	0.5	63,000
Western and Central Europe	730,000	0.3	8,000
North Africa and the Middle East	380,000	0.3	27,000
Sub-Saharan Africa	22,000,000	5.0	1,500,000
Eastern Europe and Central Asia	1,500,000	0.8	55,000
East Asia	740,000	0.1	32,000
South and South-East Asia	4,200,000	0.4	270,000
Oceania	74,000	0.3	1,200
TOTAL	33,000,000	0.8	2,000,000

Source: (UNAIDS 2008) AIDS Epidemic Update 2008

Figure 2.1: The world-wide HIV/AIDS epidemic in 2007

However co-infection of HIV and malaria or TB is extremely life threatening, 7% of new cases of TB are co-infections with HIV (WHO 2005), although exact figures are difficult to decipher since in many parts of Africa, either HIV or TB may be registered

as the sole cause of death. Together these diseases are reversing decades of improvement in life expectancy, morbidity and social strength across the continent (WHO 2004). Figure 2.1 illustrates the size of the epidemic in Africa compared to other regions of the world, using the most recently available world-wide data for 2007.

2.3 The virus

The Human Immunodeficiency Virus (HIV) is a viral infection which attacks the immune system of the patient, leaving him/her unable to recover from other infections and diseases which the body could normally tackle. It can be transmitted through contact of bodily fluids, such as blood, breast milk, semen and vaginal secretions (Shepard et al. 2000), and sexual intercourse is the primary vector of infection. Babies can become infected from HIV positive mothers, not usually in the womb, but during birth or later from breast-feeding (Fox et al. 2008). Once inside the body, HIV invades and replicates inside any cell with T4 (also called CD4) antigen receptors, which include the white blood cells used in the immune system, and certain parts of the brain, leading to dementia in the late stages of infection (Hill et al. 1987, Thompson et al. 2005). At an early stage the reproduction of HIV cells does not create fatal damage to the body, but the eventual depletion of the white blood cells restricts the ability of the immune system to respond to infection, leading to fatal complications from normally benign illnesses (Stein 2000). These are known as opportunistic infections, for example Kaposi's Sarcoma, an extremely rare cancer, the sudden proliferation of which in the 1980s alerted doctors to the presence of an immuno-suppressive disorder affecting otherwise normal healthy individuals in the USA (Osmond et al. 2002). This was the 'smoking gun' which led to the discovery of HIV. However recent research has suggested that the HIV virus first infected humans as early as 1908, probably after crossing over from a similar virus found in monkeys (Pennisi 2008).

Once infected with HIV, there is often an initial period of illness two to five weeks after infection, with symptoms similar to common influenza (Essex and Mboup 2002). Following this it is believed that immune response reduces the infection to a very low level, where it stays for a period typically from 8-12 years (Buchbinder 1994). After this period most people develop asymptomatic Acquired Immune Deficiency Syndrome (AIDS), when the immune system is weakened by a gradual increase in the amount of the HIV virus in the blood and a corresponding reduction in white blood cells, which are essentially destroyed by the replication of the virus within them (Gadd 2005). It should be noted that the reasons for the delayed development of AIDS symptoms, and the mechanism by which HIV disrupts and kills CD4 cells (Ho et al. 1995) is still a matter of some speculation. However the prolonged symptomless period means that most people do not realise they are infected, and may be perfectly healthy for many years, unknowingly spreading the virus to others.

There are several factors that affect this period of time from infection to development of AIDS, the particular strain of the HIV virus being one, but other factors include the genetic characteristics of the individual, co-infection with other diseases and environmental conditions (Winkler and O'Brian 2003). Even high levels of stress and a lack of social support have been found to hasten development of AIDS (Leserman et al 1999). In a few rare cases some people do not develop AIDS at all, yet in others it can occur in as little as 2 years (Essex and Mboup 2003). Certain genetic expressions can also create a natural resistance to HIV infection, the best known of which is individuals who do not express the CCR5 receptor, a key path of HIV infection. This genetic

deletion is much more common in European populations than in other parts of the world, especially sub-Saharan Africa, one factor that explains the higher rates of HIV infection in much of Africa (Martinson et al. 2007).

Nutrition is also a critical factor in delaying AIDS mortality, and dietary deficiencies of prealbumin, vitamin A, vitamin B12, zinc and selenium have been shown to hasten death from AIDS (Baum et al. 1997). In addition vitamins E and B6, riboflavin, copper and zinc are deficient in many people with HIV and may cause other complications (Beach et al. 1992). Malnutrition, especially in children, creates symptoms which are very similar to AIDS, especially wasting and immuno-suppression (Schuerman et al. 1988) which can complicate diagnosis. To address nutritional issues, many organisations have established recommended dietary programmes for people living with HIV/AIDS (WHO and FAO 2002, WHO 2003, NAM 2005), frequently recommending the consumption of fresh fruit and vegetables. However, as we will see later, people with low levels of food security are unlikely to get the balanced diet needed to delay the onset of AIDS symptoms.

Treatment for HIV is usually only necessary when the number of CD4 T-lymphocyte cells drops below a level of 200 per ml of blood, or when opportunistic infections, diseases that the immune system could normally tackle, begin to develop. This is the clinical definition of AIDS, and the stage at which anti-retroviral (ARV) drugs which prevent HIV from reproducing are usually prescribed (CDC 1992). For comparison, a healthy individual has something in the order of 20,000 CD4 cells per ml (NAM 2005), although some studies indicate that any level above 400 cells/ml produces normal disease resistance (Raffanti et al. 2004). For this reason it is important to identify when levels of CD4 cells are critical. However there are differences of opinion on the best time to start treatment, considering the need to strike a balance between restoring the immune system and minimising the risk of the virus developing resistance to the treatment (NAM 2005).

The virus reproduces inside an infected cell, using a process which often creates errors in the copies of the virus, which leads to high genetic diversity and rapid changes in the virus (Boyer et al. 1992, Morris and Cilliers 2005). Thus there are a large and increasing number of strains and sub-strains (Dale et al. 1996) which are characterised by varying rates of transmission (Choe et al. 1996, Renjifo et al. 2001), speed of development of the disease (Asjo et al. 1986, Kanki et al. 1999), and resistance to treatment (Schmit et al. 1996). This tendency for HIV to be in a very varied state challenges the perception that an individual is infected with 'a' virus, it maybe more accurate to describe the infection as being more fluid than static, a realisation which should impact how infections are treated: approaches need to be flexible and target the broader process, rather than target a specific aspect of the virus. These factors make treatment of the disease and creation of a vaccine extremely difficult, although most anti-retroviral drugs prescribed for treatment of HIV/AIDS seem initially effective against most sub-types of the virus (Kebba 2003).

There are also two grand types of HIV, known as HIV-1 and HIV-2. HIV-2 has closer genetic similarities to the form of the virus found in monkeys (Baran et al. 1985). However, it does not transmit as efficiently as the more common HIV-1, and was thought not to prove symptomatic in many people (Kanki et al. 1994, Marlink et al. 1994) although more recent research suggests that this observation is due to a much longer lag time to progression of symptomatic AIDS (Shanmugam et al. 2000). Recent research into HIV-2 is particularly deficient, despite a relatively high occurrence in West

Africa and the discovery that it responds to anti-retrovirals used in the treatment of HIV-1 (Smith et al. 2001). It should be noted that the majority of medical research into HIV has been conducted on HIV-1B, the strain most common in Western populations, and there are key genetic differences between the subtypes common in different parts of Africa, which are presently under-researched.

In sub-Saharan Africa most persons are identified with AIDS, not through routine testing, but when they report to hospitals or clinics with critical illness, due to extremely low levels of CD4 white blood cells, often below 20/ml. However the presence of certain correlated illnesses, which vary from area to area, such as TB, may also alert health officials (ACHAP 2004). For many people in resource limited settings, especially where stigma is high and testing is not routine, this is often their first diagnosis of HIV as well as AIDS. Ideally, a person would have an early diagnosis of HIV before it developed into AIDS, and would have regular tests of his/her CD4 count to monitor progression of the disease and identify when to start anti-retroviral treatment (Gadd 2005). Although it is possible to monitor the disease by counting the actual numbers of the virus in the blood (Kanki and Mani 2003), this is still a relatively complicated laboratory technique, and cannot register counts below 50 copies/ml (Pitcheh et al. 1999). Instead, the normal procedure for monitoring the progression to AIDS is to measure the number of white blood cells, called a CD4 count (Biberfeld and Lyamuya 2003).

2.4 Scaling up anti-retrovirals

Anti-retroviral drugs, often called ARVs, are molecules that in some way hinder the HIV virus from reproducing. The most common work by obstructing the action of the enzyme which the HIV virus uses to copy itself, thus preventing its replication. There are four types of ARVs, the first line of which are nucleoside reverse transcriptase inhibitors (Philips 1999). Azidothymidine, or AZT, was the first drug licensed to treat AIDS (Fischl et al. 1987) and falls in this category. Other drugs include non-nucleoside inhibitors which work in a similar way to nucleoside drugs by preventing genetic copying of the virus, protease inhibitors that prevent the creation of protein coats for newly forming viruses (Philips 1999), and fusion/entry inhibitors, which prevent the virus binding with receptors on the host cell and thus entering it (Avert 2005, Moore and Doms 2003). It should be noted that all these drugs stop the replication of new copies of the virus, but there is no way to remove HIV that has already entered cells. Thus there is no way to completely remove HIV from the body, which enters deep into bone marrow and lymph nodes, so these drugs cannot cure HIV (Chun and Fauci 1999).

The high rate of mutation of the virus means that HIV quickly develops a resistance to the drugs, making them ineffective (Richman et al. 1994). To counter this they are usually provided as a 'cocktail' of several different drugs that inhibit viral reproduction in different ways (Stanic and Schneider 2005), sometimes referred to as Highly Active Anti-Retroviral Therapy (HAART). Combinations of these drugs can be extremely effective over the short-to-mid term, bringing the viral count of HIV in the blood down to undetectable levels, and allowing an almost complete recovery of the immune system, evidenced by normalisation of CD4 counts, an indicator of the number of white blood cells present in blood (NAM 2005). However, these drugs do not eradicate HIV, and must be taken several times a day to prevent relapse and resistance to the treatment. Adherence to the drug regimen is essential, as missing doses can allow the virus to replicate freely, increasing the rate of mutation and thus resistance to the drugs (Sethi et

al. 2003). Over many years, an HIV infected person will need to shift from first line treatments to different generations of drugs, as the virus mutates and develops genetic resistance to treatment. The length of this process varies greatly due to a multitude of independent factors, but it should be considered that in most cases ARVs can provide over 15 years of extra life from onset of AIDS symptoms if diagnosed early (Badri et al. 2006). The current final generation of anti-retroviral drugs are entry inhibitors, that are 80 times more expensive than the standard generic ARV cocktail and usually require two painful injections every day (Kumarasamy 2003, Tashima and Carpenter 2003). Few of these last stage drug regimens are affordable for individuals in developing nations, and also currently require constant refrigeration, making storage and their transportation difficult.

Side effects of the drugs are common, and often include allergic reactions, impairment of taste, nausea and diarrhoea (Lucas et al. 1999). Some recent drugs can also cause problems with cholesterol and fat levels (Chesney 2003). The more common symptoms can become a serious barrier to adherence to the therapy in some patients, and studies in the West typically find between 10-20% of people stop taking the drugs due to side effects (Monforte et al. 2000, Roca et al. 2000, Spire et al. 2002). As many as 46% may experience some symptoms (Lucas et al. 1999) although one study in Botswana found that only 9% stopped taking ARVs due to side effects (Weiser et al. 2003). Even so, if people do experience adverse reactions, the large number of anti-retroviral drugs available usually makes it possible to change the combination of the therapy (NAM 2005). However some drugs are cheaper than others, which can cause problems in resource limited areas. It also requires a strong infrastructure of well trained medical staff to prescribe the right combinations, dosages, and to provide regular check-ups.

The effectiveness of anti-retrovirals has been widely demonstrated (Hamner et al. 1997, Kumarasamy et al. 2005), as has the ability of people from all social, economic and ethnic backgrounds to adhere to demanding drug regimens (Wester et al. 2005, WHO 2003). However the availability of these treatments depends on the cost of the drugs, and the ability (and willingness) of a nation to distribute and monitor their use. A year long course of anti-retrovirals under standard pricing can cost tens of thousands of pounds, which places them out of reach for the majority of individuals (Kumarasamy 2003). Under the terms of the World Trade Organisation Doha declaration, developing countries with declared HIV epidemics are allowed to produce generic anti-retroviral drugs for their own population and even for limited export (Smith, Martinez-Jones and Anyama 2002, WTO 2002); these generics are essentially no-brand copies which can be as cheap as \$250 per person per year (Kuntarasamy 2005) and are just as effective (Kumarasamy et al. 2005).

However the Doha declaration and the related Trade Related Agreements on Intellectual Property (TRIPS) policy have proved notoriously imprecise and legally contradictory, factors which mean that many countries are afraid to start generic production, and some such as South Africa and Brazil have been threatened with legal action by pharmaceutical companies for proposing to manufacture generic drugs (Wise 2006). This has contributed to a political climate uneasy about anti-retrovirals and HIV in general. It is hoped that these issues can be quickly resolved, as even though access to anti-retroviral treatment is increasing, new infections are occurring twice as fast (UNAIDS 2008). Meanwhile, pressure from Western pharmaceutical companies continues to threaten the availability of generic medicines for HIV/AIDS (New Scientist 2007, Wise 2006). Yet the changes that providing long-term, widespread anti-retroviral therapy can make to a nation experiencing a HIV/AIDS epidemic are largely unknown,

as so few countries have been able to achieve this aim (Brazil and Botswana being two notable exceptions). Thus it is a crucial time when many countries are just beginning to provide ARV treatment, and need to learn from the experiences of nations that have already rolled out ARV programmes.

Sub-Saharan Africa has an especially high mortality from HIV/AIDS because other leading causes of illness, such as tuberculosis (TB) and malaria become much more serious conditions for people with immune deficiency. Incidences of TB have increased rapidly in Africa in recent years, significantly fuelled by the the greater susceptibility to infection for those who have weakened immune systems from AIDS (Cantwell and Binkin 1997). An estimated 9% of new TB infections are due to HIV, and TB is considered to be the cause of 11% of deaths from HIV (Corbett et al. 2003). Malaria co-infection is particularly serious for pregnant women (Verhoeff et al. 1999), but the co-infection impact on the general population is less well known. A key question arising from these debates is the issue of the most cost effective way to reduce AIDS mortality in Sub-Saharan Africa. As most countries are unable to afford effective treatment for TB or malaria, especially as resistance to current drugs increases, many have questioned the cost-effectiveness of pushing for anti-retrovirals (Creese et al. 2002). For example diarrhoea is a common symptom of AIDS, which can effectively be treated with simple and cheap supplements (Kelly et al. 1996). However diarrhoea is also a common side-effect of some anti-retrovirals, and in many countries with poor health infrastructure, diarrhoea is often untreated, and a significant cause of death. To properly tackle the epidemic, all health care services must improve, and there must be an extensive network of well stocked and knowledgeable clinics and health workers. Providing this health network may prove to be more expensive than the cost of the drugs in some countries, but some support groups of PLWHA in sub-Saharan Africa can help mitigate some of this cost by providing education to their members on the complex drug regimes, and ensuring that people are regularly taking their medication.

Despite the cost of these programmes, the effectiveness of treating HIV/AIDS in resource limited settings with anti-retrovirals has been proven (WHO 2003), and scaling-up has become the key goal for professionals and activists currently engaged in the anti-retroviral movement, in order to slow the loss of lives and human capital in the region (DeJong 2003). Purely in terms of cost-benefit, since prevention is much cheaper than treatment (Marseille et al. 2002), for regions with lower rates of HIV it is much more cost effective to instigate effective programmes to prevent HIV infection (Lucchini et al. 2003). In countries where the epidemic is already widespread such as Botswana, protecting the human and social capital of the nation by treating AIDS is imperative (Cohen 2002). ARVs can also mitigate against the huge impact on the economic, social and political stability of nations that HIV/AIDS has threatened. Since the working age demographic is that at highest risk of death from HIV/AIDS, saving these lives prevents the loss of the countries' skilled workforce, the financial providers for children and elderly dependents, and even many of the educators, doctors and support providers that otherwise would minimise the impact of the epidemic (Whiteside et al. 2006).

2.5 The virus in Africa

One of the biggest questions in the AIDS epidemic is why it has continued to affect Africa more than any other area of the world, and this issue has caused considerable debate. Africa has a recorded history of the HIV virus for the last quarter of a century,

and there are several isolated cases posthumously diagnosed from the 1950s, decades before the disease became widespread (Chioldi et al. 1986). Sub-Saharan Africa as a whole has an estimated infection rate of between 3.5%-8.4% (AVERT 2004, Essex and Mboup 2002), with variability from 0.2% in Madagascar to 26.1% in Swaziland (UNAIDS 2008). However it is worth noting that these figures are all estimated, and are dependent on the quality of the data gathered, which varies considerably from country to country (Grassly et al. 2004). In Africa, time from infection with HIV to progression of AIDS is usually considered to be lower than in Western nations, for example one study in Uganda found that the mean time to progression of AIDS was 4.3 years (Morgan et al. 1997) compared to an average 10-12 years in developed nations. However a more recent study suggested little difference in time from infection to AIDS symptoms between developed and developing nations (Morgan et al 2002).

The time-line of HIV/AIDS in Africa varies greatly from country to country, reflecting the difference that social, economic and political forces can have on a medical crisis (Quin 1994, MacQueen 1994, Dale et al. 1996). For example, a nation which officially denies the presence of an HIV epidemic would not instigate prevention programmes, while a country that has the political will but not the resources or political stability to instigate public education programmes, may also be unable to reduce the spread of the epidemic. As with most complex systems there are large numbers of interacting factors that explain the pattern, however the epidemic is complicated by social issues such as racial prejudice, othering and the association with marginalised groups of people such as prostitutes, drug users and homosexuals (Epstein 1996, Heald 2003). The main method of infection in sub-Saharan Africa is heterosexual intercourse (UNAIDS 2004). It is estimated that only 1 in 1000 acts of unprotected penile-vaginal intercourse results in HIV transfer, yet the risk is much greater for anal sex (Bloor 1995), which is why it spread rapidly between homosexual men. The risk is increased greatly when there are other sexually transmitted diseases (STDs) present which provide open sores through which HIV can easily pass (Stein 2000). In many parts of Africa there is a lack of diagnosis and treatment of many STDs (Rugalema 2004), and this could explain some of the high transfer rates of HIV. Women are also more prone to HIV infection through intercourse than men, especially as they are more likely to have STDs such as herpes (Glynn et al. 2001) and are less able to negotiate safe sex (Laga et al. 2001).

It has often been considered that the practice of transactional sex in Africa increases risk of HIV transfer, as some women and young girls supplement their income by negotiating gifts or money in exchange for intercourse (Ackermann and de Klerk 2002, Webb 1997). There is less stigma attached to casual prostitution in some parts of Africa than in the West, and it is sometimes considered the right of men to seek polygamous relationships or to have concurrent sexual partners. There has also been strong resistance to condom use in many areas of Africa, due to traditional beliefs (Heald 2003) and religious teachings (Keenan et al. 2000), but it should be also noted that many of the factors that hinder safe sex in young people such as bravado and alcohol use are equally applicable in the West (O'Leary et al. 1992, Skurnick et al. 1998).

Many commentators have questioned the presumptions behind the description in Western literature of a different sexual culture in Africa (Heald 1995, Webb 1997), and there are certainly biological, environmental and economic factors that also increase HIV susceptibility in Africa. Patton (1990) and others have commented that the HIV/AIDS epidemic in Africa is referred to differently from the Western epidemic, it uses different language and prejudices (Sontag 1989), and proposes a different way of tackling it. Economic development has also been a major contributing factor to the

spread of the epidemic through sexual cultures. The proliferation of industry, especially mining, has led to work migration patterns where many men from rural areas move for many months to gain employment at major mining centres (Campbell and Williams 1999). The young men involved in this migration often use prostitutes or have local girlfriends when away from their wives and girlfriends in their home towns, and this fuels HIV spread between men and later to their female partners when they return (Jochelson et al. 1991). The haulage industry has been another important route for HIV infection, as sex workers are common in bars and truck stops along the major transport routes across Southern Africa. Both truck drivers and sex workers can subsequently have very high rates of HIV (Ranjee and Gouws 2002).

Conservative governments across the world have tended to shy away from issues involving sex, prostitution and homosexuality. Western governments initially adopted very negative attitudes towards HIV/AIDS sufferers when it was first discovered, especially in the United States where the Reagan administration saw the illness as limited to groups associated with blasphemous activities (Shills 1988), even as a punishment from God. This culture of stigma and denial was responsible for a huge political backlash from the groups that saw themselves being ostracised by the medical and political professions, and started a campaign of activism that still continues today, and is unique for an infectious disease (Heald 2003). However many African governments adopted a strong denialist stance, seeing the accusations from the West of HIV being an African disease as being motivated by racial prejudice, and a threat to tourism and foreign economic investment (Chirumuuta and Chirumuuta 1987). Although by 1990 there were preventative national AIDS policies in all countries in Sub-Saharan Africa (Mann et al. 1992), getting access to basic rights for people living with HIV/AIDS has until recently not been a major priority. Gruskin and Maluwa (2002, p646) note that there is “a lack of attention to care and support for HIV-infected people” and that there is a large gap between government policy on rights for people with HIV/AIDS and actions. They note high levels of stigma, discrimination, and lack of access to treatment

One of the biggest factors affecting the epidemic and fuelling its spread is stigma. Stigma is the process by which “the individual... is disqualified from full social acceptance”, made to feel “not quite human” and leads to individuals acting in a way that “reduces [their] life chances” (Goffman 1963, p11). Goffman notes that stigma is in the eye of the beholder, it is the relationships between people that define stigma, not the stigmatised attributes themselves. However the social pressure of possessing a stigmatised attribute can lead to a sense of self shame and a loss of one's self acceptance. In the HIV/AIDS epidemic, stigma has had a huge impact, impairing the seeking and provision of care, creating a negative image of those with the disease and hampering prevention efforts (Brown et al. 2003). Complicating the debate is a group of professionals who claim that there is no link between HIV and AIDS, and who have also made statements to the effect that anti-retroviral drugs cause AIDS symptoms, that AIDS is caused solely by malnutrition, and that HIV tests cannot accurately identify HIV (AIDS.org 2000). The group promoting these views expressed them as recently as 2006 (Papadopoulos-Eleopoulos et al. 2006) and as in earlier publications, their claims are based on references from the beginning of the epidemic before tests for HIV were developed, and before the virus had been isolated and its genetic structure sequenced (Delaney 2000). While it may be easy to find counter evidence to these claims, they resonated with some people in the South African government, and contributed to a slow response to the epidemic. Stigma and denial are probably the biggest barrier to tackling the epidemic (Malcolm et al 1998), because even when the finance is available to

instigate large scale responses, societal processes can impede or reverse the positive aims

For example we might expect that South Africa, with one of the highest gross domestic product (GDP) per capita of sub-Saharan African nations would have a smaller HIV epidemic due to extensive investment in education, prevention and treatment programmes. However the political and social climate of South Africa has effectively set back its AIDS programme by decades (Webb 1997), to the extent that the former President denied the existence of AIDS, and the government has as recently as 2007 fired a health minister for advocating an AIDS treatment plan (Koenig 2007). Although the government has the resources to provide large scale anti-retroviral treatment, it still seems very reluctant to do so.

In contrast Uganda, with only 13.8% of South Africa's gross national income (GNI) (World Bank 2005), has seen its HIV infection rate drop over the last decade, and remain at low levels, a difference mostly due to a forward thinking government policy (Parkhurst 2001), which as early as 1986 had an AIDS control programme (Armstrong 1995). Uganda's success has been mostly attributed to consistent, if undemocratic governance, coupled with relative political and economic stability. This has allowed for long-term plans to be administered in ways Allen and Heald (2004) have described as 'draconian' but certainly very successful. They also note the successful cross-sectoral integration of religious groups and traditional healers into the programme, and the promotion of abstinence and traditional values over condoms and sexual freedoms. However more recently infection rates in Uganda have not continued this decline, and even increased slightly in recent years, now representing an estimated 5.4% in the general population (UNAIDS 2008).

Malnutrition is common in many parts of Africa, affecting 58% of the population in Central Africa, 41% in Southern Africa, and 33% in sub-Saharan Africa as a whole (SCN 2004). Malnutrition and lack of food security greatly increases the vulnerability of a population to HIV/AIDS, as well as reducing life expectancy for those already infected (Macallan 1999, SCN 2004). De Waal and Whiteside (2003) suggest that HIV/AIDS epidemics even have the potential to cause famine, when illness strikes breadwinners and farming activities, leaving households in an increasing state of food poverty. As previously discussed, a lack of key micronutrients in the diet can effect susceptibility to infection (Semba and Tang 1999). However many nations in the continent struggle with food security, and fresh foods that are rich in vitamins, micronutrients, protein and fats are often expensive and difficult to obtain in much of sub-Saharan Africa (Low et al. 2001). These debates have been further complicated by senior officials in South Africa who have claimed that garlic, beetroot and multivitamin supplements should be used instead of anti-retroviral treatments (Baleta 2006). While there is evidence that vitamin deficiency can hasten the onset of AIDS, there is little evidence that taking vitamin supplements delays AIDS symptoms in adults, however it may help delay certain opportunistic infections (Brennan et al. 1999). It should be considered that the continuing reluctance of the South African government to pay for a full scale anti-retroviral program is consistent with its approach to promote less expensive and less effective solutions. For example a recent government sponsored clinical trial in which HIV positive patients were encouraged to take vitamin pills instead of anti-retrovirals, leading to several deaths was found illegal by the South African High Court (BBC News 2008). Even when anti-retrovirals are available, they must be taken regularly with food to be effective, which is an additional need for families unable to afford the required three meals a day.

While much has been said on transmission and treatment, there has so far been little discussion of prevention efforts, which are obviously the ideal intervention in any epidemic. Indeed some estimates, while perhaps a little outdated, estimated that prevention was 28 times more cost effective than anti-retroviral treatment (Marseille et al. 2002). This is regardless of the benefit to individuals, families and society as a whole from reducing the spread of a potentially fatal, incurable and stigmatising disease. Some measures have been very effective in sub-Saharan Africa, for example screening blood donations for HIV, testing for and treating other sexually transmitted diseases, and establishing prevention of mother-to-child transmission programmes: short courses of anti-retrovirals given to an HIV-positive mother before she gives birth (Creese et al. 2002). Another more controversial, medical intervention is male circumcision, which may reduce the risk of HIV transmission by some 60% according to some studies (Auvert et al. 2005).

Abstinence, having intercourse with only one partner and the use of condoms, the classic ABC model (Abstain, Be faithful, Condomise) is a frequently promoted, but also controversial cultural intervention to reduce HIV infection through behaviour change. There is concern that this model is influenced by conservative political and religious beliefs of donors and societies which prohibit sex before marriage (Green 2006). For example, in Uganda, considered to be the best example of implementing the ABC approach, there is still debate as to whether reductions were made due to abstinence only promotion, or due to an increase in the use of condoms (Singh 2004). When condoms are used correctly, they are nearly 100% effective at preventing HIV (European Study Group on Heterosexual Transmission of HIV 1992). However achieving sexual behaviour change in a population, and increasing condom use has proved extremely difficult in most cases (eg Barnett 2005), and is the focus of much on-going research and debate. Yet despite all of this, and some success in raising awareness of the risks of HIV in sub-Saharan Africa, the epidemic continues to grow (UNAIDS 2008), infecting more and more people with this incurable disease. Therefore it is crucial to understand the impact HIV/AIDS has had on societies, and what steps can be taken to improve the health and welfare of those already infected.

2.6 Social impacts in southern Africa

The social impact of HIV/AIDS on communities in southern Africa is wide-ranging, and there has been considerable effort in the last decade to quantify the effects the disease has had on societies as a whole, in terms of both social and economic impacts (Avert 2005). These are especially important because HIV prevalence is highest in young adults, which is the most economically and socially active age range (Cohen 2002).

The first level of impact the disease has on society is the effects from the long period of illness it creates in the people it infects, which usually leads to death. This not only has a significant emotional impact on families, friends and communities, but in the symptomatic AIDS phase the individual usually becomes a dependant, requiring time, care and financial assistance when s/he is unable to work (Whiteside 2002). Some evidence also shows that semi-skilled or skilled workers are more likely to be infected with HIV/AIDS (ING Barings 1999), especially teachers (World Bank 2000), and medical professionals (Veenstra 2004), greatly reducing the human capital of a nation. However one recent study in South Africa suggests that HIV prevalence is lower in teachers than in the general population (Bennell 2005). Even so, the erosion of this skill

set creates a serious obstacle for authorities trying to provide education and health services. The loss of healthcare workers, already seriously diminished as trained individuals emigrate to find better salaries overseas (Eastwood et al. 2005) further exacerbates the problems caused by the increased cost of providing hospital care and treatment for those with AIDS related syndromes.

In terms of financial impact on a family, Bollinger and Stover (1999) recognise four stages: firstly there is the loss of income from the HIV infected person when s/he becomes ill, an increase in medical expenditure, a loss of income from other household members as they spend time looking after the sick individual, and finally costs from the death of the infected person. This includes funeral costs, and together may result in the necessity to remove children from school to provide domestic or farm labour. Steinberg et al (2002), in a major study in South Africa, have found that the burden of care falls disproportionately on women, and that the financial pressure is massive: expenditure on health care can represent one third of total household expenditure, and funeral costs are often equivalent to four months' wages. The savings capacity, and correspondingly the long-term expenditure potential of households is thus seriously diminished (Cohen 2002) and families may resort to selling land or livestock, contributing to a cycle of increasing poverty. This clearly increases the social needs of PLWHA to include financial assistance and even the provision of food.

A key impact of death on the family has been the rapid increase in the number of orphans in sub-Saharan Africa, with some studies estimating that as many as 9% of children under 15 have lost at least one parent (Monasch and Boerma 2004). This represents a rapid increase in the number of AIDS orphans to 12 million by 2003 (USAID 2003). This has placed an extra burden on the extended family, who are becoming increasingly responsible for the needs of children, especially grandparents (Foster 2000) and elder siblings who may suddenly become caregivers for their parents and younger brothers and sisters and do much of the housework (Robson et al 2006). If such support is not available in the home, then children may also be sent to live with extended family elsewhere who have a capacity to care for them (Ansell and van Blerk 2004). In South Africa as in other south African countries, the welfare of children is becoming increasingly reliant on the government pensions of older women (Schatz and Ogunmefun 2005). The scale of the epidemic is likely to have a considerable impact on the demographic structure of the countries it affects, especially skewing the population pyramid towards dependants, as older people are generally not at risk of infection, and fertility rates may increase as more children are born to replace those that died from HIV contracted from their mothers (Ntozi 2002).

At the individual level, we can now summarise a variety of needs for PLWHA which are likely to be relevant across sub-Saharan Africa, and will be important issues in the research. These needs stem from the medical and social aspects of HIV/AIDS, and as will be discussed further in the next chapter, fall into several different categories. Practical needs include money and food, and in situations of poverty which are likely when illness in the household causes a loss of income, there is an increased risk of women adopting risky sexual behaviour to support themselves and families (Weiser 2007). Psychological needs include information about HIV and treatment, and it could be argued, a supportive community, a factor that is often hindered by stigma. This can reduce assistance from friends, family and the workplace, so this will have an impact on the amount of support that individuals can draw out.

Impacts on society as a whole are difficult to assess, especially those stemming from

bereavement, stigma and other social functions, however there is a measurable threat to livelihoods and the economic health of societies from HIV epidemics. Key to these factors is the loss of human capital and work days from illness due to HIV/AIDS causing disruption to both private businesses and government (Haacker 2004). Many countries have made attempts to measure the economic impact of AIDS, not just in terms of treatment and prevention costs, but also lost income and reduction in GDP. UNAIDS (2004) estimates that for sub-Saharan Africa as a whole, HIV/AIDS will lead to a reduction in GDP of 0.5% per capita compared to projections without the HIV epidemic, and this impact is as high as 1.5% in Botswana, Namibia and Lesotho. One aspect of the reduced number of workers is the undermining of food security caused by a reduction in agricultural labour due to increased rates of morbidity and death (Wiggins 2005). Many organisations have expressed concern that the scope of the epidemic will seriously impair the ability of households to maintain a subsistence level of agriculture and income leading to malnutrition or significant losses in standards of living (Gaffeo 2003), and may have contributed to food crises in Malawi and Zimbabwe (Wiggins 2005).

Some commentators have speculated that the size of the HIV epidemic could actually constitute a considerable threat to global security (Behrman 2004, Garrett 2005). They have argued that impact of HIV/AIDS on governments, economies and especially armed forces which tend to have very high rates of HIV infection (Nwokoji and Ajuwon 2004) could undermine stability in much of Africa, potentially eroding the last few decades of democratic improvements in the continent. Although this viewpoint is not without its critics, it is very plausible that HIV/AIDS will reduce the numbers of experienced staff in government and the civil service, reducing the effectiveness of national and local governance.

2.7 Beacon Botswana

Botswana is reported to have one of the highest HIV infection rates in the world, estimated at 33.4% (Government of Botswana 2005), which has contributed to an estimated drop in life expectancy from 72 years to 56 (Government of Botswana 2005, WHO 2004). However the Botswana HIV/AIDS Impact Survey 2004 suggests an estimated infection rate of 17.5% for the general population, based on a household sample of HIV tests, as opposed to the normal method of estimating population infection rates using data from antenatal clinics. Neither figure is likely to be entirely accurate, and the true extent of the epidemic in Botswana probably lies somewhere between the two. Botswana has a highly mobile population (Lockman et al. 2001) and patterns of moving to work in mining industries both internally and in South Africa have historically provided strong vectors for infection (MacDonald 1996), although cross-border migration has declined significantly in recent years (Crush et al. 2005). However the government has shown real commitment to tackling the epidemic, under the umbrella of the African Comprehensive HIV/AIDS Partnership (ACHAP) foundation. The 'Masa' project, meaning 'New Dawn' and founded in 2001, co-ordinates practically-free anti-retroviral treatment for currently over 34,000 patients and rising, with the ultimate goal of providing treatment for any citizen with HIV (ACHAP 2005). The programme was hailed as a role model for the rest of Africa (UNAIDS 2003).

In Botswana HIV/AIDS is a highly stigmatised condition, and this has strong implications for people living with HIV/AIDS (PLWHA) and the kind of support they can receive (Letanto 2003). People worry that HIV positive people lose their jobs, and

can be rejected by friends or family. Despite the availability of treatment, and very visual government campaigns on HIV/AIDS, few people have been tested, prompting the government to adopt an opt-out strategy, where routine testing for HIV is automatic unless people express a wish not to be tested (Weiser et al. 2006a). However, most people who are aware of their HIV/AIDS status do not publicly disclose it. This has strongly affected enrolment on the ARV programme and use of support services, either due to denial about one's condition, or through a fear of being identified through use of these services as being HIV positive. Some commentators have also speculated that the government response to HIV/AIDS actually came too early, before the disease was noticeable in the country, and this has led to increased denial (Allen and Heald 2004).

There is also contention about the extent to which the dominant Tswana culture has accepted the notion of a new disease like HIV/AIDS occurring, and whether traditional medicine has been significantly included in nationwide programmes (Livingston 2004). Haram (1991) has argued that views of traditional medicine in Botswana are flexible enough to incorporate Western views on infection and treatment, and suggested, even before HIV became endemic, that bio-medical notions of HIV would not be difficult to explain. She notes that Setswana culture teaches that certain women who behave immorally have 'hot' or diseased blood, and that some conditions can be passed through sexual transmission. Haram (1991) thus argues that these ideas can be adapted to explain transmission of HIV by promiscuous individuals. However Livingston (2004) takes a different opinion on this matter, suggesting that there has been resistance to acceptance of the Western model which has not been properly integrated with traditional beliefs, and that most people still use both traditional and bio-medicine. This is in line with findings in other countries from Liddell et al. (2004) that suggest there is great variability in beliefs, even within cultures and regions. Yet Livingston's (2004) main argument is that the government in Botswana took a Western approach that was not culturally adapted for some members of the population who still relied on traditional medicine

Women are disproportionately affected by the HIV epidemic, in terms of both higher susceptibility to infection, greater burden of care, and generally lower income (UNAIDS 2008). This puts them at greater need of supportive systems. The higher rates of infection in Botswana for women at 24.2%, compared with men with 16.9% (BHS II 2004) shows there is a serious risk of HIV for women, although it is difficult to ascertain the extent of this gender difference beyond the biological risk factors that make women more likely to contract HIV. A report by Physicians for Human Rights (PHR 2007) details research that seems to demonstrate a high level of inequality for women. Yet it does not mention that in Setswana culture women are in general highly respected, for example they have great freedom in choosing partners, and unlike in other cultures, a considerable dowry must be paid to the family of the bride by the groom, a factor that may seem patronising, but actually seems to ensure respect for daughters, and disdain for boyfriends who are unable to commit to relationships. Women can be very outspoken in the community, and have a significant, if still unequal representation in parliament, the judiciary and police force, while they make up a large proportion of civil service workers in government departments. Women were recently allowed to join the army for the first time (Afro News 22/1/06) and can gain equal property and asset rights in marriage (US Department of State 2006). However there are still strong elements of a patriarchal system which restricts other land rights, and men are still dominant in senior business and government posts (Kalabamu 2006).

Botswana is still a very traditional culture in some respects: homosexuality is illegal,

but not actively prosecuted, and there are clear distinctions between what work is suitable for women and men. For example, there was recently a debate in the media about whether women should pursue careers as taxi or bus drivers, an idea even many women found objectionable. On a less trivial note, rates of domestic violence against women are very high, and this has become a big political issue of late. It is suggested that under traditional law, a man may beat his wife to a certain degree (US Department of State 2006), but this practice is not generally acceptable, and government and NGOs have taken steps to raise awareness and prevent domestic violence. Yet it remains a serious issue, especially when coupled with alcohol abuse by men, which has been shown to increase domestic violence and risky sexual behaviour (Weiser et al 2006b). 'Passion killings' are also alarmingly frequent, newspapers often carry stories where an unfaithful partner had been killed by a jealous boyfriend (BBC News 6/02/06), and in many cases, stricken with grief, the perpetrator commits suicide afterwards (Mmegi, 20/06/08). Many reasons have been given by politicians and columnists for the alarming trend, but it seems linked to the low rates of marriage by young people in Botswana, as changes in society increase long term relationships without commitment, contributing to unfaithful behaviour. This may even be partly due to young men who cannot afford the dowry or cost of the wedding. Whatever the reason, the situation is so serious, the outgoing president Festus Mogae stated it was urgent that some solution be found by community leaders, even if it requires drastic measures (AllAfrica.com 23/01/08). In general the situation for women in Botswana since independence can be summarised as having come far, but with still a long way to go (Datta 2004).

The government response to the HIV/AIDS crisis in Botswana falls under the jurisdiction of NACA, the National AIDS Coordinating Agency, which is also involved in many partnerships with the private and voluntary sectors. Many commentators have praised the quick, forward thinking approach to the AIDS epidemic that the Botswana government has adopted.

"Botswana has clearly moved to implement the declaratory principles of global HIV/AIDS governance, the setting and enforcing of the rules and the provision of strategic direction. 'Partnership' in terms of multi-sectoral and multi-tiered engagement, so central to the primary global declarations, is a central characteristic of national HIV/AIDS governance in Botswana" (Renwick 2007, p143)

A good example is the African Comprehensive AIDS Partnerships (ACHAP), a collaborative venture between the Botswana government, Merck Pharmaceuticals and the Bill and Melissa Gates Foundation. The organisation provides funding for many HIV/AIDS projects including the Masa anti-retroviral programme. However the partnership, as well as HIV/AIDS interventions as a whole, is predominantly funded by the Government, which is in a unique position to afford such extensive interventions. The discovery of mineral wealth, especially diamonds, shortly after independence from Great Britain in 1966, has led to a lucrative mining export sector, in which most operations are majority state owned, with profits going directly into government revenue (Martin 2005). Botswana has a Gross National Income (GNI) per capita of US\$5770, slightly higher than much more populous South Africa, and one of the highest in sub-Saharan Africa (World Bank 2007). Coupled with a strong and stable political system, and a willingness to tackle the AIDS crisis, Botswana has had the resources and the impetus to create an exemplary strategy for HIV/AIDS, and thus makes it an interesting example to study, especially the strong networks of co-operation between the government and civil society.

A key part of the national strategy is building partnerships with the civil sector, and to this end many local non-governmental organisations (NGOs) are represented by the Botswana Network of AIDS Service Organisations, (BONASO) which acts as an umbrella organisation providing support, guidance and capacity building. Additionally BONEPWA, the Botswana Network of People Living With HIV and AIDS is an NGO umbrella organisation for PLWHA which amongst other activities, provides assistance to over 80 support groups across the country. The presence of so many official organisations at multiple levels leads to a situation where there is often strong interdependency, especially between smaller organisations, for sharing certain resources. However limited sources of funding mean that these organisations are often in competition with each other for grants, leading to a reduction of co-operation in the network. As Renwick notes

“Problems facing non-government agencies are well known and include shortage of funds, shortage of experienced and skilled staff and logistical support, inconsistency of representation and lack of institutionalised memory over time as personnel change, and sheer ‘workshop fatigue’” (Renwick 2007, p144)

Examining how these organisations network together, and the problems facing the organisations and individuals within them will form a key part of the study, illustrating how support works, and the consequences for PLWHA when networks fall apart.

No studies have fully considered the role of support in the context of the anti-retroviral programme, and the effect that widely available treatment has on changing the needs of people with HIV/AIDS, an issue that will become increasingly important as other nations scale up their ARV programmes. There are many government funded groups already offering suitable services, such as the Botswana Network of People Living With AIDS (BONEPWA) and the Coping Centre for People Living With AIDS (COCEPWA). One innovation of COCEPWA was a ‘buddy programme’, the aim of which was to provide a volunteer friend to diagnosed PLWHA, helping him/her with support, and most significantly adherence to medication. The programme also encouraged PLWHA to keep a positive outlook, and provided information about other support services and training on positive living (Zuyderduin 2004). Buddies were trained by local COCEPWA groups, were often PLWHA themselves, and got paid a small allowance. While the role was designed to perform similar functions to those that a good friend would provide, it was in fact a formal service that has since ceased to function, and despite many former buddies now providing similar services and home visits through support groups, without the guidance of COCEPWA and the sponsorships of NGOs to pay allowances, the programme was all but gone by the time of the fieldwork period.

In addition to these institutional sources, Botswana is particularly suited to research on informal support, as it has an extensive government assisted community home based care (CHBC) programme for AIDS sufferers, another process that will be affected by the availability of ARV drugs. This scheme is very interesting because it is run with the intention of community based organisations acting as independent service providers in partnership with the government scheme (Ndaba-Mbata and Seloilwe 2001). The CHBC programme aims to reduce the burden on both family caregivers and local hospital services (Lindsey et al. 2003) by providing check-ups, basic medical and palliative care and counselling to critically ill people in the community. Crucially the service is intended for patients of all terminal illnesses, including TB and cancer, a factor that has

helped community acceptance since the programme is not just associated with HIV/AIDS. However the importance of social support networks in this anti-retroviral context has not yet been fully researched by academic or international communities.

One study, conducted by COCEPWA, has already attempted to assess the situation for people living with HIV/AIDS in Botswana. This consisted of a questionnaire administered to 116 people with HIV/AIDS, collecting information about the effects of stigma, and which forms of support were being utilised, as well as a basic needs assessment. This report has provided useful information for support agencies in Botswana, but the report itself notes the limitations of such a quantitative method, and notes the need for a qualitative investigation to explain some of the data found in the study (Visser and Mhone 2001). This study was also conducted before the roll-out of the ARV programme, and provides an interesting reference point that documents pre-ARV support.

2.8 Conclusions

This chapter has outlined the history and details of the HIV epidemic and shown that the HIV virus is having a considerable impact on the African continent at individual, societal and economic levels. It has also illustrated that the medical challenges of treating and preventing the spread of the AIDS epidemic have yet to be adequately addressed despite rapid and impressive improvements in drug regimens, and that the social costs of the disease must be considered along with the medical needs of individuals. Treatment programmes are now being implemented in many countries, of which Botswana's anti-retroviral programme is the one of the most advanced. Yet such projects must consider the wider human context of the disease to tackle the social as well as the medical impact of the disease, and remove its taboo status. Without a cure for HIV, people will still have to cope with the ongoing social effects of the illness, so there is a considerable need for research which addresses how people living with the virus can mitigate the social effects, and seek help.

It is important to remember that the ultimate goal is to provide comprehensive health to people living with HIV, and as the WHO definition of health states, this includes mental and social well-being, as well as physical health. While it is possible to provide treatment for the physical problems caused by HIV/AIDS, it is critical to also address the mental and social well-being of PLWHA. It is hoped that eventually more nations will be able to provide comprehensive treatment for HIV, and will be able to learn successful ways to implement such a programme from the example of Botswana. This research aims to complement this with a study addressing the long-term non-medical health needs of PLWHA, using a social networking approach, which is detailed in the next chapter. Through this we can design programmes that provide a comprehensive level of health for all people living with HIV/AIDS.

Chapter Three

Social Support and Networks of Care

3.1 Introduction

The previous chapter outlined the medical and societal impact of HIV in sub-Saharan Africa, and began to introduce some of the problems facing people living with HIV/AIDS (PLWHA). It demonstrated the urgent and increasing need to provide social support for the large and increasing number of PLWHA, especially in an era when anti-retroviral treatment means that people will be able to live long lives with HIV. However there are clearly a great number of sources and types of support, and it is necessary to develop a research design which can accommodate a comprehensive study of support.

This chapter introduces the social support systems that can provide help and assistance to PLWHA, and will examine the concepts that will inform the structure of the research design. Firstly the concepts of care, support and social support will be detailed by the exploring key quotes from the literature that attempt to define what support is, and the benefits it can have. This will be followed by an attempt to describe the structure of support, in particular the idea that support can be seen as a network of interactions in society. The literature on social support networks and network analysis will be summarised and used to inform a conceptual framework on support which sees both formal support from official services and informal support from the community as integral parts of a networked system. This conceptual framework will be developed with discussion of networks in health geographies and will be informed by the recent debates within geography examining notions of scale. It will also engage with theories of social capital and actor-network theory that complement this approach.

It is crucial for this comprehensive approach that support be understood at multiple levels, incorporating individuals, communities, and organisations. Formal structures in particular will be described as both providers and recipients of support to service users, and to other organisations. To properly understand the functioning of these systems, and the variety of roles they play, the complex definitions of civil society, non-governmental, community, and state organisations will be critically assessed. Lastly, specific examples of support systems for PLWHA will be described so that in the next chapter, appropriate methods can be chosen to investigate these structures of support.

3.2 Support and care

Support has been conceptualised in many ways by different authors, and some critics see this as a weakness in the study of support functions. However it is worth considering that support is very much in the eye of the beholder, and can come in various forms and from various sources, hence it is difficult to construct an empirical definition of support. House (1981) defines support as an interpersonal transaction involving one or more of the following.

- 1 emotional concern (liking, love, empathy),
- 2 instrumental aid (goods and services),
- 3 information (about the environment), or
- 4 appraisal (information relevant to self-evaluation)

Other authors categorise support slightly differently, for example Di Matteo and Hays (1981) describe support as being tangible or psychological, and that within this, there is an objective or subjective element. This notes that support is perceived, as well as received: the subjective aspect of support is the feeling that one is being helped, either in an emotional/psychological or practical/physical way. On a more emotive level, Moss (1973, p237) describes being supported as "the subjective feeling of belonging, of being accepted or being loved, of being needed all for oneself and for what one can do". Others have stressed that critically linked to the personal feeling of being supported is the sense of belonging "to a network of communication and mutual obligation" (Cobb 1976, p300), which illustrates how important the study of networks and social context is to support.

In contrast with the psychological scope of support, care is concerned more with physical provision of medical assistance (Parr 2003). The provision of care and support can be considered a moral debate, especially as when outside a profession, for example nursing, caring may be altruistic behaviour, although of course it may be offered in exchange or with an expectation of reciprocal care. For example there is evidence of automatic biological as well as learnt behaviour to provide care to babies and children (eg Morton and Browne 1998), but in most societies elderly parents are later cared for by their own children. Lawson (2007) introduces the notion of 'care ethics' to explain some of this, and notes that 'we build spatially extensive connections of interdependence and mutuality' (Lawson 2007, p1), a notion which fits well with a network approach to examining support. However, it could be argued that in much of Lawson's article, the care she is referring to would usually be classed as support – it is emotive care, not medical care. While care is discussed in the research, the primary focus is on support, reflecting the aim to assess non-medical needs.

Support can be given in many different forms, and not just face to face, as even interaction through the internet can provide beneficial support (Fahy 2003). However Burleson et al. (1994) recognise that it is difficult to provide support, supportive behaviour, or supportive messages that are useful: people must be sympathetic, and address difficult emotional and personal topics. In addition, it has been shown that good supportive messages (Burleson 1994) have a better effect on people, challenging some theories that suggest the perception of being supported is more important than the type of support itself (eg Reinhardt et al. 2006). In general, support can take many different forms, and come from many different people. Therefore support comes largely from

other people, from relationships and social links, thus support must be analysed as a social function

3.3 Social support

“Social interaction is the basis of social life, and social networks provide the mechanism (interaction) through which individuals learn about, come to understand, and attempt to handle difficulties.” Pescosolido (1992, p1096)

Shumaker and Brownell (1984, p13) define social support as **“an exchange of resources between at least two individuals perceived by the provider or the recipient to be intended to enhance the well being of the recipient”**. The precursor of the concept of social support could be considered to be Durkheim's classic study into suicide (Lett et al. 2005), which described notions of attachment within groups, that he called **“social integration”**. He postulated that individuals with very low levels of integration, or even very high levels in very controlling societies, were at greater risk of suicide. Durkheim (1952, p210) suggests that there exists **“in a cohesive and animated society a constant interchange of ideas and feelings from all to each and each to all, something like a mutual moral support, which instead of throwing the individual on his own resources, leads him to share in the collective energy and supports his own when exhausted”**. In effect, Durkheim is describing a supportive network.

Beyond just a mechanism for preventing self harm, it has been discovered that mutual support can bring psychological and medical advantages. In particular social support gained credence after the publication of two key papers, one by Cassel (1976) and another by Cobb (1976) showed that by mediating pressures of life in people with illness, social support allowed people to recover from illness more quickly, or could have a preventive effect for some conditions. Much research has been done into the effect of social support and coronary heart disease, conclusively showing that those with lower levels of support have increased risk of heart disease (Lett et al. 2005). Studies have also demonstrated that support increases survival rates for sufferers of breast cancer (Maunsell et al. 1995) and has benefits for the functioning of immune, endocrine and cardiovascular systems (Uchino et al. 1996). Crucially, evidence from the USA has also shown that people with HIV/AIDS taking anti-retroviral treatment had lower levels of HIV in their blood if they felt they had strong social support (Burgoyne 2005). However, it is also clear that this effect varies a great deal between individuals, some are more independent, and support themselves better than others. These people are better at coping with stress and stressful situations (Cooper and Payne 1991). There are clearly benefits from support beyond the psychological, at least to mitigate against many illnesses triggered or exacerbated by stressful life events (Lin et al. 1979).

There are two key models for explaining the measured benefits of social support, the first is that it acts as a buffer against 'stressors' – stressful situations in life, such as bereavement, loss of a job, or diagnosis with illness. The hypothesis is that these stressful situations are easier to cope with if someone has a supportive network. The second model is that social support provides additional benefits that compensate for negative situations, for example a better network of information (Pilisuk and Parks 1986). While literature tends to focus on the buffering theory, vague definitions of social support and buffering create differences between studies which makes comparison between the two approaches difficult (Alloway and Bebbington 1987). This study will not attempt to impose either theory on the data, since it is methodologically impossible

in this context to separate the effects of buffering or active support processes, since most support will surely constitute a certain amount of both of these functions. While psychological experiments in controlled repeatable situations can suggest answers to these questions, for example Cohen and Syme (1984) this is not possible in lived experience, especially as denying a source of support to examine the consequences would not constitute morally acceptable research.

To differentiate between social networks and social support, one must consider the hierarchy of social functions. At the top is the notion of social integration, essentially how well connected and active individuals are in society. The level of social integration will affect the strength and density of a person's social network, his/her strength of contacts, friends, family, organisations and associates. Some of these will sometimes provide network resources, in effect where the relationships begin to provide tangible benefits such as information, time or favours. Finally from these come supportive behaviours, those network resources that actually form assistance for an individual (Lairellera and Baumann 1992). Thus we can conceptualise social support as being a function of both social networking, which is community dependant, and social integration, which is dependent on the individual.

Burleson et al. (1994) recognise three different approaches that have been utilised for the study of social support, describing it as acting through social networks, psychological effect, and as a function of communication or interaction. The network analysis method is based on the study of the existence of ties, and the density and size of networks rather than the methods and messages used within them. This is the most quantifiable approach, although it often lacks an ability to assess the quality of support, and tends to see all support as being positive. However, from this approach a more qualitative approach to the study of social networks has evolved, which looks at the function of relationships.

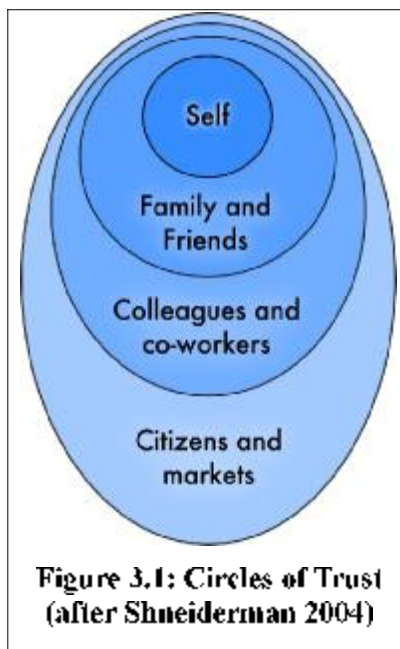


Figure 3.1: Circles of Trust (after Shneiderman 2004)

While not the first to visualise trust and relationships in terms of concentric circles, or use the terms networks of trust or circles of networks (eg Baier 1986), Shneiderman envisaged a user's experience of society through overlapping circles of trust (Figure 3.1), with self at the centre, and general society at the outside (Shneiderman 2004, p81). This visualisation suggests people have stronger levels of trust with those closest to them, namely their family and close friends, and as one's sphere of association increases to include wider circles of acquaintances, such as neighbours, co-workers and finally the whole community, that level of trust decreases. Fukuyama (2001) describes society in a similar way as being comprised of many overlapping 'radii of trust' comprised of people with common co-operative norms, founded in social capital. One of the earliest thinkers on social networks, Carol Attneave, developed a similar and interesting model of concentric social networks (Fig 3.2), where self is not

explicitly the centre of the network, but crucially includes 'negative people' a recognition that not all people in one's social network are trustworthy.

This is a crucial aspect of networked relationships. Not all actions in the network are positive, social support can also have a negative effect on individuals. For example families can often contain difficult relationships, or there may be an absence of support, and even when support is being given, it can be “perceived as inadequate, misinformed, misguided, excessive or unwanted” (Eli 1996, p174). This recognises that even if the intention is good, bad support can make a situation worse. In some situations, stigmatising illnesses can actually lead to negative social interactions which affect quality of life (Yanos et al. 2001), or if people are afraid of revealing their HIV status, they limit the support they can get from their social network (Stulberg and Buckingham 1988).

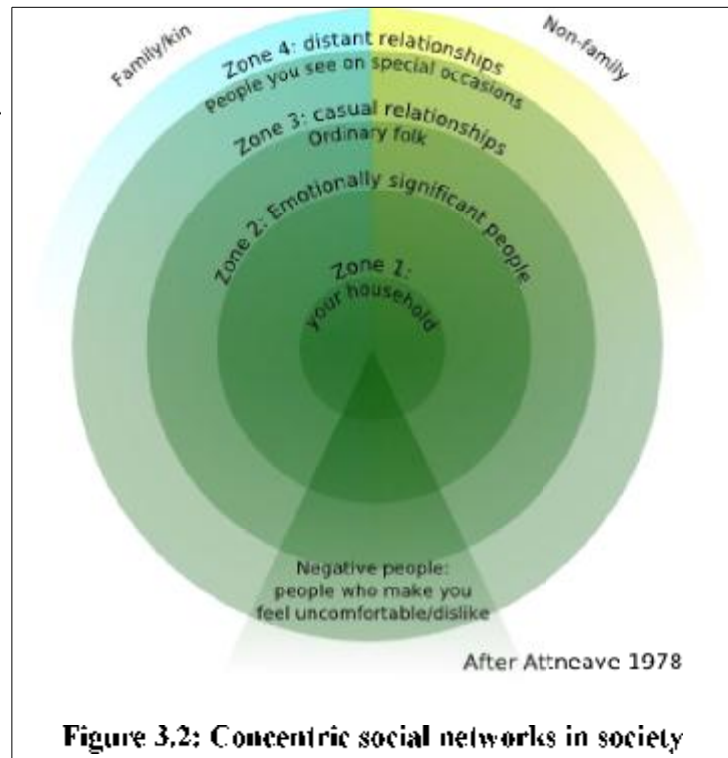


Figure 3.2: Concentric social networks in society

Nevertheless, these models are significant because they suggest that support will be at least partially dependent on trust, and therefore we should see that more support comes from close family and friends than strangers in the community. It is also a theory which holds the self at the centre of trust; the one person we can perhaps trust, share cooperative norms with and know best is ourself. This leads to a theory that the self is the start of all support, an assertion that will be borne out later in this chapter.

In fact, in the case of people living with HIV/AIDS (PLWHA), we may find a distinct polarization of experience which questions this model of trust. With regards to a stigmatising condition such as HIV, some individuals actually may find some family or friends to be almost 'too close for comfort': they do not want to go to them for support as they are afraid of being dis-communicated because of their HIV status (eg Kalichman et al. 2003). Curiously we then discover a situation in which relatively unconnected people in social or professional circles become a better source of support, as they are unable to spread information about someone's HIV status through a network of friends or family. This role of close strangers is generally performed by support groups, who provide many of the psychological and practical services usually offered by close friends and family through people who are essentially not part of an individual's network or close circle of trust. It is this distance that allows the anonymity craved by so many PLWHA. The conceptual literature on networks of support needs to be expanded so that the model is better applicable to stigmatised conditions.

To assess support at different levels, this research defines three different levels of support, the individual, community and institutional. Similar to Shneiderman's diagram, these definitions are overlapping, for example both the community and institutions are made up of individuals, while individuals may act in different institutions or community

groups and so on. The delineation between these groups is left deliberately vague, as while an individual may perform a supportive role as a counsellor in an institution such as a clinic, s/he may go beyond the formal role to offer companionship and friendship, and many co-workers also grow to become friends, just as support may be garnered from a community or institution that you have a family member in. However it is useful to define groupings beyond the individual, especially when PLWHA perceive support to be coming from a particular institution or group. The structure of society also includes institutions and community groups as sources for service delivery, and the project aims to examine the views of agencies as well as individual service users.

3.4 Why networks?

In essence, this research is studying service delivery to PLWHA in a region where a multitude of organisations, government departments, community based organisations and individuals are all providing services. Crucially these agencies do not act alone, but interact in a series of formal and informal relationships which form a network with a common aim of meeting the needs of PLWHA. To examine these services, it is necessary to study the whole network that provides them, not only to get the complete picture of what is provided and lacking, and to whom, but also to show the benefits and problems inherent in the network, and their effect on service provision.

Wellman (1984) observed that traditional study of societies focused on countries or geographic regions as a whole, and did not consider variations in participation that occur within communities. Social network analysis allows a new way of looking at geography, to examine proximity of ties beyond the level of physical distance at the scale of mapping human relations.

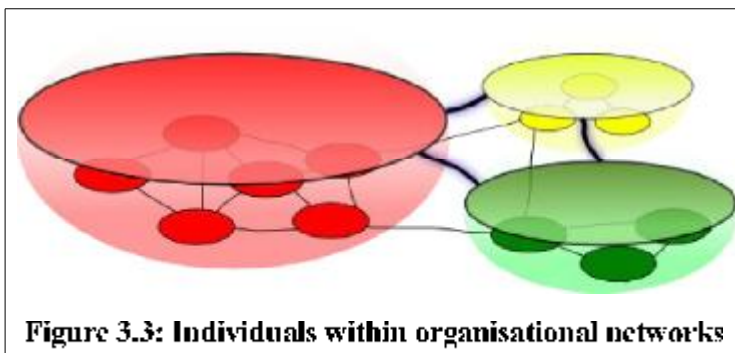


Figure 3.3: Individuals within organisational networks

However to consider a system of organisations one must consider the quandary of the “duality of the link between individuals and organisational activities” (Porta and Diani 2006, p115). Essentially this reminds us that organisations are all formed of individuals, with their

own motivations and network links (see Fig 3.3). The individuals within organisations can have their own motives and problems, which can impact on the body they are part of, and the sum of these actions shapes the actions of the organisation. This is an important consideration when considering the scale of organisations, since while organisations may have a global reach, their actions should be considered a function of actors at a more local or individual level, these effects can accumulate at different levels of scale within globalised movements (Escobar 2007). As Marwel et al. (1998, p502) observed “participants in social movement organisations are usually recruited through preexisting social ties and that mobilisation is more likely when the members of the beneficiary position are linked by social ties than when they are not”. Thus we need a framework that allows us to explain the structure of networks in this way.

To study affect in systems, it is important to understand the actions of individuals, even

when acting as a group such as a community or organisation, as methodological individualism describes all action in society as the cumulation and interaction of the action of individuals. Elster (1982, p453) describes this way of analysing society as “the doctrine that social phenomena (their structure and change) are in principle explicable only in terms of individuals: their properties goals and beliefs”. From this Elster infers that actions can be explained by opportunities (what one can do) and desires (what one wants to do) (Elster 1989, p14). In terms of this language we can describe a network as a function through which actors with similar desires can maximise their opportunities by sharing resources.

Governments have actively set up structures to promote civil society organisations, and facilitate networking between them to maximise service delivery with minimum resources. The contra argument is that a multitude of groups can create redundancy through overlap of services, and when resources are limited they may become competitive rather than co-operative. Ideally, Provan and Sebastian (1998, p453) find that “Integration occurs when organisations that provide services to a particular client group work together to coordinate the services these clients need. Integration may be formal or informal and may involve a simple exchange of information about a client or a full-scale sharing of resources and programmes”.

These ties between organisations and within organisations are the key part and unit of analysis in studying social networks. White (1992, p62) defines these ties as “the whole set of stories defining the historical relation of that pair of identities”, suggesting a strategy to illuminate networks, not just through the study of the links and nodes, but the narratives and history behind them. These stories form the basis of trust based on previous experience between two or more people, and the set of mutual obligations which are often described as social capital. These ties exist between and within organisations, and crucially between service providers and their clients. This research will look at the nature of all these ties

Previous research has considered social networks of both service delivery organisations (Alter 1990, Provan and Sebastian 1998, Provan and Milward 2001) and social movements (Marwell et al. 1988, Diani and McAdam 2003), both of which will be appropriate in a study which looks at organisations which may provide both support and advocacy for PLWHA.

3.5 Social network analysis

Social network analysis has been used before to investigate the spread of sexually transmitted diseases, especially HIV (eg Helleringer and Kohler 2007), since people tend to have relationships and sexual relationships with people they know, either directly or indirectly, such as friends of friends. However this has traditionally been part of an effort to understand and prevent the spread of disease (Rollenberg and Narramore 1996), using it to examine how a supportive system works for PLWHA in sub-Saharan Africa is a unique and fertile approach: people are familiar with the concept of studying support in terms of network structures, as organisations are encouraged to network to achieve their aims. Consequently social network analysis becomes an appropriate strategy for research in this formally tied situation.

While it is possible to use detailed quantitative network analysis to assess the linkages between AIDS service organisations (ASOs) (Shumate et al 2005), this approach is

more suited to evaluative or modelling scenarios rather than exploratory exercises. The context of this study favours qualitative data collection, so it will not be possible, or desirable to do mathematical social network analysis. However, this level of analysis does also provide a language of structures which can also be used to qualitatively describe networks.

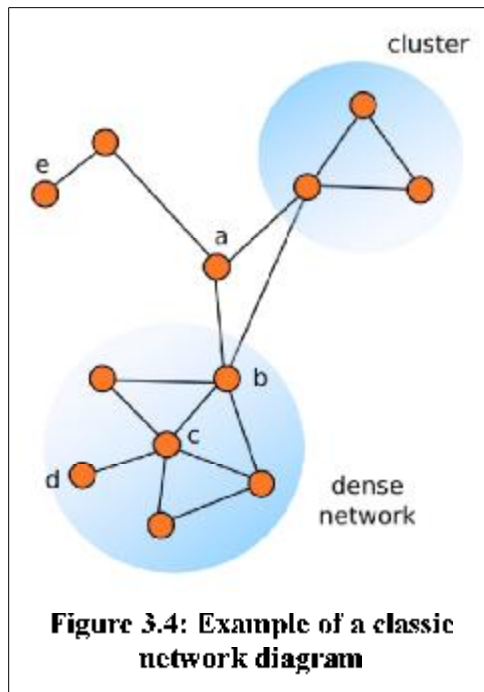


Figure 3.4 shows an example of a network diagram with nodes representing actors as orange dots, and the links shown by the lines that connect them. Social network analysis provides a variety of mathematical tools that analyse and parse the network and reveal information about its structure (Wasserman and Faust 1994). For example point **e** is clearly an outlier this is because it has few links to the network, and is many steps away from the rest of the network, for example 5 nodes away from point **d**. However points **a** and **b** are no more than 3 nodes away from any other point in the network, this is their **reach**, and as they have a high level of **closeness**, they are able to act quickly through the network. Another measure of this is **betweenness**, which is a measure of the number of direct links to other actors. point **c** has the highest level of betweenness. These two measures are important, because in some networks where influence does not spread well

through secondary links, having a high level of betweenness is more important to an actor than having a high level of closeness. If information is diluted or distorted through each link in the chain, again betweenness is critical.

Clusters, cliques, density and cohesion are all terms that are used differently to examine the essential interconnection of a network. Cliques are clusters which have strong internal links, but few links to outsiders: they are exclusionary. The top right cluster is a strong clique with a high level of cohesion, as all links are connected directly to each other. The bottom cluster while having a larger number of actors and ties, is actually less cohesive, because not all actors have direct links: points **c** and **b** are intermediaries. Where networks are not cohesive, they can be vulnerable to the removal of several key actors. in this example, removing **a** and **b** would produce three unconnected clusters, and the network would fail to work. Analysing networks in this way will be important for this study to examine the effect of one organisation failing in the network, and showing how information and resources flow. It is also useful to conceptualise the links in a network further: as conduits for resources and information, an idea which will be outlined in the next section.

Despite the strengths inherent in investigating systems as networks, there are also problems with this approach. First of all, when society is viewed as a series of networks and relations, it can imply that to a certain extent all actions and social actors are interconnected, which raises the problem of defining where the boundaries of effect lie, especially methodologically (Laumann et al 1992). Deciding how far to investigate the reach of a network or individual actor is an important consideration for the researcher, and any attempt to create a diagrammatical depiction of a network will inevitably leave

out weak links and nodes the researcher feels are insignificant. However, it could be argued that this is a problem in most research, as at some level researchers must always decide where the boundaries of relevance lie, since no method can completely represent the infinite minutiae of social life. Yet there still remains the problem of bounding the networks, imposing on them artificially constructed distinctions that are in reality more complex, such as the distinctions between local and national organisations, or the extent that networks are embedded in national or international processes. It is important to consider the complexity of these issues when attempting to measure and analysing networks

Actually measuring social networks is itself problematic, and despite the use of a variety of indicators and ways of assessing ties, these can at best represent an approximation of the relationships between actors (Glass et al. 1997). In addition, the variety of methods for measuring ties, and even how networks are conceptualised often makes comparisons between studies difficult. Another sound criticism of research into social networks is that historically the focus has been on quantitative study, and qualitative research has tended to examine processes around notions of social capital instead: currently qualitative social network analysis is comparatively weak. Additionally, traditional social network analysis has not engaged with problems of defining scales and hierarchies, and dealing with the fluidity of networks, issues which are discussed in the next section. However, it is hoped that studies like this will develop social networks as a framework for analysing social issues, and increase interest in their use.

3.6 Geographies of care and scale

Health geography has a strong literature investigating the spatialities of HIV, from classical studies of the geographical spread of the epidemic (eg Gould 1993), to investigations into how people with HIV/AIDS use space differently (Wilton 1996) and formal government responses to the epidemic (Brown 2000). Lastly, geography has also provided critical insight into the way that the body is itself a physical space, almost territorially controlled by health professionals who diagnose it according to certain medicalised norms (Parr 2002). This insight is important, even in a non-medical study, because it opens the door for the individual to be a space of research, as already demonstrated in the previous section detailing the importance of self.

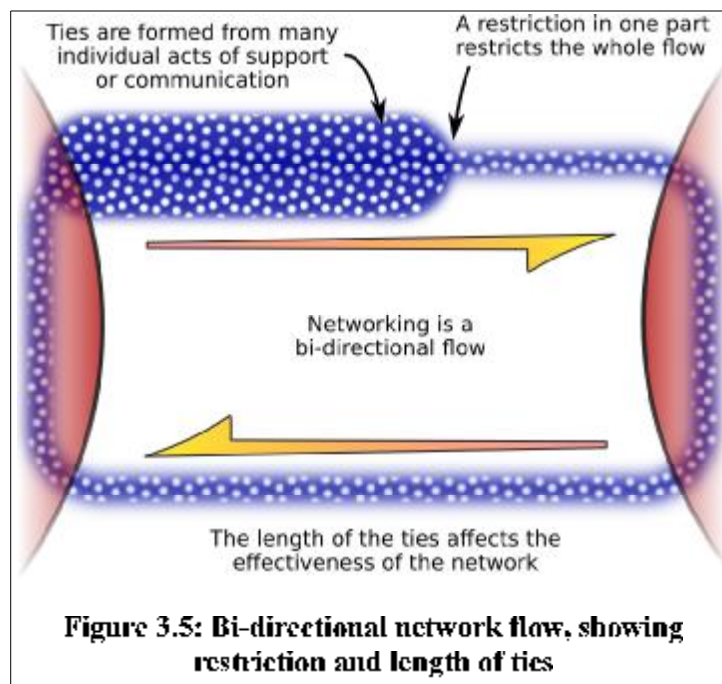
Parr (2003) suggested that health geography is comprised of two strands: the geographical spread of diseases, and access to healthcare. In the Western context, the phrase 'landscape of care' is conventionally used to describe landscape in terms of several modes of physical space in which care is acted, for example to describe public hospitals or private homes, and a shift between their use as spaces where care is enacted (eg Milligan 2000, Pinfold 2000). This study also makes use of the term the 'landscape of care', to broadly mean the combination of all care in a system, how it interacts, and its accessibility. The term is deliberately evocative of a physical landscape, but here in a different way than is often used. In this study the landscape of care may comprise of physical spaces, such as homes, through home visits, home based care programmes, educational media on TV or radio, and the homes of friends and family. Geography has made a strong case for homes to be included as sites of power and struggle (eg Marston 2001), and to recognise them as important spaces where care is enacted, often by unpaid family members. There may also be support group centres which form a kind of private communal space for providing support, and traditional care spaces such as public hospitals and clinics for other kinds of care. These are specific 'spaces of care'

(Conradson 2003) of the more medical 'therapeutic landscapes' described by Gesler (1992), a concept increasingly expanded to include a more holistic attitude to health that considers the significance of spaces on the psychological and social well-being of an individual (Conradson 2005). In a Western setting, this seems to be the focus of most theorising around the geography of care, since the dominant issue is the experience of care, rather than a lack of access to it.

Parr (2005) noted that care literature in developing areas has a different focus, and cites examples where it has looked at who is providing care, such as the example of Robson (2000), where the women and children who provide the most care in the system are almost hidden in the landscape of care, because they enact care at home, rather than in a formal public space. However, the difference in focus between Western and development literature on geographies of care is so great that it seems awkward to group such research together, with the possible exception of Del Casino's (2001) investigation into HIV support groups in Thailand, which recognises the importance of including networks of support into the conceptual landscape. But to integrate this landscape of care literature with the concepts of the ideas of social support networks, it is important that the landscape is not just representative of physical Euclidean space, but also the topology of the network of actors and services, as suggested by Law and Hassard (1999). Smyth (2005) also notes this need to integrate places, spaces and networks in studying the geography of care. The reason for introducing this approach is to understand the complexity of the support system for PLWHA, by visualising it as a landscape of many different places that people do not just have to visit, but also have to get access to. This is the fusion of the landscape of care and network analysis: here we are concerned with not just the places of care, but the distance between them, and the links and connections of the support providers in the network.

For example, one can imagine that the landscape of care has physical features which represent different potential sources of support, where the topology reflects the ease of access to resources. Here high summits represent difficult to use and exclusionary spaces, while wide low valleys show where support is easily obtained. This landscape also has processes which act on the landscape, as Conradson (2005) suggests, the landscape should be seen as resulting from the interaction of physical, biological and social systems. Well worn paths connect commonly used sources of support, and erosional factors in the system may change the landscape, wearing down mountains and filling in valleys. Just as in physical systems, strong flows of support will tend to erode down through the land creating a valley, setting in action a positive feedback cycle that increases the tendency of other flows of support to run into or through it, and the number of people that are drawn down into the valley. Paths between different sources of support may become difficult to travel, if rarely used they might become overgrown, or blocked by something, and without action to clear it, this hinders flows along that path. These are frictional surfaces between organisations, and the lower the friction, the easier the path is to travel, and hence the easier support is to obtain. The length of the path shows how close links are, and how easy they are to travel. They may also have a third dimension, height, where it is an easy downhill link to one organisation, but more of a struggle back the other way, demonstrating unequal relationships. Both the connections and relationships between service users and providers can be demonstrated in this system.

While all this may be an abstract thought exercise, it very closely mirrors the language of social network analysis, and illuminates the characteristics of network links. For example, we can consider the linkages in a networked system to be like two way paths



where the flow is dependent on the gradient, the friction of the surface, and the width of the path. In a network system, the flow of resources is also subject to frictional processes and restrictions (Fig 3.5) such as bureaucracy, miscommunication, and the availability of communication devices, for example post, which is slow, or fax, phones or e-mails, which have a cost to operate. Williamson describes these processes as transaction costs, which are equivalent to frictional surfaces which slow or impede the flow of resources along them (Williamson 1985). Poor relationships

between actors are frictional surfaces, they can slow, alter, or completely impede the flow of resources

Needless to say, travellers into the landscape of care may need guidance, for example a map or list of available support services. Yet in everyday life the landscape is transversed by many people using markers in the topology, such as familiar paths or obvious landmarks that form clear destinations or passing points. There is also the ability to interact with others in the same landscape, asking directions or travelling together, essentially learning and sharing knowledge about where to receive support. This is how information about the landscape of care flows through the supportive network and how new links and paths are forged. Viewing the landscape of care in this way illuminates the processes which hinder or aid connections, and the effect these can have on the users of the network

Scale is also an important consideration when examining networks, and an important area in geographical literature. Howitt (2002) suggests scale should be perceived as having three components: the size, or spatial extent of an entity, the level at which processes operate, and relations, the networking between different sizes and levels of effect. There is increasing recognition that scale is a complicated term, fluid and with social constructions (Marston 2000), and there is also a challenge to the conventional way of looking at scale:

“traditional Euclidian, Cartesian and Westphalian notions of geographical scale as a fixed, bounded, self-enclosed and pregiven container are currently being superseded... by a highly productive emphasis on process, evolution, dynamism and sociopolitical contestation.” Brenner (2001, p592)

Part of these debates is the notion that in an increasingly globalised world, individuals and organisations can often have a global impact. This is evident in issues such as global capitalism, business and governance (Swyngedouw 2000), protest (Mamadouh et al. 2004) and most critically for this research, NGOs (Ars 2004). When reconsidering

scale, there is an important realisation that the boundaries between what constitutes a local organisation and an international movement are blurred. For example, networks of like minded organisations campaigning on issues of environmental and social change can gain support and lobby governments across the world (Ars 2004). Conversely, individuals and 'local' organisations are impacted upon by the policies and decisions of 'global' donors and organisations, which we must remember are still comprised at some level by local actors. A new era in global governance in the last 50 years has seen organisations like the UN, and networks of states such as the EU, G8 and multi-national trade blocs have increased political clout (Swygedouw 2000). In addition, there is also consideration of the scale of individual actors, and especially the sites formed by bodies, and the spaces in which they are able to act as part of wider networks (eg Ansel 2008). When it is realised that individuals, NGOs, business and nation states all have power and influence at multiple scales, the traditional hierarchies of scale can be challenged, and some authors feel that instead, scale should be more of a mosaic of multiple and interconnected actors (Brenner 2001), and that traditional hierarchical ways of looking at scale where the local is subservient to the global should be reconsidered. For this reason there are also theorists who believe that the whole concept of scale should be abandoned (eg Marston et al. 2005). They suggest that since scale is socially constructed, it is a fictitious construct forced on social processes, and propose replacing scale with ontological flatness, in which there is a blurred distinction between local and global actions.

Within this conceptual understanding of scale, the Euclidean reach or influence of an individual organisation becomes less important than the local and global networks it can act through. This is an important idea in Actor-Network Theory (ANT) which will be discussed later, as well as another compelling reason to adopt a network approach to studying support systems. However, it could be considered that Marston et al. (2005) are unjustified in abandoning scale and suggesting it is unworkable, especially since most of their criticisms seem levied at hierarchical scale, an approach already criticised by others (eg McGuirk 1997). Marston et al. (2005) also suggest that network theory cannot be used to cover up weaknesses in scale, because for them, network theory can only represent 'a jumble of unrestricted flows' (Marston et al. p423), completely disregarding the ability of network theory to show friction and restrictive ties, as outlined above and later noted in Jones et al. (2007). Other critiques are that Marston et al. (2005) do not adequately consider the notion of power in flat ontology (Leitner and Miller 2007), an important factor to consider when there are inherent dominant systems in globalised society that do exert power over local processes. Flows of power are not one-way, the local does impact on and form part of the global, so scales cannot be easily compartmentalised, and the globalised connected society can reduce the separation of time and space (Massey 1993). However, there are still inequalities in the system, which are well represented by scales of effect and organisations that are not well linked to global systems. It may be that some small organisations are not privy to a level playing field, nor are they able to contribute to global processes that affect them. It is also important to consider that where organisations are concerned with direct service delivery, as in the context of this research, there must be a physical scale in which they can operate, both defined and limited by the resources they have available. This thesis will argue that hierarchical scale still seems to exist in systems where there are deliberately created organising structures and umbrella organisations, but also note that individuals can also wield power in networks. Viewing network flows as hierarchical, but not one-way, restrictable but with impact not limited to physical reach, is an attempt to update the study of social networks with these contemporary critiques of structure, and provide a strong framework for investigation.

3.7 Social networks and social capital

Having critically evaluated social network analysis it is also important to engage with the popular concept of social capital, a way of studying social systems that analyses “the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalised relationships of mutual acquaintance or recognition” (Bourdieu 1985, p248). Bourdieu also stated that “the profits which accrue from membership in a group are the basis of the solidarity which makes them profitable” (Bourdieu 1985, p249). This view of society places the benefit of the individual as the central motivation for action, and networks as being primarily exclusionary to non-members who do not bring profit to the network. However, other theorists have developed Bourdieu's original definition of social capital further, taking it as a broader societal process which is not just economic. Fukuyama describes it in a much broader way as “an instantiated informal norm that promotes co-operation between two or more individuals” (Fukuyama 2001, p7). Although social capital is often used as a theoretical framework within research into health service provision, it could be argued that informal supportive actions often stem from altruistic feelings (Barbee 1990, Elster 1990) and social capital might struggle to explain this, or at least actions that do not bring a direct reciprocal benefit. It is also difficult to conceptualise some networks that exist to provide services to the wider community in terms of reciprocal benefits. While the study will show that some people do join support groups for their personal benefit, this can fit into social network analysis through the use of non-reciprocal ties. Stansfield (1999) in fact finds that in the case of support, giving can be as beneficial to the provider as the receiver, when providing support is rewarding, it is not just a one-way flow.

However, in the case of networks of support for PLWHA in Botswana, there are often few material resources to share or trade, thus there are low levels of physical capital to share, and ties of trust and obligation are more important. These are much more difficult to analyse in a social capital approach as Bourdieu demands “the ultimate reduction of all forms to economic capital” (Portes 1998, p4). Many contemporary authors such as Putnam have extended notions of social capital to human social relations in the community (Putnam 2001) and more recently immigrant communities, (Putnam 2007). Yet there are also examples of researchers who have struggled to apply social capital to these wider non-economic applications (Dwyer et al 2006) and consider it to be sometimes applied to inappropriate areas (Baum 1999). Most damningly, Portes (1998) stated that

“Social capital has evolved into something of a cure-all for the maladies affecting society at home and abroad” Portes (1998, p1)

Thus it is important to ensure it is applied to appropriate situations. In contrast, social network analysis shifts the focus from the individual motives of actors to the ties that connect them, which are easier to measure and map, and also more relevant to study. This is especially true when there are pre-existing network structures between organisations and individuals. Social support concepts, which are well documented in health and support fields (eg Cohen and Syme 1985) situate the individual within the community context, and examine the interconnected nodes in social networks of support (Berkman 1995), an approach which is much more appropriate for this context. While Coleman states that social capital also “inheres in the structure of relations between

actors and among actors” (Coleman 1988, p898) it is best applied to ties between institutions that bring economic benefit to both parties and where social relations have financial benefits (Campbell 2000). Social capital frameworks are largely based around Coleman's attempts to bring together the concept of actor and economic streams (Coleman 1988), and it is difficult to describe service delivery in this context as primarily being an economic stream. However, a crucial factor in the functioning of the support network is the flow of resources from the state and international donors to civil society organisations that provide support services. It could be argued that these linkages fit well into a social capital framework, however, here these flows are in the form of grants or donations as the capital flow is one way. Yet these grants are dependent on feedback and evidence of success in a constant, reciprocal flow, which is much more complicated than the donor-to-recipient model. This fits neatly in social network analysis, where “actors and their actions are viewed as interdependent rather than independent, autonomous units” (Wasserman and Faust 1994, p4), a recognition that all information and action is dynamic and based on reciprocal interactions with other actors. It is also important to ensure that networks are seen to be fluid, reflecting the many changes that can occur in a system that impact widely on their connections.

This research will draw on this network based approach to conceptualise support as a bi-directional flow of resources and commitments that can be useful or a hindrance (Veiel and Baumann 1992). Crucially this network approach will be able to examine interdependency between formal organisations as well as between individuals, allowing comparisons to be drawn at both the macro and micro level. By fully considering the dynamics of support, and applying this framework to a field in which it serves a crucial function, this project will take a unique approach to the study of both community and institutional support in a developing country. Engaging with this context is important, especially to examining the level of extendedness of networks: how the trust and transactions that take place in them are deeply rooted in the socially constructed culture in which they exist (Hess 2004).

Social network analysis contains several conceptual differences from standard approaches to studying service systems which work well in this context. In this conceptualisation “relational ties (linkages) between actors are channels for transfer or ‘flow’ of resources (either material or nonmaterial)” which form a “network structural environment... providing opportunities for or constraints on individual action” (Wasserman and Faust et al 1994, p4). This means two things, resources in a network flow between people or organisations that have some sort of relationship, and that a variety of factors that affect these ties can either facilitate, or impede the flow of resources. For example, good relationships coupled with good communication help organisations work together, while organisations which are competitive with each other and lack telephones, fax machines or e-mail, have poor network links, and become isolated from resource flows

There is a clear overlap in approach from social capital and social network theory, indeed social capital clearly grew out of social network theory, and there is certainly scope for the integration of the two to develop theories of ‘networked social capital’ (Burt 2000). But the key difference of approach in this application is that essentially, social network analysis is more concerned with the links between individuals, and the overall structure of the network, while social capital focuses more on analysis at the individual level.

Another framework which emphasises the links over the nodes is actor-network theory

(ANT), which “views the world as being made up of a multiplicity of interconnections between people, objects, nature and spaces” (Hall 2005, p2674). This has had an important impact on geography, in part because its unifying vision of the world, including all things, allows for an alternative to Euclidean space, as a network system can be seen as an alternative to physical mapping or topology (Law 1999). Yet it is anticipated that spatiality and distance will be very important in a study examining accessibility to services in a resource limited setting, and social network analysis provides a tighter framework of investigation, and an easier concept for participants to engage with. Nevertheless, the influence of ANT on the approach taken in this study is significant, for example the approach to integrate all aspects of the support system: the formal and informal systems, and the assertion in the previous chapter that the medical aspects of the epidemic should not be separated from the social, strongly echoes the research of Hall (1999) who used ANT to explore the forced differences in language, experience and treatment of hypertension in northern Britain.

3.8 Networks of support for HIV

From as far back as 1987, the World Health Organisation's Global Programme on AIDS (WHO-GPA) adopted a strategy for tackling the HIV/AIDS epidemic emphasising cooperation with NGOs (Jónsson and Söderholm 1995), a philosophy that may in part have been due to the role of community groups, especially in the homosexual community in the USA who lobbied for a greater national and international response to AIDS in the 1980s. Jónsson and Söderholm (1995) found that these international networks of HIV/AIDS were formed more through the actions of individuals on an informal basis, than by formal partnerships between organisations. This raises an important issue: are these networks defined by the networking efforts of organisations, or the actions of individuals within them? This dialectic will become an important issue in the study, especially in the consideration of identity of the organisations as a collective of individual actors

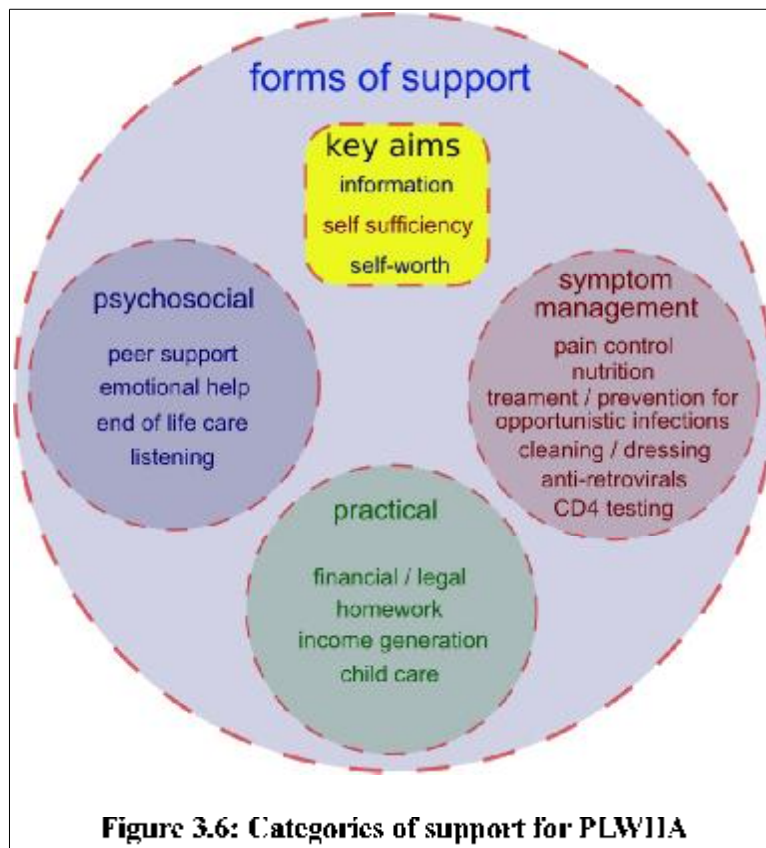
Beuner et al. (2004, p193) talk of an increasing level of 'networked governance' "at the intersection of the public, private and not-for-profit sectors [which] reflect the transformation of governance in an increasingly interdependent world". In no sphere is this more apparent than the HIV epidemic, where an international network of organisations, states, and individuals come together to influence policy, and implement prevention and treatment programmes. The interaction between different levels is considerable, and represents much of the 'new global order' that has shaped power relations. For example, UNAIDS and the WHO have an international level of governance, supported by power and resources seconded by individual states. These states also have their own local, and often international programmes independent of these bodies, providing direct foreign assistance, or domestic national strategies. There are also international networks of AIDS activists, PLWHA and national organisations that lobby and campaign at national and international levels for HIV treatment, the rights of PLWHA, or better prevention strategies. Some of these networks are formal, formed through umbrella bodies, or international coalitions, others may be based around informal links, activists meeting through conferences or protests, sharing ideas and building a campaigning consensus. In an increasingly networked world, PLWHA in Botswana can read about new treatments, support groups and 'buddy' programmes being used by PLWHA in the USA, connect over a common condition, and develop local solutions

At national levels, coalitions of NGOs can co-ordinate the response of civil society by providing a way for organisations to network. These are sometimes known as umbrella bodies, and often take the form of an NGO themselves. If we then consider that these NGOs are networks of individuals, and that society itself is a network of individuals, then we can conceptualise support providers at all levels as forming networks that can offer support to people living with HIV/AIDS.

3.9 Support for HIV

A key aim of this study is to consider a broad definition of support to build a complete picture of assistance available for people living with HIV/AIDS. Much of the literature and assistance for HIV/AIDS in developing countries focuses on prevention strategies and not care and support for the millions already infected (Jones 2004). Research that does consider support tends to see it largely as part of HIV testing, in which pre and post-counselling is made available, also known as Voluntary Counselling and Testing (VCT). Little consideration is given to the factors that affect people before this test, and that many people may be encouraged to go for the test by friends, clergy, counsellors or doctors. Thus support may start even before the decision to take an HIV test, and continue long after a positive, or even negative result.

After a positive test result, one can consider three groups of needs: medical, practical and psychosocial, summarised in Fig 3.6. Medical needs, essentially symptom management, will change during the course of HIV through to AIDS, and patients must learn a new language of treatment options, CD4 tests to follow progression of the illness, nutritional and dietary advice, and drugs to tackle opportunistic infections (Bisset and Gray 1992). Practical needs can be thought of as limitations to livelihoods



caused either directly by the illness, or by seeking care, especially days off for medical appointments, extra childcare, housework and food needs (Drimie 2002). If one's positive status leads to unemployment, either as a result of discrimination or sickness, legal and financial support can be critical. In general, a report found that PLWHA in southern Africa experience "deepening poverty, isolation, an inability to satisfy basic needs such as food and shelter, and rejection in communities and formal services and fear for

their children.” (Russel and Schneider 2000, p3). Psychological needs are perhaps the most frequently overlooked in research in developing nations. As AIDS is not only a fatal disease, but also one that is strongly ostracised by the community, people can feel depressed and isolated. This effect may also place an extra burden on caregivers, perhaps even leaving them with the risk of isolation from the community should they be seen allying themselves with an HIV/AIDS sufferer. Caregivers are also likely to need support, especially informal debriefing (Hansell et al. 1998). Although specifically addressing the emotional problems faced by mothers with HIV, who are in effect caregivers already, this quote illustrates the importance of psychological and emotional support for PLWHA:

“Emotional support for HIV positive parents throughout their illness is critical... Community support groups for people living with HIV and AIDS can provide a forum for sharing strategies for prolonging health, overcoming stigma, and coping with illness. Hope for the future can help mothers stay healthy longer, and increase their confidence to get access, and encourage better adherence, to treatment.” (D’Allesandro 2006, p9)

These three types of support can come from a variety of sources, and there may be overlap in service provision. Key institutions include government run services and clinics, private clinics, church groups, NGOs and volunteer organisations. It is also important to contextualise these formal support sources with assistance that people receive from friends, family and the general community, and this will be a key objective of the study.

Having already described support as being a function of society, Russel and Schneider (2000) categorised community based care service organisation for people living with HIV in South Africa into five groups providing:

- 1 Funding, technical assistance and support programmes that act as umbrella structures to channel funds and provide technical assistance
- 2 Advocacy and community mobilisation groups that protect the rights of individuals and facilitate access to health and welfare service and schooling
- 3 Drop-in centres and support programmes which provide support groups and counselling, education and often have an income generating activity
- 4 Community home-based care programmes, which provide the above and also offer some home visiting
- 5 Comprehensive home-based care programmes which provide the above and varying levels of nursing care

All these needs may be met by different sources, so the next step is to examine the different types and levels of support providers, starting with individuals, who are those with direct connections to the person seeking support through personal relationships or extended family. Garbarino (1983) recognised that most people seek help from friends, family, relatives and neighbours, the first two spheres of support, before they attempt to receive professional support from doctors or counsellors. Yet the first unit of analysis is actually the person who is seeking support. The notion of self and self support is crucial, because one’s self is always the first source of support, or barrier to support seeking, as

well as the first node in the network.

3.10 Self and self-efficacy

In general, support in any system may be sought or offered. In some instances another person might notice a change in behaviour or appearance that suggests a problem, and may offer supportive behaviour. In the case of medical issues, check-ups or doctors' appointments for other problems may reveal a situation that requires assistance. For psychological or emotional problems, news that someone has suffered a death in the family, or lost a job, may trigger offers of support from close associates. The next crucial stage is a decision as to whether to accept offers of support. This requires at least three prerequisites, first that someone acknowledges that something is wrong, that someone has a desire to improve that situation, and lastly that s/he has a belief that asking for support will be worthwhile (Forsyth and Carey 1998). Understanding support as dependent on all these factors suggests that to understand support, we must understand why individuals do or do not seek it.

Theory and research on stigmatised conditions and stressful life events all suggest that denial often comes before acceptance as part of a long psychological adjustment process, which hopefully ends in positive behaviour change (Reeves et al 1999). This is especially true for HIV/AIDS, when before diagnosis, an individual might deny s/he are at risk of infection, or be completely unaware s/he is already infected. Even when symptomatic, many people do not immediately equate pain or changes in the body with sickness, and even after diagnosis many people can be in denial about their condition. Thus before one can seek support, an individual must be aware that there is a need for help.

The next condition, a desire to seek help, is largely influenced by self-efficacy, which is the confidence an individual has in his/her ability to modify his/her own behaviour or environment (Forsyth and Carey 1998). In general, people with a high level of self-efficacy should be better at changing destructive behaviours such as smoking or drinking, adhering to medication and coping with stressful situations (O'Leary 1984), as they have confidence in their own ability to change, or look after themselves. Even if they have little confidence in their ability to change their own situation, seeking support from others still requires some self-efficacy to believe they are worth helping, and that change is possible. Previous experience is also important with regard to external support; if they have previously had bad experiences, they may have little faith that other people or institutions will provide effective help.

The psychological approach to social support is based on the perception of support by the individual, exemplified by the work of Sarason et al (1990). In this conceptualisation the effects of support are only important if they are acknowledged as being beneficial by the beholder. This approach also acknowledges that some social links can be perceived by the recipient as stressful and not beneficial, and therefore not always helpful, even when they are well meaning. However this approach can be criticised for making analysis the relationship between people as more important than the specific actions within it (Gottlieb 1985), when clearly weak relationships can offer useful support to the same extent that strong but difficult relationships can be a hindrance.

The last approach focuses on specific actions within networks or relationships, why help

is offered, and what constitutes helpful interactions. Burleson et al. (1994) examine functions of support through communication, supportive messages, interactions, and relationships. They see communication as being central to the study of support, not just because most support involves at least some form of verbal communication, but also because communication forms the basis of social networks and the primary method for the investigation of support. When we consider the types of support listed by House (1981) we can see that all the emotional, appraisal and informational forms will heavily or exclusively involve communication. Thus for Burleson et al. (1994) making sure that these forms of communication are helpful and effective is paramount. This will become a very important aspect of the study, especially because the opposite is also true: when communication of support stops or is inadequate, the support network can suffer.

3.11 Organisations in civil society

Activists in the fight against HIV/AIDS from across the world are brought together by an international network of organisations, providing support and lobbying governments. These range from large official bodies such as UNAIDS, to coalitions of HIV/AIDS activists at international and regional levels, and organisations that work at national or even small local scales. Defining all these bodies invokes a complex literature on civil society: a term which essentially means groups of concerned individuals (Foley and Edwards 1996), representing a variety of potential sources of support.

Within this sphere of civil society exist groups of individuals, which are mostly defined according to their scale of operation: Community Based Organisations (CBOs) or Grass-Roots Organisations (GROs) work with individual communities, while Non-Governmental Organisations (NGOs) typically have a national scope. Faith-Based Organisations (FBOs) may operate at either level, but are often closely related to religious beliefs, often originating from congregations at churches, mosques or synagogues, up to a national network of faith communities. Above this scale lie many larger bodies, most commonly International Non-Governmental Organisations (INGOs) but also donor-organized NGOs (DO-NGOs) and another layer of organisations that straddle the boundary of civil society and the state, Government Organised NGOs (GO-NGOs) and quasi-NGOs (Carapico 2000), or 'quangos': organisations which are essentially run and/or completely funded by the government, with the appearance of state independence. However, many researchers have also noted that blurrings of the traditional notions of scale mean that many organisations have local and global impact, especially in an increasingly globalised arena (Arts 2004).

One further acronym should be defined here, AIDS Service Organisations (ASOs) which are organisations at all levels that deliver services to PLWHA. In brief, these are all non-profit organisations that provide services where states or markets do not. They are sometimes called the 'third sector' between the two spheres of government and private enterprise (Seibel and Anheier 1990). Korten (1990) categorises NGOs and CBOs a little differently from the norm, as being either 'Voluntary Organizations' (VOs) or 'Public Service Contractors' (PSCs), organisations which aim to provide services to the community, largely by winning grants from development partners. Korten (1990) suggests that these donor NGOs target PSCs rather than smaller, more informal VOs. The influx of NGOs on the world scene is an attempt by development agencies to appeal to a 'bottom-up' approach over the traditional 'top-down' approach to development and indeed governance.

All these organisations and their definitions are complex and frequently politicised in the literature, especially in development studies (eg Mercer 2002), as they have become increasingly important actors on the world stage and at a national level. Often the debate on the value and importance of NGOs is wrapped up in political ideology, with a binary vision of viewpoints which are either liberal or conservative (eg Kamat 2003). It is often suggested that the 'neo-liberal' political climate in which developing states are made to cut expenditure has facilitated the rise of NGOs (Eade 2000). However both sides of the debate comment that increasing the power of civil society by increasing the role of NGOs can correspondingly reduce the power of the state (eg Held and McGrew 2002, Rosenau 2002). There is also a corresponding warning that NGOs represent privately run organisations which are not inherently democratic, and their proliferation over state mechanisms, which are in general accountable to voters, risks undermining the democratic process in weaker states (Kamat 2004, Uphoff 1995). However, others (eg Woods 2002, Risse 2002) believe that many states actively partner with NGOs to outsource service delivery, and increase the amount of funds which are available for development projects from international donors. Since more and more money is being made available to NGOs and CBOs (Mercer 2006), states and civil society organisations with common objectives can partner to maximise the impact of particular programmes (Edwards and Hulme 1992). There are even situations where donor organisations mandate that states partner with NGOs for service delivery, as is the case with many Global Fund grants, thus partnerships may not always be voluntary. All these factors lead to a multitude of organisations at the community level offering support services, and as the research will show, a complex network for both donors and service users to negotiate.

However, it is common to find literature that considers NGO-oriented development models to be as flawed as traditional monolithic state-centric development (eg Zaidi 1999). There is a widespread challenge to the notion that NGOs are democratic, representative of communities, and accountable service providers to developing nations. Uphoff (1995) argues that unless NGOs are run by and for members, as in a co-operative organisation, they cannot be considered democratic. Many NGOs, especially the larger national organisations in Botswana, are however run like this, with a membership that pays dues and elects a board. Yet as Gariyo (1995) notes, many of these organisations are mostly dependent on money from international donors, rather than their members, so the poorer contributors have little say in the organisation, which must meet the demands of NGOs or the state for funding. The same issue also holds true at a state level, as when a nation provides little funding for NGOs, local needs have less influence than shifting priorities of international donors (Parks 2008). Indeed, there is the potential for serious discrepancies between the views of donors, states, NGOs, service providers and the needs of the service users, an issue which will be discussed more specifically in section 7.8. This raises problems with local, national, and international power relations, and illustrates the importance of networking between all these levels to provide effective systems.

Mercer (2002) discusses the cultural appropriateness of democratisation or intervention, a wide and topical issue, but in this case specifically relating to NGOs. She suggests that such organisations may be more prevalent in societies where there is a long history of similar democratic structures, and countries that lack this network are considered to be deficient (presumably by the international community) and these structures need to be actively developed. Yet despite the notion that NGOs represent civil society, some authors (eg Uphoff 1995, Kamat 2004) caution that technically an NGO may be responsible to no-one, suggesting that they are best considered to be a 'third sector':

private organisations, which even if not-for-profit, may aim to serve a community, but are not necessarily owned by it. It is often suggested that Western zeal for providing funding through NGOs (ODI 1995) means they are more responsible to the donors they are dependent on than to the people they serve.

Since development NGOs rarely have blanket sources of income, either from the state or their membership, or for services they deliver (which are usually free or at cost), they are dependent on receiving donations or grants. In a simplistic model, donors give funding to recipients in a one way, power dependent relationship. Donors may be western NGOs, governments, national government, or local NGOs, and give funding mostly in the form of grants, for the provision of a particular service. There is an increasing awareness of the effects of conditionality on grants or aid money, power rests with the people with money to give, they can decide who to give it to, and for what aim. Increasingly, donations are passed along a long chain of organisations, for example from an INGO, to a national NGO, to a CBO that actually provides the service (Stirrat and Henkel 1997). Yet in this chain the power is still seen to rest primarily with the donor, who can decide what and whom to fund, even when donors attempt to act in partnership with their recipients (Lister 2000). Yet it seems better to see this as a loop rather than a chain, and it seems to be much more of a reciprocal relationship: while the grass-roots NGO partners need money from the donors, the donors also need feedback from these projects. For donors to be able to justify their funding decisions, and gain further support from individuals or governments who provide the funding, donor organisations must show that their money is being spent in a productive way. In this case we can consider that this flow of information back through the network facilitates the flow of resources

In Botswana, describing the role and function of civil society organisations is made relatively easy for several reasons, first, they are almost entirely service organisations, and rarely engage in political pressure or discourse. Thus it is easy to place them within this myriad of definitions, as organisations that have grown to serve the needs of disadvantaged people that are not met by the state. However, one complication is the complicity of the state here in actively encouraging NGO and CBO development (Datta 2004). Is this so that the government can legitimise state activity (Benner et al. 2004) and acquire more international funding, considering that most international donors now stipulate the involvement of civil society groups? Or is this a genuine recognition that government is unable to meet all the needs of PLWHA, and wants to encourage engagement from the community in the HIV/AIDS epidemic? Realistically it could be both, a genuine recognition that international funding often requires civil society involvement, and a perception that NGOs will be a cost effective way of providing services. In fact, considering the relative weakness of civil society in Botswana described by Renwick (2007), Botswana itself is a challenge to the notion that strong democracies breed strong civil society (Thomas 1996). This is especially significant considering the strong organisational networks in Eastern Europe and South America around which many notions of civil society are based (Foley and Edwards 1996). There is little development literature looking at strong states with weak civil society, the tendency is to focus on the opposite situation (eg Whaites 2000).

The simple conclusion to these debates is one that actually fits neatly with the networking concepts underpinning this research: that power in today's globally connected world flows across and between states, societies and international NGOs. Geographies of scale and power support this notion of a rich mosaic of organisations (Brenner 2001), and it also connects with notions of a 'Global Civil Society' (GCS), a

dynamic dialectic between all levels of actors that shape and change each other (Lipschutz 2005). In this model, states are not subservient to NGOs, or vice versa, but each exist in a symbiotic relationship (Risse 2007). Support groups, a key service provider for PLWHA run by peers, fits this idea well, as having started as grass-roots organisations to provide services that were lacking, they are increasingly seen by governments to be important partners for service delivery.

3.12 Support groups

Support groups, also called self-help groups, scarcely feature in the literature on HIV/AIDS in Africa, despite a considerable proliferation of them in most nations experiencing HIV epidemics, including Western nations, where there has been much more research into them. They are however common for a variety of stigmatising medical and social conditions

“These groups of patients or family members have as their primary purpose the provision of mutual aid for adapting to problems created by chronic illness, addictive disease, and other physical or mental impairments”
Pilisuk and Parks (1986, p160).

In a broad review of studies on 15 support groups for PLWHA in North America, Spirig (1998) notes several concepts which they share: alleviation of stress, empowerment, social support, group support and quality of life improvement.

‘Support group’ is the term universally used in Botswana and most other African nations to describe an autonomous organisation of individuals infected or affected by HIV that come together to offer support to one another in a peer setting. Helgeson and Gottlieb (2000, p222) define support groups differently, “in that they have a closed membership, involve expert leader(s), usually have a fixed duration, and do not engage in advocacy activities”. characteristics that do not describe any of the support groups in the study. They would describe the groups in Botswana as being more akin to self-help groups, except that these groups are not anonymous, and are usually set up as formal organisations. To prevent confusion, this study will always refer to the groups in Botswana as support groups, since they are referred to as such by all participants at individual and organisational levels. However it is worth exploring the definition further, and the differences between the peer support, self-help and therapy groups that Helgeson and Gottlieb describe. The key characteristic between all these groups is the coming together of several people who are experiencing the same stressful life event, in this case HIV/AIDS, but also other critical diseases such as cancer, and conditions like alcoholism and bereavement. The basic tenet is that people in a situation that is stressful and often difficult to discuss openly with others can benefit by the:

“sharing of feelings and concerns participants previously thought were theirs alone. The discovery that others have experienced similar problems helps assure members that their anxieties are normal- a sense of relief that helps develop individual morale and a sense of identification among group members. This sharing then leads to an exchange of ideas about effective ways to handle problems” Pilisuk and Parks (1986, p160).

In other words it could be argued that at some level these groups advocate a philosophy that support from people in the same situation is needed or is even preferential to

sympathy or empathy from family members, or in the case of 'self-help groups' even trained professionals. Again, it is difficult to describe support groups more accurately or as succinctly as Pilisuk and Parks (1986) do.

"Members may retrieve information about their condition that was unavailable to them... important in helping group members to accept their situation realistically and evaluate their options... groups assist members in assessing the adequacy and appropriateness of the care they have received. From these insights, members gradually begin to resolve their own problems and to turn their energies outward. The group may then reach out to help others with similar afflictions, and it may also attempt to make health professionals and institutions more responsive to their needs." Pilisuk and Parks (1986, p 161)

From this description it is clear support groups have benefits to disadvantaged people, either because they have a stigmatising condition, or because there is a lack of adequate formal assistance available to them. Although the support group movement may have started in western nations, their importance in resource limited settings is obvious, and currently understated in development literature. They may provide services lacking from government provision, as well as a forum to challenge the quality of available treatment.

While there has been little research into support groups for PLWHA in sub-Saharan Africa, the most researched are the groups belonging to The AIDS Service Organisation or 'TASO' in Uganda (Kalibala and Kaleeba 1989, Hanpton 1990, Seeley et al. 1991, Kaleeba et al 1997) although this research also examines the wider services of the organisation, such as their counselling services. Much literature refers in passing to HIV/AIDS support groups, for example in the context of providing counselling or adherence, but there is seemingly none specifically about support groups in this context. Yet there is evidence of an extensive network of support groups; a basic internet search will find examples of support groups in almost every country in sub-Saharan Africa. One piece of research has shown the importance of networks of support groups for PLWHA, but with a focus on Thailand (Del Casino 2001), a very different context in terms of culture, population density and availability of medical treatment.

The Botswana Network of People With AIDS (BONEPWA) is the network organisation that represents PLWHA in Botswana, and estimates there are over 100 support groups for people with HIV in Botswana. This represents a total membership of 4000 people (BONEPWA Annual Plan 2006), either infected or affected by HIV/AIDS, an average of 40 registered members per support group. BONEPWA's own definition of support groups is any situation in which five or more people infected or affected by HIV/AIDS come together to form a supportive group (BONEPWA 2006). Two interesting points are made here, first that there is a minimum number, which presumably is necessary for both the practical registration and sustainability of the group. It is obvious that it is difficult to call just two or three people meeting a group, as there will be a large impact of one person not attending for any reason, and thus problems with the stability and the legal registration of a group. BONEPWA management guidelines requires volunteers for standard committee positions, for example chairperson, secretary, or finance officer. The second point is that these groups are not just for those with common experience of having HIV/AIDS, but also those who may be HIV negative, but have been closely affected by the illness of a friend or family member. This is sometimes a point of difficulty with confidentiality in some groups, since some members may not want the group to be open to the public. This represents a common problem with what the role or

target of the group is, and also the definition of supportive groups by Helgeson and Gottlieb (2000), since people start to have wider differences in experience if it does not just comprise HIV infected people. Yet conversely this is also important to the confidentiality of group members, because if a group is not exclusively for PLWHA, their attendance at group meetings does not automatically make them HIV positive in the eyes of outsiders, and allows people who have not been public with their status before to sample the group experience and assess its trustworthiness before they commit themselves to telling group members their HIV status.

3.13 Official support

The role of the state has already been briefly introduced during discussions about civil society, but it is an important service provider, and also sets national policy for engaging with the HIV/AIDS epidemic. Much has already been written about the importance of political will in instigating programmes to tackle HIV/AIDS (Putzel 2004), demonstrating the importance of strong leadership in creating effective programmes for prevention. Unfortunately, this is another issue where research and literature tends to focus on prevention and not care and support, although Patterson (2005) notes that this focus is also prescribed by states, donors and NGOs. These tend to take the form of educational programmes, through media, schools and public forums on the risks of HIV, and how to prevent the epidemic, for example through the ABC model. Nevertheless, the state has played an important role in sub-Saharan Africa in providing services for PLWHA, although with a variety of success.

These services include state medical services, especially health care in the forms of clinics and hospitals which can provide diagnosis and treatment for HIV and opportunistic infections. In most African countries, anti-retroviral drugs are not freely provided, mostly due to the cost burden of implementing these programmes. However this is also compounded by neo-liberal funding policies from western institutions which demand indebted states reduce their expenditure by cutting government services (Patterson 2005). Thus in many nations, state health services for PLWHA focus on the treatment of AIDS symptoms, but only provide specific medication for those who can afford it privately. The numbers of people infected often put pressure on health services, and many governments have designed home based care (HBC) programmes to provide basic and cost-effective on-going treatment in the community, to relieve the strain on central hospital services and release hospital beds (Moalosi et al. 2003).

In addition to these general health services, many countries have established specific HIV testing programmes, coupled with counselling services, to encourage more people to know their HIV status, from which citizens can begin behaviour modification to prevent the further spread of the disease, and also begin to seek treatment where available. This is the level of intervention that the Botswana government has implemented, coupled with a long running anti-retroviral (ARV) programme which offers free drugs and treatment to any citizen (ACHAP 2004). This makes Botswana almost unique in sub-Saharan Africa, and the most interesting location to study for a number of reasons. Firstly there are strong formal services, as Botswana has the resources and political will to invest in HIV prevention and treatment campaigns, making for a strong balance between official and community services for PLWHA. Secondly, the availability of ARV drugs not only provides a unique context in itself, but also means that there will be more focus towards the social needs which this study is interested in, as medical needs should be already met. In other countries there would be

much more importance in meeting basic medical needs, which is more appropriate for a medical, rather than social geography based study. Of course it is hoped that eventually all countries across the world will offer ARV treatment, and this thesis, in investigating the needs of PLWHA in a country with an advanced programme, will hopefully provide insights which will be of use to other countries scaling up their own treatment programmes.

3.14 Conclusions

This chapter has outlined the key concepts of support, and its importance in the HIV epidemic. It has also shown how support exists as a social function, and introduced a theoretical framework for the investigation of support for people living with HIV/AIDS, social network analysis, which conceptualises support as a function of a number of networked bodies. Examining support systems as networks allows an approach that integrates formal and informal support, coming from individuals, voluntary organisations and state services. This enables a picture to be drawn of the complete landscape of care, which will show where weaknesses in the system lie that are hindering the provision of support for PLWHA. However, to achieve this, a rich literature from health geography, sociology, psychology, ANT, social capital, and debates into the geographies of scale must be used to strengthen the research framework, and ensure a fertile path for analysing the significance of later results.

Engaging with the literature on support services has raised many questions which need to be answered by the research, for example; what support is needed by PLWHA, and from where is that support most often received? Previous research suggests that practical and psychological support is needed by people with HIV in addition to medical treatment. However insufficient literature addresses how these social needs are being met in the context of the HIV epidemic in sub-Saharan Africa, especially in the era of anti-retroviral medication. Having established the research context and a framework to base the research on, in the next chapter appropriate methods of investigation can be adopted to address the research questions that will guide the thesis design.

To investigate the multiple levels of support, a multi-method, multiple scale strategy will be adopted, conceptualising care from three different viewpoints: institutional, community and individual. It is not intended that these levels should be conceptualised as being hierarchical: as this chapter has demonstrated, all levels are functions of the other, the individual is as much a product of the community as the community is a product of the input of individuals, and institutions are as much a product of the community as they are the input from individuals. In investigating support through networks, the project can be designed to integrate formal and informal support, allowing comparisons between the two. Also, the research objectives need to structure the research towards investigating the support services available for PLWHA in an era of ARV therapy, putting a focus on the provision of social, not medical support. Although Botswana will provide an interesting study area, different locations for research will be chosen, for example urban and rural sites, so that the research can also examine if informal support is more important in areas where there is less official assistance from government and NGO services. Thus it should be possible to show an example of the complete landscape of care for people living with HIV/AIDS in Botswana.

Chapter Four

Methodology

4.1 Introduction

Previous chapters have illustrated the extent of the HIV/AIDS epidemic, and discussed some of the social issues facing People Living With HIV/AIDS (PLWHA) in places where anti-retroviral medication is available. Potential assistance to these PLWHA has been described as coming from many different sources at formal and informal levels, which combine together to form a complete network of social support. To keep the investigation consistent across these levels, there are four key research questions that were investigated:

- 1 Identify the main sources and forms of support for people with HIV/AIDS in the study areas
- 2 Examine the current role and functions offered by support groups, how users experience them, and how support networks are evolving
- 3 Explore the needs of persons on ARV treatment, and how these needs are met by formal and informal methods of support
- 4 Explain the variance in objectives 1-3 along lines of social difference e.g. gender and location, from which appropriate support strategies for people on ARV treatment can be formulated

These four objectives structured the research towards investigating the support services available for PLWHA in an era of ARV therapy, and investigated support through social networks. The project was designed to integrate formal and informal support to allow comparisons between the two. To address objective four, multiple groups in different locations were chosen for investigation, including groups from urban and rural sites, so that the research could examine if informal support is more important in areas where there is less official assistance from government and NGO services. Thus it should be possible to show an example of the complete landscape of care for people living with HIV/AIDS in Botswana.

To study this network of support, the research project employed a multi-method strategy of inquiry, collecting data from both users and providers of support to create a picture of the complete landscape of care and support. 11 semi-structured interviews showed the

problems and experiences of support providers at a formal and organisational level, including respondents from government departments, civil society organisations and international donors. To get the perception of support from PLWHA, 5 participatory focus groups were conducted with support groups, and 9 participant diaries gave an individual perspective on networks of support for people living with HIV/AIDS in a developing country context. Ethnographic strategies, especially participant observation, provided more extensive detail on the operation and roles of support groups for PLWHA, and were conducted with support groups over a period of several months. Lastly, two workshops were organised to inform the project, one with support groups from across the country, and another which brought research participants from all levels together to give feedback on the project.

This chapter will introduce the key aims of the research, and critically evaluate the methods used to answer them. Before starting any piece of research, it is essential for the researcher to understand the values and problems associated with different data collection methods before suitable approaches can be chosen for the research design. It is also important to engage with the philosophy of research, to consider how knowledge is being created, the reliability of data, and the influence of prejudice and positionality from the researcher. It will also consider problems with power relations inherent in researching vulnerable groups of people, and the importance of ensuring that research benefits the communities it engages with. This chapter will outline each of these factors, and engage with literature debating the issues associated with each method used for the project including details of how the methods were used in the field.

4.2 Epistemology

Firstly, it is important to situate the research in a philosophical and methodological framework, and justify a practical approach to the investigation of the aims and objectives. As a meta-theory, research should be situated in a core epistemological framework, which states the researcher's position on the pursuit and limits of knowledge. As a philosophy, Bateson (1979, p242) defines epistemology as "the study of necessary limits and other characteristics of the process of knowing, thinking and deciding". A researcher has multiple roles in a project, the primary aim of which is to address the research questions through the collection of data and the formation of conclusions. If we consider, as some thinkers have, that it is impossible for researchers to conduct completely impartial research (Lather 1991, Barnes et al. 1996), then we must acknowledge that researchers explicitly 'think and decide' and thus this process should be made transparent. This helps expose bias that taints the conclusions and even the methodological approach to research. Oakley (1999) expresses a common contemporary feminist viewpoint, that the tools that researchers use are themselves socially constructed, especially in terms of who can use them and for what purpose. However Atkinson and Hammersley (1994) are among many authors who express caution in this area, noting that while some scepticism and critique of knowledge creation is healthy, it is important not to take this too far: to the point where the debate is debilitating and limits discoveries. The researcher still has a valid voice, and should be able to make engaged and considered judgements through the research process.

Post-modern concepts of knowledge suggest that linguistic and societal influences change how individuals construct experience, and thus the experts in describing social reality can be considered those experiencing it themselves (Anderson 1997), but it is still the job of the researcher to coax out and interpret this knowledge. This strongly

echoes traditional social constructivist theories which state that all knowledge is constructed as the result of social interactions (Berger and Luckmann 1966) and thus that society is a human construction as well. These philosophies could be interpreted as suggesting a qualitative method of inquiry which aims to examine in depth how individuals perceive their society and functions within it, as a way of understanding how society is constructed. This is often seen as a cultural realist viewpoint, in which things are defined by their cultural norms (Putnam 1983). In terms of research, methodological relativism is often applied in this fashion, especially in anthropology, which states that one must consider things in their cultural context, and that researchers should thus immerse themselves in the culture they are studying, attempting to leave their own interpretations behind. To understand the experiences of PLWHA in a very different context to the Western, white, and male middle class position of the researcher, considerable effort was made to spend time with the support groups in daily activities. This provided a greater depth of cultural context for the study and built trust in the researcher.

Since the research shows varying differences between the experiences of PLWHA and also the opinions of formal service providers and their users, it is important to explain this by detailing a little of the philosophy into relativism. Relativism is the epistemological belief that the "truth of a claim can hold only relative to some knower" (Moser et al. 1998, p11) which some relativists interpret as implying that there is no absolute truth. While not all relativists would suggest that this applies to everything, Baghranian (2004, p3) suggests that a property is relative "if its correct ascription depends on additional background factors", for example poverty is a relative measure, its use relies on an pre-existing belief of what the boundaries of poverty are. Extrapolating this idea wider into lived experience, relativists question notions of truth, beauty and quality as being constructed norms, and not absolutes. Baghranian (2004, p303) notes that this view leads to a different way of viewing the formation of society and actors, as our perspectives are "permeated by our concepts, our interests and our historical conditions. Our encounters with our social and natural environment can be described to that extent and one might even say, experienced in different ways".

Hughes and Sharrock (1997, p12) take this argument one step further, and see society as being better described as the product of networks.

"social life is neither something constituted solely by individuals, nor comprised of self-subsistent social wholes, but is, instead, a network of social relations, and ensemble of given positions and associated activities and practices, which are occupied by individuals who are agents capable of making decision and choices and who... may transform the structure that they or others will subsequently occupy"

Thus we can see everything in society as being interdependent, influencing how society is interpreted and reproduced. This leads us on to consider how the social network theory described in the previous chapter can be applied to this methodological framework

England (1994) and others reject the notion of pure impartial and objective-free research, and argue that it is impossible to get away from the pervasive politics of culture, society, academia and personal experience/prejudice to create completely impartial research. It is also argued that there is an inherent power relation in research, with researchers having power over their subjects in their ability to direct questioning,

have the final say in interpreting the data, and forming ultimate conclusions (Nast 1994, Smith 1996). Mayall et al. (1999) recognise that all research is political, although they note that researchers rarely have the power to influence policy. There are many ways to mitigate the effects of this power relation over participants, for example by rejecting positivist and quantitative approaches which are seen as patriarchal (Oakley 1999) and using participatory methods which encourage disadvantaged people to take more control of the research. Regardless, there are still underlying issues, especially with the power researchers have over analysis and publication (Mullings 1999). If this opinion is true, then the best course of action for researchers who are aware of the power relations in their research, is to acknowledge that there are always biases in research, and attempt to minimise them, or at the very least make the opinions of the researcher clear

(Crang 2005). The positionality statement given in Figure 4.1 is an attempt to make the potential biases of the researcher transparent, not just to readers and people wishing to interpret the research, but also to the researcher himself. Yet Bourdieu (2003) argues that researchers should go further than this, and recognise that just as the lives and actions of those being researched are socially constructed, so are the methods and institutions from which the research is instigated. Researchers should recognise that academic disciplines and departments each have their own norms, traditions and socially constructed methods, and to achieve full reflexivity one must also take this into account. In acknowledging the privileged position of the researcher, the aim is to ensure that the researcher takes steps to mitigate the power relations, bias and prejudice in research, and provide greater respect to the people who are the focus of this study.

The use of a multi-method strategy for research fits in well with a methodological relativism epistemology, as it will provide a level of comparison and multiple ways of extracting details of lived experience. These methods must however have a conceptual framework that allows them to facilitate each other (Greene et al. 1989), one should not pick and choose favourable results from multiple methods; McKendrick (1999) would describe this as tactical deployment. Triangulation, although often erroneously applied in research (Mathison 1988) needs to be specified before induction of the data collection to draw inferences from multiple data sources. Here it is an important method of analysis since it will be important to draw comparisons across the different data collection methods, especially the focus groups and diaries of PLWHA. There are a variety of approaches to triangulation, which can be used to either converge and thus

Figure 4.1: Positionality statement of the researcher:

I am a white, middle-class, able-bodied, heterosexual male, born and raised in England, to parents who are both in social care professions. My mother is a nurse in a children's hospice, perhaps leading to an interest in palliative care, and my father is a medicator in the NHS. My political views are left of centre, and I am an atheist.

I studied Human Geography as an undergraduate, and my dissertation was based around a hypothesis that HIV rates were highest in the most developed areas in sub-Saharan Africa. However, I had not visited any part of Africa before I started this PhD project. I have had an interest in HIV/AIDS issues for the last 6 years, both in an academic context and in campaigning, having been involved in organising HIV/AIDS awareness events at University, and direct political lobbying.

My personal feelings about the context of my thesis are that there is not enough importance placed on the welfare of people already living with HIV/AIDS, and that anti-retoviral treatment should be provided to all that need it. I also feel that people have more than just medical needs in the epidemic, hence my decision to research social support.

validate common themes, diverge to explore differences in experience and data collection, or bracketing to more closely specify findings (Greene et al. 1989). Brewer (1989) notes that the triangulation process adds in effect an extra layer of analysis as the researcher has to evaluate issues of convergence and divergence between the different methods.

A distinction needs to be made here between multi-method and mixed-method approaches. Mixed-method typically exemplifies the use of both qualitative and quantitative methods in a research design, which may provide both validation and explanation. However the mixing of conflicting paradigms into one study has been criticised by some (eg Smith 1983). Multi-method on the other hand uses different approaches, but from the same base theorem. Brewer (1989 p17) views multi-method research as a reaction to the acknowledgement of imperfection in methods, and advocates using "an arsenal of methods that have non-overlapping weaknesses in addition to their complementary strengths".

Sampling is another problematic issue in qualitative research, especially in researching sensitive topics where randomly selecting people from a marginalised group may be practically or ethically impossible. Gerson and Horowitz (2002) note in these cases that it is the responsibility of the researcher to be cautious in the selection of participants, and be conscious of, and thus aware of possible biases that may undermine a fair selection. They state that in all research "the goal is to select a group of respondents who are strategically located to shed light on the larger forces and processes under investigation" (Gerson and Horowitz 2002, p204). For the purposes of this research project, we can consider three different types of sampling, 'theoretical sampling', 'selective sampling' and 'chain-referral sampling'. Glaser (1978, p36) describes theoretical sampling as "the process of data collection for generating theory whereby the analysis jointly collects, codes, and analyses his[sic] data and decides which data to collect next and where to find them, in order to develop his theory as it emerges", and goes on to state the importance of the data collection process being controlled by the substantive or formal theory underlying the work, to develop grounded theory. In theoretical sampling the risk is that if the research is not well grounded with a pre-determined theory, the research can become tangential to the original aims of the project, resulting in unfocused and unscientific conclusions.

It is important not to confuse theoretical sampling with snowball sampling, sometimes referred to as 'chain-referral sampling' which explores networks whereby an individual recruited to the study recommends peers from the same group, for example other drug users, people with HIV or those who use the same facilities (Biernacki and Waldorf 1981). Snowball sampling is often considered to be a less than ideal sampling method, because it may only sample particular people who are friends/associates and well linked socially, not a broader random sample. However in research with stigmatised and sensitive groups, it is often the only practical way to recruit for research, and is well advocated (Watters and Biernacki 1989, Faugier and Sargeant 1997), making it a suitable choice for this research with people with HIV/AIDS, as they often are not public about their status, and it is important to protect their confidentiality.

Selective or purposeful sampling is based on a conscious, but informed attempt by the researcher to select recipients that will meet the criteria for research and that cover all required variables, such as age, gender and ethnicity (Coyne 1997). Advocated by Schatzman and Strauss (1973), selective sampling is a response to practical limitations on a researcher's time and the accessibility of subjects that restricts the ability to use a

large random sample. The researcher should be familiar with the subject area and population, and preferably have undertaken sufficient studies or research into the field site to be able to select participants to meet the aims of the research (Schatzman and Strauss 1973). For this reason, the researcher made a one month scoping trip to Botswana during the research design process, to select suitable sites and gauge the level of support for the project with certain support groups and national organisations. Following this, some nine months of fieldwork were conducted, of which much of the first few months was taken selecting and building a rapport with organisations and individuals. While selective sampling could be done much more quickly in other circumstances, as few people were public with their HIV status, it was a slow process to identify suitable groups for the project.

4.3 Field sites

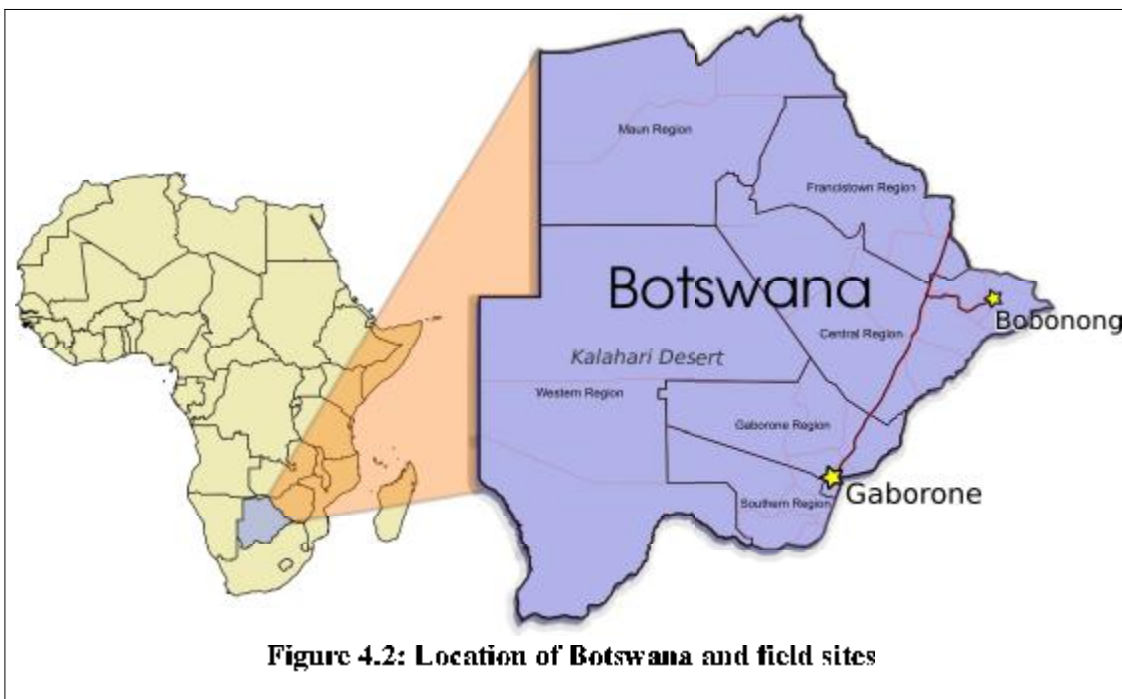


Figure 4.2: Location of Botswana and field sites

As introduced in the previous chapter, Botswana is a relatively wealthy country in southern Africa, with a small population, but a large HIV epidemic. It has a GDP per capita of \$5,280 (World Bank 2004), although this disguises a large level of inequality and high rates of unemployment. Healthcare and education have been free until very recently, when the government introduced a small school fee. Literacy is officially at 79.8% (CIA 2005), although it is much higher in younger people. The main language is Setswana, the indigenous language of the Tswana, who are the largest ethnic group in Botswana, and were the focus of the study. However English is the official language used in legal, national government and business circles. Most people are fluent in both, although proficiency is higher in Setswana. Since independence as a protectorate of the United Kingdom in 1966, Botswana has been a peaceful, and stable multi-party democracy, although the conservative Botswana Democratic Party has so far always held a majority in parliament (Teith 2005)

The conditions of the research permit (Appendix vii) granted permission only for a few specific locations, so two field sites were chosen to give a contrast between urban and

rural experiences of support. The urban site, the capital city Gaborone, was a logical choice because it is by far the largest settlement in the country with a population of 208,000 (Government of Botswana 2005b) and has many well established support groups and community organisations. As almost all the formal organisations and government departments are based here, it was also where interviews would be conducted and was the main area of research. As the capital city, people are employed in a wide range of occupations, although informal employment is common, especially for women. This may comprise of running street stalls selling fruit or snacks, or 'piece jobs', essentially housework or odd jobs. The research focused in one particular low income area of the city, Old Naledi. This was essentially an upgraded squatter settlement, which had been improved with permanent housing and sanitation in the last 20 years. Although the government census does not provide statistics for districts within Gaborone, it is estimated that Old Naledi has a population of between 20-30,000 (Lindsey et al 2003). Most people rented small houses with little land and were on low incomes, although would maintain close links with their extended family in rural villages where they had access to more land. Considering some districts of Gaborone are very affluent, the low income and high levels of informal employment in Old Naledi make comparisons easier with a rural site, where there are similarly high levels of informal employment and less disposable income. However, some support groups were chosen from semi-rural outlying regions of Gaborone, which in some ways had similar socio-economic characteristics to suburbs in other cities: middle class people seemed to have moved to these areas to have bigger houses and more land, and people tended to commute into the centre of Gaborone for work. This allowed for some basic comparisons between regions of different socio-economic status, although since data is only available for Gaborone as a whole, it is difficult to quantify the difference in incomes between these areas.

A focus on Gaborone presented a skewed vision of support, as it represented an environment where a large number of official and unofficial services were operating. In contrast a more rural area was needed to show the experience of PLWHA outside the urban setting. The village of Bobonong, in the North East of the country (Figure 4.2) was chosen as the second field site, since it was a large enough village to have most basic services, including a long-running home based care system, and had already been identified on the scoping trip as having a well established support group. It has an estimated population of around 9000 people (Ntse 2001) although exact figures are difficult to assess, since most people are engaged in rural agriculture, and live on remote farms during part of the year. It is also close to the mining town of Selebi-Phikwe, and some people commute there for work. It was not advisable to choose a smaller location, because while this would have provided a better picture of support for very rural PLWHA, it would offer too few sources of support to study.

The most recent figures available show that Gaborone has an HIV prevalence in pregnant women measured at 34.2%, while Bobirwa district, where Bobonong is located has a slightly lower rate of 29.8% (Government of Botswana 2005). The national average for pregnant women is estimated at around 37.4% (NACA 2003), and for the general population at 28%. Clearly both sites and the country as a whole are suffering a major HIV epidemic, and the need for investigating support for PLWHA is easily justified. There are also a number of network bodies in Botswana, which provide many opportunities for examining the role that organisations play in both supporting PLWHA, and other organisations. The National Strategic Framework (NACA 2003), the main document which describes Botswana's national policy on HIV/AIDS, describes four network organisations which link to government. These are,

BONASO, the **BO**tswana **N**etwork of **A**IDS **S**ervice **O**rganisations, facilitates information and channels international and government assistance to a wide range of mostly larger NGOs, but also includes many support groups as members.

BONEPWA is an abbreviation of the **BO**tswana **N**etwork of **P**eople **W**ith **A**IDS, which actually focuses on representing and assisting support groups more than individual PLWHA.

BOCAIP is a network of Christian AIDS centres, the **BO**tswana **C**hristian **A**IDS **I**ntervention **P**rogramme, that focuses on outreach and drop in counselling, co-ordinates Faith Based Organisations (FBOs) and also runs support groups. Lastly

BONELA, the **BO**tswana **N**etwork on **E**thics, **L**aw and **A**IDS is very active in lobbying for the rights of PLWHA, and providing anti-discrimination legal assistance, but does not co-ordinate other organisations.

The inclusion of **BONELA** at this level in the framework is interesting. While it is certainly a large organisation with a remit that does not overlap any of the other bodies, it represents individuals as well as groups, does not have affiliation requirements, and does not particularly have a coordinating role over community groups as the other umbrella bodies do. The exclusion of **COCEPWA** (the now defunct network of **C**oping **C**entres for **P**eople **W**ith **A**IDS) from this list may indicate either that it was never considered to be a major coordinating body of groups, or that it was already considered to be non-functioning in 2003, and thus did not form part of the government framework.

The fieldwork period was from June 2006 to March 2007, with the scoping trip taking place in June 2005. During the main fieldwork, the researcher lived in central Gaborone with a Motswana (Botswanan citizen) in government social housing. A strong effort was made to learn Setswana, the main language of Botswana, through the assistance of many Motswana, other researchers, and a course at the University of Botswana. This provided, while not a fluent proficiency in the short time available, enough to be able to form basic conversations, and to understand most of the important words used in the research, such as help, family and treatment. Most of the fieldwork was spent in the Gaborone area, working closely with around 10 support groups and community organisations who had agreed to take part in the research.

4.4 Focus groups

Support groups were an important focus and source of information for the study, and 4 support groups took part in the detailed part of the study that included focus groups, participant diaries, and ethnographic placement. The names of the groups have been anonymised to protect the confidentiality of the respondents, and to prevent the possibility of identification, some exact details such as founding dates have been approximated.

Group 1 was attached to one of the hospices operating in the Gaborone area, in a predominantly urban, low income area. It seems to have had the largest number of active members, with around 14 people taking part in the focus groups. There were too many participants for group discussion, so two focus groups were conducted, representing Group 1 and Group 4. Group 1 was conducted in a community hall, an

excellent venue in which discussion lasted longer than three hours, while group 4 was in a more formal setting which made for a comparatively more subdued focus group. The support group was comprised mostly of women with perhaps two or three active men, in an age range from approximately 25 to 45. This group had a relatively high rate of formal employment, especially in AIDS NGOs, and was the highest proportion of church goers in any of the groups in the study. The constitution of the group stated the main aim was to provide love, care and support to PLWHA. The group did not have any premises or office space available to it, although they attempted to acquire a small Portacabin during the fieldwork period {Research Diary}. This limited the places where the group could meet, and the income generating activities they could perform.

Group 2 was in a less central area of Gaborone, and was attached to a national NGO. The members generally met in the home of one of the group leaders, where the focus group was conducted, and there are usually 6 active participants. This group spoke the least English during the discussion, which lasted under two hours. The group had the highest age range, with young people as well as some members over 50, but had only one regular male participant. The group had a strong focus on organising community outreach in line with the operations of the NGO, specifically on youth and orphans and vulnerable children (OVC) support. The group emphasised emotional support and empowerment training, and included both PLWHA and affected family carers, few of which were primary income earners. The group was not running income generation projects at the time of the research, and seemed to have minimal financial needs.

Group 3 was another group in urban Gaborone, and the only one in the study with rented land and office space, which acted as a drop in centre, with space for a vegetable garden as an income generating project. This was the venue for the focus group, and the researcher spent most time volunteering with this group. The support group had the highest average age of all the groups, with most members over 40, and two active male members from a total of around 7. The group offered a great number of services, including food, home based care, income generation and projects with Orphans and Vulnerable Children (OVCs). This group also had the most equipment, and the most ambitions for expanding, although this coincided with large ongoing running costs. Employment in the group members was very low, and in general restricted to the informal sector.

Group 4 was the group from the rural area of Bobonong, and had numbers of active members that varied from 4-8 depending on the farming season. There was a mix of ages, but only one regular male participant. The group has land for building a drop-in centre and office, which was being built during the fieldwork by volunteers. Currently meetings are held in the offices of the local government home based care programme, which many members are part of. The group has some craft based income generating projects, with plans for new activities, and does a lot of community outreach on stigma reduction. Most members are employed in agriculture, or in community AIDS programmes.

Together these groups offered an opportunity to learn about the experiences of support from a variety of PLWHA and their carers, including a wide range of ages, and groups from different levels of rural and urban settings. The groups included male and female adults (all over 18), resident in the area of the research for at least 3 months, as there was a danger that people new to the area may not be aware of, or have any experience of many of the available services. The aim of the groups was to get the opinion of PLWHA and their carers on which were the key sources and types of support they relied

upon, and why people had different networks of support. The varied composition of these groups helped in addressing research question 4, the factors that explain differences of experience for PLWHA, as the membership included different levels of employment, and practical and social needs. As the results chapters will illustrate, the different experiences within and between groups, and the group nature of discussion, allowed for vibrant debate on support for PLWHA.

Since these support groups provide a safe and comfortable environment for people infected and affected by HIV to provide peer support in a group setting, focus groups were a natural research tool for investigating the experiences of PLWHA at a group level. Focus groups are an inclusive qualitative method that are used in many varied spheres of social research. Goss (1996) describes the term as being a combination of focused interviews in which there are no structured lines of inquiry, and group discussion in which a selected group discusses questions raised by a moderator. In an ideal focus group situation there should be an open and inclusive forum in which "individuals freely discuss their experiences and values while observers attempt to infer unconscious motivations from their interactions" (Goss 1996, p113). However Bloor sees focus groups differently, he sees them as being more of a collaborative venture between the researcher and researched in which the aims of the research are explicit and fed back to the participants (Bloor 2001).

Bloor has written extensively on focus groups, and sees them both as a tool for "generat[ing] data on the group meanings that lie behind... collective assessments" and a feedback mechanism designed to discuss provisional findings with interested parties (Bloor 2001, p17). Indeed he explicitly states that focus groups are not suitable as an isolated method of collecting data and should form part of a multi-method strategy for data collection, as used in this research. Morgan and Kruger (1996) suggest that as the experts in a focus group are the participants, they are best placed to introduce new researchers to a particular field, and the most suitable individuals to present initial results to the community for feedback and evaluation (Bloor 2001). Indeed, during the research many groups commented that the focus groups allowed the groups new insights into support for PLWHA.

The major strengths and weaknesses surrounding focus groups are based on the notion that, as opposed to questionnaire and interview data, focus groups represent collective opinion and discussion. It is very important to realise that focus groups are social, time-limited events, indeed Goss and Leinbach (1996, p115) describe them as being a "collaborative performance". In such groups one is not collecting data on several individuals simultaneously, but the collective responses of a group, a method that will probably yield very different views and experiences to those shared in a one-to-one interview. However, since support groups are a key focus of the research, getting a group opinion here is actually extremely relevant, and the partnership with diary methods allows for both individual and group opinions to be recorded.

There can also be practical limitations involved with groups, especially with transcription. The multitude of voices and performative nature of the groups in which people may not finish sentences, talk over each other, or make sounds of agreement or disagreement, makes transcription very difficult and time consuming (Bloor 2001). In addition, these discussions took place in both English and Setswana, adding an extra level of complexity. To ensure accurate transcription, an experienced research assistant who was fluent in Setswana and English moderated and transcribed the sessions, with the assistance of her notes and a recording from a high quality digital dictaphone.

Standard methods for qualitative data analysis such as indexing and analytic induction are as appropriate for focus groups as interview or diary methods, but again it is important to realise the plural nature of the data, and thus appreciate the wider context of the debate.

Conducting research in this way can be very useful in certain areas, especially in this scenario when one is intending to study a community response rather than the actions of key individuals. Goss and Leinbach (1996, p117) find that “with an audience of peers, participants are more likely to describe their experiences in locally relevant terms” as opposed to attempting to flatter the interviewer or give the researcher the answers s/he expects. In a well run focus group, there is no interviewer, rather a moderator, often the researcher or an assistant, in this case both, who is not there to ask questions or be talked to, but to take part when appropriate and facilitate a discussion between people with similar experiences. Bloor (2001) mentions the importance of arranging chairs and tables so that the moderator/researcher is not at the head of a table, expecting responses to be directed toward him/her, but is positioned in the same dynamic as the rest of the group. The focus group sessions were always conducted in a circle, in a familiar environment for the participants to facilitate the discussion.

Focus groups are widely considered to be a valuable way to conduct research into sensitive subjects or disadvantaged groups like PLWHA for a multitude of reasons. The first is that in a group setting, if a topic is being discussed which a participant is uncomfortable with, s/he can choose to keep silent, while the debate may be carried by other members of the group. For this reason and also due to the less direct level of inquisition, focus groups can offer greater control over what information is disclosed and be a less intimidating experience. Kitzinger (1995) notes that they allow stigmatised group members to support each other in discussing mutual feelings and views that may differ from mainstream culture. However Morgan and Krueger (1998) note that over-disclosure in group settings can also be a problem. They note that, especially when discussing taboo or stigmatised topics in which participants may be able to speak openly for the first time, a level of release and enthusiasm can lead to individuals going too far and revealing more personal details than they intended to. In this research, attempts were made to limit this by presenting groups with a transcript of the focus group session, which they could approve before coding was completed.

Focus groups are still preferential for sensitive topic areas because they can represent a more even power dynamic, and allow members of the group to engage in an experience that can be insightful and positive for both the researcher and the group members (Goss and Leinbach 1996, Bowser and Sieber 1993). In the context of developing countries Goss and Leinbach (1996), studying transmigration in Indonesia, also found that focus groups were well received in their local community, and that the act of speaking out on difficult topics created greater levels of trust in the group members as the sessions were reconvened. In Botswana, focus groups are especially appropriate, since the cornerstone of their local political system is the 'kgotla', community meetings where everyone is allowed to speak, for days if necessary, to influence the leaders and decision makers (Dingake 2008). From this traditional practice comes the phrase 'Mntualebe o bua lagagwe', which translates as 'Everyone's voice matters'. This was used as the title for the feedback document presented to participants, and the fact that the research was interested in recording everyone's views was stated in the introduction to the group sessions. This phrase also became a good humoured way of encouraging more vocal members of the group to allow others a chance to speak.

In a different context Bowser and Sieber (1993), working with people living with HIV/AIDS in a developed country, found that focus groups were a critical methodology that allowed the participants to feel truly involved in the project. Their groups, which they termed 'consultant focus groups', only began when

"participants fully understand the need for the research, [and] feel that they are very important to the success of the project and understand that they can make a real contribution. In our focus groups, participants were encouraged to become personally invested in the research." (Bowser and Sieber 1993, p166)

Their research used focus groups to get feedback on the hypothesis and conclusions of the research as well as collecting data. These are both principles that were used in the focus groups for this research on people living with HIV/AIDS as they seemed to be an inclusive and empowering method of research. The focus groups were not only similar in structure to some support groups that many people receiving care use, but they also mirror the interconnected social networks of informal care given by people living with HIV/AIDS to each other

One obvious disadvantage to using focus groups over interviews and questionnaires is that there is less confidentiality, due to the group nature of the discussion. In fact in HIV/AIDS research where participants rarely disclose their HIV status, the very presence of being in the group provides information to the other participants. However, as pre-existing support groups were used to form the focus groups, this risk was nullified. The groups were comprised of people who already know one another, and each other's status. However it is important to reiterate that these groups did not solely include PLWHA, partly due to practicality and confidentiality. If groups had been formed based on participants' HIV status, this would have not only created ethical disclosure and recruitment difficulties, but also may have discouraged some from participating if their HIV status was not publicly known. Being seen at one of these group sessions would not allow others outside the group to assume that they were HIV positive, as they may just be carers. Also, by including care givers and receivers, the research not only includes the views of both sides of support, but acknowledges that these boundaries are often blurred, and that people may give as much support as they receive. The opinions of caregivers are important for the research, and they clearly had much to contribute on providing support. Bloor (2001) discusses at great length this use of pre-existing groups of perhaps friends or support groups for conducting focus groups, and suggests that this approach can have many benefits. For example an already acquainted group are likely to already have a level of trust and comradeship, which can greatly facilitate meetings. They may also be able to prompt other members by reminding them of shared experiences that had otherwise been forgotten.

The size of the group and selection of people in it can have a great effect on the group dynamic and amount and level of information gained from it. Recommendations vary, and are obviously dependant on the topic being discussed, but Kitzinger (1995) is typical in suggesting groups of 4-8 people for sessions that last from between one and two hours. This was the guide that was used for the focus group discussions in the research, with sizes ranging from 5 to 9 participants. With regards to compensation for participants, payment is not given for focus groups in academic research, however covering costs for travel, or childcare may be appropriate, but was not necessary for any of the groups who regularly met in a similar way for support group meetings. Refreshments were provided, including snacks, drinks and sweets, which are seemingly highly valued as a treat in Botswana. The researcher also baked cakes for some of the

group sessions, which the participants found both amusing and impressive, and acted as a great icebreaker. In one case a rather muted discussion became much more vibrant once they realised refreshments were provided. This small token went a long way in showing respect to the group members who gave up their time to take part. Yet it is important to remember that as research with human participants should always be optional, none of these small offerings were intended as bribery or coercion.

Focus groups can be valuable participatory activities which should be used to include communities in the development and discussion of research projects. If care is taken in their planning and implementation they can be appropriate in some research into sensitive topics, and may prove equally enlightening for the participants and researchers. They have been successfully used in non-Western countries for HIV research (Kitzinger 1994, Konde-Lule et al. 1993), however usually to assess knowledge of HIV transmission or risk, not specifically for social impacts. The notable exception is Kaleeba et al. (1997) who used focus groups to assess support from one NGO for HIV positive persons in Uganda. Even in literature in developed countries, most research has assessed social impacts of HIV infection through interviews or questionnaires (Friedland et al. 1996, Sowell et al. 1997).

Although there were always some participants who needed to be encouraged by the facilitator to contribute to the discussions, in general groups were keen to discuss support, and not afraid of expressing different opinions. This led to vibrant and fertile discussion, for both the researcher and group members, and many group leaders commented that they had learnt a lot themselves. While some groups set a specific time limit on the discussions, most sessions went over time with participants were eager to have their opinions heard: and one session even lasted over three hours. However, it was necessary to provide material for discussion, and to ensure that there was a commonality between support discussed in each group so that comparisons could be drawn. To achieve this, a participatory exercise was designed for the focus groups to be a stimulus for discussion

4.5 Participatory methods

As this research recognises that the people providing and receiving support are the experts, the focus groups included participatory methods that enable them to alter the exercises used, create their own categories, and give more control of the research to the people being investigated. Participatory techniques are becoming popular across social sciences, including in Geography, where community mapping techniques are particularly relevant. Using visual methods such as these have been, perhaps optimistically, considered to be comprehensible in most cultures and able to permeate difficulties with language and literacy (Pain and Francis 2003).

For this research, simple participatory exercises were designed, built around a set of cards which

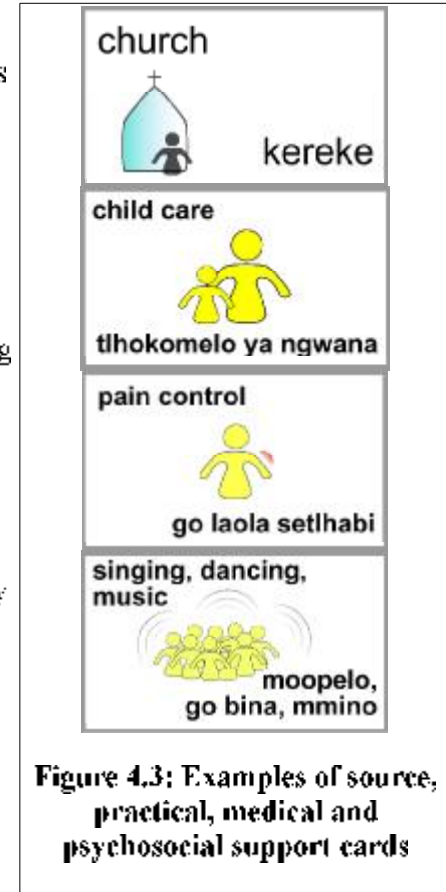


Figure 4.3: Examples of source, practical, medical and psychosocial support cards



Figure 4.4: Group 1 participatory ranking exercise

represented a large list of types and sources of support, with blank cards left for participants to add categories of their own. The cards show 19 sources of support, 19 types of psychosocial support, 10 types of medical support and 10 types of practical support, with illustrations and descriptions in both English and Setswana. These were chosen by the researcher before the exercise, based on discussions with service providers in the scoping trip and some of the literature on support. Examples of the cards can be seen in Figure 4.3, and a full list is in Appendix (j). These were intended to be used either in ranking exercises, which created the most discussion but took too long, or a simpler set-up where groups had to decide whether a source or type of support was important, or not-important. Participants quickly wanted to put some cards in the middle, and some groups chose to rank to some extent as well. The flexibility of this exercise was deliberate, and lets groups have control over how they want to engage with and design the research. For example, Group 2 thought the ranking or sorting exercise superfluous, and chose just to discuss each card in turn, which still provoked detailed and enlightening discussion. The real outcome from the sessions was the discussion, not the final ranking of the cards, useful though this was. Figure 4.4 shows a photograph taken of the ranking exercise from Group 1, in which the most important cards are on the top left in descending order of significance, and least important on the far right. The group chose to group some cards together, and not to include some at all. Although there are no set methods for use in participatory research, there are some exercises that are often used to stimulate research, for example creating maps, Venn diagrams, time lines and flow diagrams (Mukherjee 2002). It is important to remember that the discussion from these exercises is more important than materials generated in the session, and even the exercises themselves (Stringer 1996). A list of several exercises was envisioned for the focus groups, but in the end the ranking exercise alone provoked more than enough discussion.

Only one extra card was added by participants, this was a card to represent support from God. It was felt important by the groups to show this as different from support from the church, and highlighted an important cultural factor that had been overlooked by the researcher. Here the flexible participatory approach had allowed groups to correct this oversight, leading to a more appropriate and accurate portrayal of their views. The exercises certainly seemed useful to the groups, several participants noted there were support sources they had never considered before, and many groups requested to keep the cards so that they could use them for later group discussion exercises. Clearly this was more than a data-mining exercise; the process of the research, even before the results had been presented, proved useful and informative to the participants.

This type of participatory methods has grown out of a popular movement from development practitioners called PRA or Participatory Rural Appraisal, which in turn grew from Rapid Rural Assessment (Chambers 1980, Chambers 1994). Initially the researchers were trying to develop a method of quickly finding out about livelihoods in rural villages by using group exercises to create diagrams and maps of the lives and societies of communities (Chambers 1984). These methods grew out of a desire to conduct more inclusive research on development issues engaging with local people, rather than doing research on them, and in a way that was much quicker than long term anthropological studies (Chambers and Blackburn 1996). They have become very popular with NGOs, researchers and government institutions in developing and developed country settings for guiding service building projects, and are strongly advocated by the World Bank (Bhatnagar and Williams 1992). A key aim of participatory methods is the change in power they should promote, where participants instigate and control the forms and outcomes of research and subsequent decision making (Wright and Nelson 1995). Holland and Blackburn (1998 p1) describe this as an approach that “aims to create the conditions for local analysis of existing realities and local ownership of subsequent courses of action to change those realities”. They are primarily used to involve disadvantaged people in policy formulation, those usually unable to take part in consultation or who have little political influence (Chambers and Blackburn 1996).

Many commentators have stated that it is not the methods themselves that make participatory methods different, but the way they are used, and the attitudes of those facilitating the work (Cornwall and Jewkes 1995, Mukherjee 2002). Mukherjee describes this as an important conceptual shift, in which the researcher must change attitudes within him/herself to become a facilitator rather than lecturer (Mukherjee 2002). The movement also reflects shifts at an institutional level, and an attempt in development to move from top-down approaches to viewing the local as a strong potential source of knowledge and empowerment (Mohan and Stokke 2000). This was exactly the case in the fieldwork, the PLWHA and their carers in the support groups were the experts on support for PLWHA, and by getting the participants to describe support for themselves, it avoided information being overlooked if the researcher did not ask the right questions.

However, there have also been vocal critics of participation techniques, especially those which see the term participation as being applied to all kinds of research that are not participatory (Hagey 1997, IDS 2005). Some also speculate that true participatory research when instigated by academics is a contradiction in terms; as the project, agenda, and outputs are usually controlled by the researcher (Gaventa 1993, Stoecker 1999). This is certainly a valid criticism in the context of this research, unlike in policy

forming exercises, a PhD study requires considerable design and analysis input from the researcher. However including any degree of participation into a research project is likely to increase user involvement and reflexivity (Kesby et al. 2005). When initiating a piece of participatory research it is critical that the instigators design ways in which the project can feed back to the communities that take part, to prevent the research being exploitative, and to give people a better incentive to take part (Attwood and Gaveta 1997). Because academic research is rarely instigated by the people who it will study and affect, it is crucial in a participatory framework to ensure that there is no 'data mining' effect, where fieldwork is used only to extract information without benefiting the people who take part (Ausell 2001). In conversations with NGO officials during the fieldwork phase, it became clear that many previous researchers had used just this approach, collecting data in the country for a few weeks or even days, and then leaving without providing feedback. Thus it was essential to take steps to respect the people taking part in the project, both to gain trust and provide feedback to the community. Another criticism of participatory approaches, especially when coupled with development concerns, is that they form part of an over focus on the local, and can lead to projects that create a binary between local/global issues, and perhaps even ignore the influence of the state or international actors if they do not have a direct influence on affairs in a specific local area (Mohan and Stokke 2000). Yet the multi-method strategy here includes semi-structured interviews that include the voices of the state and international actors as formal service providers.

Participatory methods have been used successfully in HIV related research in developing countries, but again not specifically in the context of social support. Kesby (2000a, 2000b) found that compared to focus groups, participatory diagramming provided more detail for discussing HIV and sexual activity for women in Zimbabwe. Kesby (2000b) used flow diagrams to connect issues or causes to central themes and noted that these diagrams left results that were more accessible, immediate and relevant to the community than a scientific paper or report, and this helped stimulate discussion. The focus group sessions revealed similar conclusions to published research using quantitative and other qualitative methods, allowing Kesby (2000b) to conclude that participatory diagramming used in similar contexts to this research can reach accurate and verifiable conclusions. Another standard participatory approach used in HIV research is the 'Stepping Stones' tool, a participatory package used to educate rural communities in developing contexts about HIV prevention, involving exercises about power, communication, sexual relations and gender issues (Welbourn 1995). In that example, participatory methods were being used to facilitate discussion and education of people about HIV, rather than specifically to collect views as in this case here. However the success of the project in helping to reduce infection rates in communities suggests that participatory methods are suitable and effective in rural disadvantaged settings (Jewkes et al. 2006). Although other attempts have been made to use participatory action research concepts in HIV research, (Stevens and Hall 1998) these have again tended to focus on education and prevention rather than the experiences of people living with HIV. Thus it could be suggested that this research is contributing to the literature on participatory methods by using them to analyse social support for PLWHA

In addition to the focus groups, two workshop exercises were conducted which also provided valuable information for the research project. The first was a session conducted at the Botswana PLWHA Week 2005, which included representatives from support groups all over the country who came together for a programme of educational and empowering activities. The researcher helped organised this event, and ran one

session in which representatives from support groups introduced themselves to each other, and discussed their plans and current limitations. This served both to share experience between the network of support groups, and also for the researcher to learn about support groups from across the country. The session became an open discussion, and was facilitated by support group members themselves. Participants gave consent for the session to be recorded for the use of the research project, and this provided valuable context to compare the experiences of the support groups in the study sites.

The second workshop was run at the end of the fieldwork as a feedback session, using a preliminary report on the findings of the project as a stimulus for discussion on problems facing support networks. Representatives from government, NGOs, donors and support groups attended, often meeting each other for the first time. Again the discussion was recorded and transcribed with the permission of the attendees, stimulated using participatory diagramming techniques in which participants were encouraged to draw the support network of particular service providers at different levels, and discuss their opinions with the rest of the group. In fact the discussion proved very interesting, mostly because issues of funding and support for organisations were raised in an environment in which both the funders and recipients were present, leading to a lively, and informative debate.

4.6 Interviews

Interviews have been a mainstay of quantitative and qualitative research for decades, and are essentially 'conversations with a purpose' (Burgess 1984, p102) although their format, structure and formality may vary. Interviews as a social research method hinge around the premise that

"it is possible to investigate elements of the social by asking people to talk, and to gather or construct knowledge by listening to and interpreting what they say and how they say it" (Silverman 2000, p291-292).

Semi-structured interviews were chosen as the best approach for gaining information from organisations and government departments, loosely structured around a set of key issues, a copy of which can be found in appendix (ii). These included questions on what support services the organisation offered, unmet needs, the impact of ARV availability on their operations, key sources of funding and information and their opinions on the networking of AIDS Service Organisations (ASOs). The aim of these questions was to not only build up a picture of what support services were available, but also how the network was working, and how impacts such as ARVs and funding had affected their operations over time. As the same themes were raised in interview, comparisons could be made between different interviews, while also allowing for specific questions more suited to each type of organisation. For example questions on sources of funding were more significant for NGOs than government departments.

The level of structuring in an interview is an important consideration, the most common method, especially for quantitative research, is structured interviews, in which responses to a pre-written and standardised questionnaire are recorded. The aim of this approach is to maximise the consistency and therefore the comparability of interviews, by minimising the variation in each interview (May 1997). In this type of interview there should be no attempt by the interviewer to improvise or ask additional non-scripted questions, and should not prompt or infer any meaning from the responses at this stage

(Fontana and Frey 1994). These restrictions can limit the ability to question in depth certain relevant, unique or ambiguous topics that may arise, and does not represent an equal dialogue between the interviewer and interviewee, thus having the potential to be exploitative. Considering the wide range of participants anticipated in the research, fully structured interviews were not considered appropriate.

Researchers can also use semi-structured or unstructured interviews, which as their name implies allows varying levels of pre-scripting and improvisation. In semi-structured interviews, "questions are normally specified, but the interviewer is more free to probe beyond the answers...[and] enter into a dialogue with the interviewee" (May 1997, p111). In these situations the researcher themselves usually conducts the interviews, or provides clear thematic guides as to what issues are considered relevant to the discussion. This was the case in this research, as all interviewees at official levels spoke fluent English, and there was no need for a research assistant. In unstructured or focused interviews, the emphasis is on creating dialogue between the researcher and the interviewee, and allows those being questioned to "talk about the subject in their own frames of reference" (May 1997 p111). It should however be noted that these less structured forms of interviewing can potentially lead to research being skewed in new or unexpected directions, and that if this is the case and followed through, it can potentially undermine the methodological underpinnings of the research by tempting researchers to abandon their original research aims and hypotheses and write new ones retroactively. This could be considered poor research practice, and may only be suitable for citations such as piloting research, some feminist or action orientated research strategies, or when the framework is based on grounded theory. This approach was not appropriate for this research, and the semi-structured interview questions helped the interviews stay focused on the key aims of the research.

A digital dictaphone was used to record the sessions, allowing the researcher to concentrate on guiding the discussion rather than constantly taking notes. This also ensured an accurate record of the session, protecting both the researcher and the participant, and several interviewees took up the offer of having a written transcript of the interview. These transcripts were coded, and used later in analysis. The use of the dictaphone was made optional to participants at the start of the interview, but in the end only one person did not wish to be recorded. Consent forms were collected for all participants, shown in Appendix (iii) and served two additional purposes, one part was left with the respondent containing contact details for the researcher and a brief summary of the research. The researcher also kept contact details for the respondent, so that they could be invited to the feedback workshop at the end of the project, and/or receive a copy of the draft report produced to inform participants about the first findings of the research.

The interviewees were recruited from organisations, NGOs or service providers which provide some form of support specifically targeted at people with HIV/AIDS. These included formal or informal groups, NGOs or government funded schemes, which provided practical (eg legal, financial) or emotional support. Institutions providing only medical care were not included. The study does not intend to specifically study the functioning of biomedical provision of care, except to discuss in the focus groups how frequent and universal their use is, and hence show the different experiences of those receiving treatment. Organisations were largely selected by affiliation to the Botswana Network of AIDS Service Organisations (BONASO) – an umbrella organisation that has a database of over a hundred organisations providing HIV support. Some non-affiliated groups were also selected to ensure fair coverage of the care landscape. In the one

situation where these initially selected organisations were unable or unwilling to participate, invitations were extended to other institutions offering similar services to ensure fair selection, however rejection was rare.

Interviews were conducted either with a senior member of staff, or a representative who was responsible for the execution of a support project. For interviews to be successful, Moser and Graham (1983) suggest that the interviewee needs to have three key factors: accessibility, or a useful insight into the issue, cognition, that they understand their role and purpose in the research, and motivation, that their answers and participation in the project is valued. It must be the responsibility of the researcher to facilitate an environment in which the interviewee feels willing and able to participate. In all cases, the interviews were conducted in the office of the interviewee, a familiar and comfortable space for the participant. Interviews typically lasted from between one and two hours, and participants were in all cases knowledgeable and happy to co-operate with the research.

In total 11 fully transcribed interviews were used in the research, all in the Gaborone region. Three were from government departments providing support services to PLWHA, one each from the community home based care (CHBC) team, the Masa ARV programme and the National AIDS Co-ordinating Agency. In addition one interview was conducted with a representative from the Botswana Network of AIDS Service Organisations (BONASO), an NGO which co-ordinates ASOs. There were five interviews with local NGOs providing support to PLWHA in Botswana, including two hospices, which provided a range of services beyond palliative care, two counselling services, and a former co-ordinator of support groups. In addition there was an interview with the local office of a major international funding body, and a senior minister from an Anglican church which was running several community services for PLWHA. Additional informal interviews were also conducted with two local government officials in Bobonong to provide context and show the difference between the urban and rural locations. This mix allows the researcher to see the whole network of support services, including official bodies, funding organisations, as well as the grass-root networks that provide local services to PLWHA. It also illuminates strength and cliques in the network, showing which organisations co-operate with each other, and those which are outliers.

Despite their ubiquity, there have been vocal critiques of the use and especially interpretation of interviews in social science. Some feel that not enough consideration has been made to the social situation of interviewing, and how the interviewee can manipulate his/her answers (eg Briggs 1986). It is important to consider that the interview is a social event, shaped by the context of the interview and the relationship and social norms which surround the interviewer and interviewee (Herod 1993, Herzog 2005). It is also critical to read the interview in the correct way. Foddy (1993) notes that communication typically consists of the disclosure of messages indicating a concept, not the direct application of meaning. Thus the interviewer must decode these messages, and pay attention during the interview and analysis to both the content of the communication and the subtext in which it is delivered (Wengraf 2001). To minimise this effect, the researcher both conducted and transcribed the interviews, and only formulated coding and interpretation at the end of the fieldwork, after several readings and a long period of immersion in the field which provided familiarity with the context of the subject matter. Even so, an interview will always take place in the context of power relations, personal expectations and self-interest which will cloud the meaning of the communication (Rose 1997). Some feminist researchers go so far as to say that this

effectively means that as no questions or answers can be framed in a completely context and objective-free way, we cannot assume any results to be a completely accurate portrayal of the subject, and have to aim for relative interpretation (Lather 1991). In a qualitative study such as this one, this is an important concept to keep in mind, especially when later formulating conclusions.

These interviews have other limitations, as even when semi-structured, they are time-limited events, restricted to a certain extent by the ability of the researcher to ask the right questions, and get encourage participants to provide useful responses. While the interviews provided a formal structure which suited the culture of organisations, they were a less appropriate method for asking sensitive questions of vulnerable and disadvantaged people, especially in a what would be a rather intense one-on-one session. Another method was needed to get an individual angle on support, and complement the group and organisational perspectives already collected. The solution was to ask support group members to keep dairies.

4.7 Diaries

To get an individual perspective on support over a period of time, 9 participants from the focus groups were asked to keep dairies for two weeks, to record every instance when they gave or received support. The idea behind this was to both validate and expand on the information about support collected in the focus groups, and also allow the researcher to get an idea about the kind of support that support group members were giving in the community. Bell (1998, p72) defines these solicited dairies as “an account produced specifically at the researcher's request, by an informant or informants” a definition which is vague enough to possibly cover some kinds of self-administered questionnaire, but is careful to negate the use of previously written personal dairies. Perhaps a better definition might be that dairies represent a self-reflexive autobiographical record of a period of time written to inform focused research. One problem with this definition is that Meth (2003) found her informants also detailed past events they felt were relevant, and contextualised their reactions to current incidences. However, both current and past events were useful for the research, since the emphasis was on registering the types and forms of support used, rather than the time-scale involved. Participants were encouraged to write about past as well as current events, and many chose to do so.

Dairies are becoming increasingly popular in medical and social research, being seen as a valuable way to collect accurate information over long periods of time, and to include the voices of participants in the research process. They have been used as both quantitative and qualitative tools, often simultaneously, and have become common in medical research examining the lives of people living with particular illnesses, attempting to examine coping strategies or evaluate new drugs or treatments (eg Wagner 2002). In social research they have been often used in the last decade in the United States for recording information about sexual practices, drug and alcohol abuse (Garry et al. 2002, Leigh et al. 1998, Stopka et al. 2004). They have practical advantages over interviews for participants, as the author has control over what s:he writes, and can write whenever is most convenient for them (Thomas 2006), and the authors can feel they are making their opinions on the research topic heard.

Participants were already aware of the aims of the research from the focus groups, but were also given additional briefing on the information required in the dairies. Each

Guidelines for Diaries

Please write about all times when you receive any kind of help, care or support.

For example, if someone listens to you or gives advice about something that is worrying you, or helps you with housework, or lends you some money.

Please write about anything that makes you feel better about yourself, anything that makes you say 'Danke!' or 'Ke lebogala!'

Please write about

- **Mang?**: Who the help came from, for example a friend or nurse,
- **Eng?**: What kind of help it was,
- **Goreng?**: Why it was important to you,
- **Leng?**: When it happened

Try to write everyday and put the date and day at the top of each page. You can write as little or as much as you like, and you don't need to use any names, to keep you and others anonymous. Please give the diary back when you have finished, and after it has been copied, you will be able to keep it if you wish. You can also write about anything else you want, in Setswana or English, but we are mostly interested in types of help.

Thank you!

If you have any questions,
call or sms Daniel 72518793

Figure 4.5: Guidelines for diary authors

participant was given a pen and small notebook with a set of guidelines in Setswana, an English translation of which is shown in Figure 4.5. It encouraged participants to write about every time they gave or received support, no matter how small, and to note who the support came from, and what it was. This was used to show what kind of support was being given, and the networks of support being used, especially informal networks of friends and family. By indicating the direction of support, it was also possible to show the balance of support, and the extent that it was a two way flow.

In terms of recording current events, many studies referring to quantitative data have found diaries to be more accurate than recall methods, especially when users are encouraged to write something every day (Garry et al. 2002). One could also assume that accuracy would be better in qualitative accounts as well, but to what extent is some self-

analytical insight gained when people can contemplate an event over a period of time before it is written? It could even be argued that the report can be embellished or new conclusions drawn from later experiences. On the opposite end of the scale, we have no way of knowing what aspects of people's lives get left out. Another issue is connected to the individual nature of these texts, they represent only one viewpoint, and thus cannot always be assumed to be a fair and balanced description of events in which the narrator is personally involved. When used to analyse meaning behind actions, these methodological issues need to be considered carefully, but in this case, it is mostly intended that authors just log instances of support. Thus it is important that entries from the diary are not over analysed, and used in tandem with other methods such as the support groups that can verify some of their findings.

Using diaries in areas with low or variable levels of literacy can lead to additional practical issues. Meth's (2003) research into homeless women in South Africa used diaries, and was surprised to find that most of the participants had sufficient literacy to keep a diary. However, for those that did not, there were other options available, for example some people had their daughters or other family members transcribe the diary for them. Other options include leaving people with tape recorders to verbally record a journal entry every day, or visiting participants regularly to dictate a verbal diary. These options all have issues, especially with regards to privacy of sensitive issues. If another person is transcribing the diary, the sense of privacy associated with a written diary is lost (Thomas 2006), and even though the power relation would be different, may feel more like an interview. Tape recorded diaries are more difficult to conceal than written ones, and the author may be easy to identify by voice. The risk with diary methods is that they may exclude subsets of the population who have low levels of literacy, potentially skewing results.

For this project, the researcher brought several cheap MP3 players, which had a voice record function and built in microphone, in addition to an FM radio and music playback. It was intended that these small devices would be given to participants who expressed a difficulty in writing a diary, so they could record a verbal one whenever they needed too. These were cheap enough (£12) that they could be lost or given as gifts to the participants, were simple to operate, small enough that they could be carried everywhere, and also should not draw attention, since they looked identical to common pocket radios. At the end of the diary period, the MP3 players would be returned to the researcher, who could instantly transfer a digital recording of the diary onto a laptop computer for transcription or translation. Issues such as the need to find a private place to record the diary and the risk of it being found by a family member remain, but are also common to the written diaries. Yet no participant expressed problems with writing in this particular setting, and in the end this system was not needed, despite interest in the idea from some of the support groups.

The use of diaries for HIV and sexual health related research is common in the United States and Canada, as it allows for more accurate recall of private events than interviews (Garry et al. 2002, Leigh et al. 1998) or for measuring adherence to ARV drugs (Wagner 2002). In these situations the extra temporal dimension that diaries allow is very important for demonstrating frequency and accuracy. One study in Malawi used diaries carried by local research assistants to record casual talk they overheard or were involved with about AIDS in bars and buses (Kaler 2004). This allowed researchers to hear not only how people talked about HIV/AIDS in daily life, but also demonstrated that men were making very different statements about HIV and sex in peer settings (such as bars) than in formal interviews or focus groups. A similar finding was observed in this research project, people expressed many problems and sources of support that had not been mentioned in the focus groups. Thomas (2006) used solicited diaries to successfully record experiences of women living with HIV in the Caprivi region of Namibia who were receiving home based care. In this example many of the diaries were written by a carer who already visited the individual on a regular basis, due to low literacy levels. The diaries revealed a detailed level of emotional feeling, and documented particular instances of conflict and personal difficulty which helped contextualise the other data collection methods utilised

This was exactly the situation in this study, where the diaries offered a very different view on the research topic. There were no problems with literacy, and every participant who was asked to keep a diary completed it, although participants wrote very different amounts. The diaries added not only an individual level of detail, but as they are event-based, not anecdotal as in the opinions expressed in groups, they allowed for the validation of themes from the focus groups. The inclusion of the dimension of time was a valuable addition, allowing the frequency of support use from different sources to be shown, as well as interesting insights because authors were allowed to write what they wished. Although not all entries were strictly relevant, it was very important that the diaries listed a lot of support that was part of daily life not directly related to HIV/AIDS. This added an essential context to the study that would have otherwise been overlooked: most support was not specific to the needs of people living with HIV/AIDS.

Keeping diaries seemed to be a positive experience for the participants, they enjoyed writing them, and in most cases wanted to write another, although part of this may have been due to the monetary compensation (about £8) they received for their time. All authors wanted their dairies back after they had been translated by the research assistant

and transcribed, and there was a roughly even mix of diaries in English and Setswana, and sometimes both. A decision was also made to give some support group administrators diaries, which was invaluable in gaining insights into links with other organisations, their attendance of community meetings, HIV awareness events and the launching of new organisations. This illuminated the network of HIV/AIDS organisations better than many of the semi-structured interviews. However, the interviews were still very important sources of information, and it would have been quite inappropriate to ask some government officials to keep such diaries.

4.8 Participant observation

In addition to the participant diaries, the researcher also kept a fieldwork journal or research diary (McNiff et al 2003), detailing key events on a day to day basis that helped log instances of support and networking seen while volunteering with support groups and NGOs. This was the main method of recording the observations of the researcher while undertaking several months of volunteering with support groups and NGOs in Gaborone as part of an ethnographic analysis. It was also a space to record feelings, positionality issues and instances where there may have been an impact on group activities due to the presence of the researcher. The purpose of this was to not only see what services support groups were providing, and who they were networking with, but also to better understand the context of support for PLWHA. The placements were also necessary to earn the trust of groups and individuals who had almost all been involved in research projects before, and had sometimes felt that they had not received any reciprocal benefit. It was not only right, but in fact essential to do more than a quick 'data mining' exercise, and this had clearly been the norm for previous research. Indeed the almost universal response from government departments and groups was surprise when they found that the researcher would be in the country for many months, instead of a few weeks. However despite an interactive volunteering approach, this could not be considered action-oriented research, as there was no attempt to instigate change into the network (Gustavsen 2001). Instead, in the basic roles of secretary or driver, great care was taken that the researcher was always commanded and not commander.

Ethnographic study and participant observation has grown from anthropological fieldwork which "aims at developing an intimate an understanding as possible of the phenomena investigated" (Eriksen 2001, p24) through an immersion in the field for a period of months or years. Atkinson and Hammersley (1994) recognise that there are two types of participant observation, essentially passive and interactive, the latter which can be described as:

"the conduct of an ethnologist who immerses her- or himself in a foreign social universe so as to observe an activity, a ritual, or a ceremony while, ideally, taking part in it." Bourdieu (2003, p281)

The aim is to obtain a much greater understanding and comprehension of social phenomena than could be obtained with purely descriptive surveys, especially those using quantitative methods. However, in this case the emphasis was on interacting in very limited roles, since the groups performed sensitive and confidential work which it would have been inappropriate for an outsider without proper training to take part in. During the nine months of fieldwork, approximately three months were spent with three different NGOs and one support group, visiting each organisation several times a week, sometimes seeing all of them in one day. The researcher offered organisations assistance

with a variety of tasks, including writing letters to donors, organising events, and producing promotional materials. None of these activities was instigated by the researcher as an attempt at action-oriented research, but reflected the ordinary projects of the group.

A key component in ethnography is the creation of texts, recorded forms of the voices and interactions of everyday life (Denzin 1997). Denzin (1997) suggests that ethnographers use methods including audio recordings, photographs and as well as written transcriptions to represent the 'other' in research. While this project has certainly used all these approaches to a limited extent, the main component of the ethnographic section of the research

was the researcher's fieldwork diary, in which key events were recorded. A good example of this text is given in Figure 4.6, in which the researcher was able to record the organisations which one group has worked with during the year while helping them type thank-you letters. This demonstrates the type of volunteer work undertaken, often as a secretary and driver, since the researcher was privileged to have a computer and car. As Delamont (2004) notes, while participant observation may include occasionally helping out, the intention is usually to watch the work being done, not actually do it. It should be noted that groups were explicitly informed that the researcher was using this time to observe the group activities, and since the organisations had all been involved in other parts of the research, they had a prior understanding for the aims of the research.

Katz (1994) noted at the time that ethnography was rarely a central part of research in geography, but recently much more research has begun to incorporate an ethnographic function. There are even several studies that have looked specifically at HIV issues (eg Hirsch et al 2007, Sivaram et al. 2007), the latter even successfully using participant observation to examine social networks, similar to the aims of this project. However so far this research has focused on examining risk of HIV infection, not the support needs of PLWHA. An ethnographic component was ideal for a study in networks of support, because the researcher was able to observe which organisations visited and were visited by organisations over a period of time, detailing the network links which could then be mapped (see section 7.1). It also allowed the researcher to observe first-hand the collapse of groups, collecting data in circumstances where participants were too busy or stressed to be formally interviewed. Active volunteering with the groups not only made the long time more worthwhile than just sitting on a chair and observing, but also gave the researcher a closer view of the projects the groups were running, and how they tackled problems. The diary also became an important personal record of the fieldwork for the researcher, recoding memories and feelings from a sometimes stressful and culturally isolating experience. These aspects are discussed further in section 4.12.

However, there are also problems inherent with this kind of approach, especially in a danger of the research becoming too loosely focused. Bourdieu (2003) notes that there

First head to ***** support group. There are lots of people there, cooking meat and other things, and there is now lots of furniture, more posters on the wall and some very old computers, which they say they have just been leant for a while, but there is no power cable for them. But the desks and things are a donation from the department of supplies, who apparently have an AIDS committee – or does the group have friends in high places? We write thank you letters to people that have helped them that year, and invitation letters for an end of year party to people like local counsellors, BONEPWA, CEYOH, CresMark [a clothes store], the people that sponsored the rent for the few months, and the local MP, and some other couples that have helped them. Then we do letters asking for donations of caps and shoes and transport...

Figure 4.6: Example fieldwork diary extract

is an inherent difficult position when the researcher aims to be involved in the experiences of the social context they are studying, and becomes both subject and object. Atkinson and Hammersley (1994) also realise that the differentiation between 'self' and 'other' in ethnographic texts is a problematic issue. Bourdieu (2003) suggests countering this by examining the 'self' in the same way: since positionality of the researcher is so important in this approach, there must be an attempt to put the researcher's ethnographic experience through the same sort of analytical depth that is applied to the the data collected more explicitly 'on' participants. However, since the approach taken in this project was to not become involved in the functional work of the group, this duality is minimised. However, it was important to consider the impact the research had on the groups, sometimes perhaps acting as a source of practical support for the organisation, and also reflecting on the research diary during the fieldwork period to identify issues with positionality. One such issue was during the organisation of the PLWHA week workshops, where there was a risk of the researcher becoming too involved in the planning process, and a decision to step back from the process showed how groups were dividing responsibilities themselves. Every data collection method affects the research process in some way, and it is impossible to interact with the field of study without causing some kind of influence. Researchers should be aware of this, and take steps to minimise any interference which could skew the findings.

Even taking into account these limitations, there are important areas of the research which the ethnographic study can illuminate, especially in describing the operations and structure of the support groups, and several instances where support groups experienced difficulty. Ethnographic methods are also inherently flexible, and for areas where there has been little detailed research, for example in the roles of support groups for PLWHA, an open approach can be illuminating, and an important foundation for further investigation. As expected, the participant observation led to a greater understanding of the reasons behind processes in the network, but in addition also allowed the researcher to act as a 'fly-on-the-wall' when two groups collapsed. As normal sources of funding dried up, the researcher was able to watch the groups attempt to gain support from other organisations and individuals, directly demonstrating the functioning of the support network for individuals and groups. Restrictions also limited the services the groups were able to offer, and by observing which services were the last to be cut, it was possible to see the priorities of support that were offered, as well as how individual supportive relationships continued between group members after the formal structure had ceased to function. These discoveries are detailed in Chapter 7.

4.9 Transcription and analysis

Transcriptions were coded with the use of qualitative computer assisted analysis, to tag and code sections of text with key themes (Dey 1993, Pope et al. 2000). This involved creating a coded database of a transcription, where sentences and words can be highlighted to draw attention to recurring themes. It should be noted that although this process often allows the potential to 'quantify' this data, for example by allowing conclusions to be drawn from the number of times certain key words/themes appear, this can be misleading and unless a clear deductive analysis framework has been specified, can be contradictory to the research design (Pope et al. 2000).

Some researchers have advocated Interpretative Phenomenological Analysis to extract perceptions of lived experience in health and psychology settings, and this can be an additional fertile approach to the analysis of transcribed texts (Smith, Jarman and

Osborn 1999). However it is commonly considered that the best way to get a feel for groups and themes is to conduct multiple readings of the transcribed sessions before attempting computer based analysis (Gerson and Horowitz 2002), and this was the approach taken in this research project. at least three readings of the text were made before coding and analysis.

Creating accurate transcriptions, especially from semi-structured or unstructured interviews or group sessions can be problematic, even impossible. Kvale (1996, p113) notes that transcriptions are “artificial constructions from an oral to written mode of communication” and that researchers usually see written transcriptions as being like raw data, the central, unedited and impartial data source. In fact, Kvale (1996, p113) points out that “every transcription from one context to another involves a series of judgements and decisions” and that it is very difficult in a written transcript to get the full nuance of a spoken event. Coding schemes that record pauses, inflections and even sarcasm should be consistently applied, and consideration given to who conducts the transcription, as the researcher or research assistant rather than a third party may be the best choice. Attempting to keep the nuances of oral texts is important to capture the complexity of ethnography, and not give priority to written texts over oral texts (Crang 2005), a difficult balance to achieve in the context of a PhD thesis. To keep the feel of the transcripts as close to the sessions as possible, there was little attempt made to 'correct' the speech in terms of grammar when English was used, and pauses and hesitations were noted. This can not only show where participants have paused because they are discussing a problematic issue, but also prevents the researcher making corrections to sentence structure which might subtly alter the thrust of the argument. The timing of the transcription process is also important, it is generally considered to do it as soon after the event as possible, Weingraf (2001) recommends immediately. This was precisely the approach taken here, semi-structured interviews and focus groups were transcribed in the same week they were conducted using an audio recording of the session. This was done by the research assistant for the focus groups which were at least partially in Setswana, while the interviews in English were transcribed by the researcher. Diaries were similarly transcribed by the research assistant when in Setswana, and the researcher when in English. Names and places were immediately anonymised, and replaced with codes or numbers for each participant. Each sentence was kept in a separate cell in a spreadsheet, together with a number, the code name of the speaker, for example Respondent 5, and an approximate time to allow the researcher to check the audio recording if the meaning of a sentence was unclear. When referring to the transcripts in the results chapters, each quote is identified by the group or interview, and then the sentence number in the transcription, for example {Group 3, 243}, allowing each quote to be verified from the full transcription.

A set of 21 codes were used to tag each sentence in the focus groups and interview transcriptions, to allow analysis of the complex texts which were created from the audio recordings. These codes are shown in Figure 4.7, and grew from the themes identified in each sentence. After transcription, a list of all themes mentioned in each sentence was recorded, for example family, stigma or education. After this process had been completed for all the interviews and groups, the key themes were chosen based on the most significant themes which occurred in all the texts, and the aims of the research questions. Another reading was made, this time tagging each sentence with one of the codes in Figure 4.7. An example of a coded transcript is found in Appendix (iv). This process was an attempt to let the text itself suggest themes for coding and analysis, and to limit the biases of the researcher when choosing themes. Even so, the researcher is still making decisions and imposing categories at this stage, but considering the

reflexivity process, multiple readings and immersion in the field, it is hoped that this process is both transparent and informed. Regardless, this stage still represents a lack of participant control over the post-discussion analysis, and this is often seen as a potential weakness in participatory research (Moss 1994). Mullings (1999) also notes that researchers almost always have more power than participants when coding data, and it is important for the researcher to consider this in research design and coding. However others have argued that participatory research by its design and application automatically involves some processes of peer verification and triangulation (Kesby et al. 2005), as methods are used to discuss differences and provide a multiplicity of debated opinions, rather than one answer.

ARVr	Anti-retrovirals
Comm	Communication
Delta	Change in situation
Dntr	Donations
Drctv	Directives - formal plans or documents
Fnd	Funding
Frct	Friction - something that slows networking
Gds	Goods, equipment
Gndr	Gender
Info	Information
Int	Internal issues/problems
Kee	A key quote
Nds	Needs
NetGOV	Network with Government
NetIND	Network with Individuals
NetNGO	Networking with NGOs
Pltv	Palliative care
SG	Support Groups
Skl	Skills, human capital
Sppt	Support
Srv	Services for PLWHA

Figure 4.7: Codes used for triangulation

With regards to focus group analysis, there is an added need to represent these multiple individual voices in the analysis, as well as the group consensus. Catterall and Maclaran (1997) note that coding on its own cannot adequately capture group dynamics or the flow of opinions during the session, and advocate coding and note taking directly onto the script, in addition to the selection of key sentences for coding that tend to form limited isolated 'snapshots' of what they see as a moving process. For this reason, there is an additional tag used to code 'Key' sentences, parts of the debate that were particularly interesting or vibrant and would be suitable to quote in the results chapters. Albrecht, Johnson and Walther (1993) see opinion forming as being a progressive group process, and caution that it is important to reflect this in analysis to obtain a deeper level of understanding, hence the inclusion in the results chapters of several full debates showing the multiple viewpoints expressed in the group sessions. This need to represent multiple voices and the likely presence of disagreement and overlapping discussions makes transcribing focus group sessions much more difficult than one-on-one interviews, transcription may take up to five times the actual length of the session (Bloor et al. 2001). Identifying voices may also be difficult, so it is recommended that the facilitator address people by name as often as possible.

Triangulation was used to draw the multi-method strategy together, validate findings (Mathison 1998) and to evaluate why different methods of inquiry may suggest different conclusions (Patton 1980). This triangulation was easy to perform with a computer aided system, once the transcripts had been coded with the key themes. Instead of using dated computer aided analysis software such as NUD*IST and Nvivo, it is now possible to perform much quicker analysis using standard desktop search software and SQL. This software allows the user to search for words within files, and highlights documents which contain the search terms. Transcripts were typed directly into a spreadsheet, with separate columns for the transcription, themes and codes. The unique codes for each key theme (for example Sppt for Support) did not occur anywhere else in the text, so using this search package to search for Sppt instantly highlights each transcription which contains this code, not only in one file, but simultaneously across all the focus group

and interview transcripts, and ranked according to the relevance of each document. In addition, the software shows extracts of each text, highlighting where the code was used. So in effect, running a search for Sppt instantly shows every sentence from the sessions tagged about support, and how often it was quoted in each session.

This approach can be used in a variety of standard search packages, for example 'Google Desktop', and 'Beagle' for the Linux operating system, which was used for this project. This innovative approach saved many hours coding and formulating searches in specialised software, and allowed for a quicker and more flexible way to analyse the data. Triangulation was demonstrated by the occurrence of similar themes across the data sources, from which the full text was compared and discussed in the following chapters. This approach was also used to illustrate networking, as the researcher could search the name of a particular organisation, and the software would show every transcript as well as every diary, research journal entry and even official documents where that organisation was mentioned. These key official documents included government policy documents and reports on AIDS services, annual reports of NGOs, and the constitution of support groups. These provided an additional official level of information, and allowed the research to examine the differences between the intentions of support services, and how they were perceived by their users.

Analysis of the diaries used similar techniques and the same code set, but additionally examined the temporal aspect, by logging the frequency that specific events or issues are utilised or referred to. Aside from extracting quotes and triangulating with data from the other methods, this also allows the creation of visual pie charts, to show the balance in direction of support, proportion of each source used and the types of support received or given. This was not quantified with percentages or absolute numbers, since this is primarily a qualitative research method, and it would be wrong to infer quantitative data from it. However, they show the rough proportions, and quickly inform the reader as to which sources of support were used more than others.

Giving transcripts to the groups who participated in the focus group sessions proved popular, even when the text was translated to English, and offered further opportunity for discussion and ensuring the accuracy of the recording. These transcripts were also highly valued as formal records of the meeting, giving the groups a feeling that they had not been 'data-mined' and even acted as a stimulus for action and new projects. In at least one case a group started taking formal minutes of meetings in reaction to the focus and direction offered by the transcribed discussion.

4.10 Research assistants and translation

Conducting research in communities who speak a different language to the researcher raises many issues, not just in terms of practicality, but also in terms of reflexivity and interpretation. Translators do not literally find alternatives for words, but concepts as well (Simon 1996) and this will inevitably be structured by different cultural influences between the languages. The use of language shapes, and is shaped by, the identity, religion and ethnicity of an individual and society (Temple and Edwards 2002). Thus it is difficult to claim that a translated transcript has the exact same meaning and nuance as the original dialogue, just as interpretation by the researcher can affect the reading of a text (Wengral 2001), a translator/interpreter adds an extra layer of conscious or unconscious influence. Smith (1996) suggests that translations be considered as a hybrid text of both languages and cultures. In realising this, many researchers are beginning to

explicitly acknowledge the presence of translators/interpreters in research, where previously they were as invisible as dictaphones or typewriters, and some researchers have even given assistants a voice, biography and co-authorship in some cases (Meth and Malaza 2003, Rose 1997). Devereux and Hoddinott (1993, p27) describe their ideal research assistant as having "perceptive intelligence, inexhaustible patience, unflinching dependability and an ability to get on with all elements of the local population".

Recruiting the research assistant can often be a difficult task, and many potential candidates should be interviewed for suitability. In this case, a local supervisor at the University of Botswana was able to recommend several research assistants he had used on similar projects, who had all been previously selected for their experience. A research assistant for this research, Ms Malehogo Makgalemele, was recruited through these contacts at the University of Botswana, and her previous experience in facilitating focus groups was very helpful. She was a native Motswana, and had previously acted as research assistant for a larger HIV/AIDS research project, giving her not just valuable experience, but also an understanding of the sensitivity of the issues and respecting the confidentiality of participants. In group sessions she was quickly able to earn participants trust. She acted as co-facilitator in the focus groups which were conducted in a mixture of English and Setswana, and translated the research diaries which had been written in Setswana. All semi-structured interviews were conducted in English, the predominant language for official business, and so did not require a translator. With regards to accuracy of translation, there were certainly a few situations where the meaning of words in Setswana was difficult to translate, and the common usage of colourful similes and sayings could have been confusing had they not been explained by the research assistant, or sometimes the groups themselves.

Because a translator or research assistant may have commonalities with the participants in attributes beyond language, such as cultural background and ethnicity, the researcher can feel isolated from his/her own research if people choose to only interact with the research assistant (Pasquin and Olaniyan 2004). This effect was minimised by a basic knowledge of Setswana by the researcher, allowing him to participate in sessions, even when they were not in English. This encouraged people to talk directly to the researcher, and explain things in clearer terms, rather than talk amongst each-other or just to the research assistant. However, if a research assistant is selected from a social group or ethnicity that participants have had conflict with, or previous bad experience, this may lead to participants refusing to work with the research assistant (Twyman et al 1999). Ms Makgalemele had previously worked with HIV/AIDS research projects, and even personally knew many AIDS activists, an experience the groups appreciated, and was impressive to many group members. This certainly helped the trust the groups had in the research assistant, and facilitated fluid discussion. It was also important that the same research assistant facilitated and transcribed the focus groups, as she was able to understand separate voices and recall the thrust of discussion during some noisy debates.

Focus group discussions were often quite animated, and it was extremely beneficial for the researcher to have a basic knowledge of Setswana, not just so that discussion could be understood and directed towards particular issues, but also because it made a huge difference to mutual respect. Many groups appreciated and were even amused by the researcher's ability to understand and speak basic phrases, it was clearly a greater effort than some previous researchers had made, and demonstrated respect for the participants' voices.

4.11 Gatekeepers and negotiating access

Gaining access to individuals and organisations to conduct research is problematic for all kinds of research, especially where the project may involve confidential information about businesses or dealing with sensitive issues, such as HIV/AIDS. Obtaining access requires not just negotiating entry to an organisation but also ensuring that individuals within the organisation will meaningfully participate in the study and provide useful information (Shenton and Hayter 2004). Gatekeepers are “individuals or groups who control information and can grant formal or informal *entry* and *access* to the setting and participants” (Holloway 1997, p77). Holloway also notes that there can be official and unofficial gatekeepers within organisations, for example while managers may have technical responsibility over access, it is often secretaries that must be won over for the researcher to gain access to individuals or information. This was certainly the case with one donor organisation, who made it difficult to directly contact project officials. Patience and a polite attitude were essential tools in conducting the research, an observation echoed by other researchers (eg Moser 2008). Sometimes even when gatekeepers have been persuaded to assist in the research, they can still deny access to people who may be most relevant to the research, may have their own agendas or only recommend their personal friends (Valentine 2005). Individuals can also have gatekeepers, often husbands act as gatekeepers for their wives, and must be constantly negotiated with to gain and maintain access and trust (Mandel 2003). In situations where the recruitment of people with particular stigmatised medical conditions is required, doctors or medical professionals may act as gatekeepers, either to details of patients, or to individuals themselves.

Thus research must have strategies for gaining access and negotiating with gatekeepers. Providing information about the research is a key step, not only to convince people that the project is worthwhile, but also that it might be in their interest to get involved. In some situations the researcher may need to offer incentives, possibly information, or a long term strategy with becoming part of the relevant community may be necessary (Shenton and Hayter 2004). This was the case with one of the support groups, who were reluctant to take part in the research before the researcher had agreed to assist the group by volunteering on a particular project as part of the participant observation. Gatekeepers can also exist within the academic community, restricting research into sensitive or controversial topics, and directing themes and aims of research (Broadhead and Rist 1976).

The biggest problem encountered in this area was obtaining a research permit to conduct the fieldwork. Clearly there were a great number of applications for research in Botswana, and making a convincing case for a social rather than medical study was difficult. This was combined with logistical issues, including applications lost in the post, and the Botswana research department moving offices, which led to a 6 month delay in starting fieldwork. The research permit was granted with strict conditions on where fieldwork could take place, which while compatible with the original research plan, limited the options available for recruiting other support groups when two collapsed during the fieldwork period. On a more positive note, the research permit required the co-operation of local supervisors in the University of Botswana who were an invaluable source of support and expertise. Once the project was accepted, gaining trust with some organisations still proved difficult, although this seemed to be more to do with wider issues, for example some organisations were having with issues with stability and trusting others, rather than a reaction to the research specifically. Most

organisations were very willing to be involved, and government departments were very open about participating in research, much more so than private funding bodies. In every case a gradual building of trust was necessary to facilitate access to organisations and individuals. However there is clearly research fatigue in Botswana, and several organisations commented that they rarely received any results from research they had participated in. In these cases the researcher spent many months volunteering with NGOs and CBOs to gain trust, an insight into the workings of the organisations, and to improve the perception of researchers for future studies.

4.12 'In the field' and 'Leaving the field'

In recent decades, traditional ways of conceptualising 'the field' and what constitutes fieldwork has been challenged, especially by feminist thinking which aimed to pluralise and blur the old dichotomy between fieldwork where data is collected, and desk work (Katz 1994). These notions have highlighted the concept that not only can one be interacting with aspects of 'the field' through telephone conversations, the internet and mainstream media, but also that researchers are 'always in the field' (Katz 1994 p67), thinking and studying where ever they are (England 1994). We must also consider that field-sites and research institutions are all influenced by global factors, the local is an expression of global forces, and must be considered in this context.

For example one must consider the relationship between the academic community and the host country, which might have political reasons to be suspicious of research from foreign institutions (Devereux and Hoddinoff 1993). Although the formulation of this discourse may not have a direct bearing on the researcher in question or the group being researched, the wider cultural and social context can have an impact on the success and possible depth of research. The most obvious example of this is cultural norms surrounding race, gender and ethnicity (Kobayashi 1994), and there are certainly issues of equality based on gender, race and sexuality in Botswana. However, foreign workers and researchers seem to be welcomed in general, and there seems to be little stigma attached in society to being of black or white skin.

Devereux and Hoddinoff (1993) recommend that researchers build links with research institutions in the country of proposed research, to build local support and ensure that findings of the research benefit the host community. Such links were made with several researchers at the University of Botswana, who made useful suggestions, and had considerable experience on producing culturally relevant research. The degree to which one immerses oneself in the field can have a great effect on the success and depth of knowledge that can be extracted from a period of research. Even when not conducting ethnography as a formal research method, Devereux and Hoddinoff (1993) suggest living as close to the community being researched as possible, as this can increase trust in the researcher, diminishing their status as an 'outsider' and give a greater insight into local processes. Conducting a close period of ethnographic fieldwork for several months certainly helped the researcher understand the context of PLWHA and support groups.

Field research in the social sciences often involves developing close relationships with individuals and communities for set periods of time. This can be problematic because research can function as an expression of social relationships between the researcher and the research, especially when in-depth qualitative research methods are used as here. Close relationships were formed especially while volunteering with organisations, with the researcher being invited to some social functions run by the groups. This can

potentially cause some ethical problems, especially when the proximity of the researcher to people from disadvantaged groups can conflict with notions of impartiality and anonymity in academic research (Laine 2000). In these situations Laine (2000) suggests that it is critical to continue a trust based relationship from the field into print, so that the written report reflects the same sensitivity and norms that would be used in the field. Considering that the research permit stipulates that copies of this thesis are made available to the Botswana department of health and the University of Botswana, there is a useful pressure when writing the research to ensure that the document is respectful to participants, not just because it is the right approach, but also because participants could be expected to read the conclusions.

Entering the field can be stressful experience. the researcher had few friends and no social contacts for the first few weeks, although there was a group of fellow research students from the University of Botswana and across the world who quickly formed a model example of a social support network. 'Settling in' to the Botswana context took time, not just in terms of finding accommodation, transport and meeting practical needs, but learning Setswana and understanding cultural norms were important processes in the first few months. Sharing accommodation with a Mofswana certainly helped in learning how to fit in, but informal support and assistance, especially with language and advice was also given by many people working with HIV/AIDS organisations during the course of the research

There are also issues inherent with leaving 'the field' after an extensive piece of fieldwork. Obligations to people who were involved in research may continue, even if there is no follow-up, in many cases social bonds are created. Indeed it was difficult for the researcher to leave individuals and organisations when so many months had been spent volunteering and working with them, and once back in the UK there were occasionally feelings of guilt that it was no longer possible to help groups with problems and events. It could be argued that the long period of volunteering with groups could have been harmful, due to interference with the research, and dependency on the researcher as a volunteer. However groups were always aware of the length of the fieldwork process, and knew when the researcher was leaving. While offers of time and services were always made to groups, a guideline of not providing monetary assistance, although at times difficult to adhere to, was understood by the groups and reduced at least this level of dependency. As for interfering with research by having the researcher become a form of support to a certain extent, this probably had a minimal impact, no group mentioned the researcher as a source of support in the exercises, and assistance was usually on a procedural level. For example printing letters or driving group members to meetings. This support was always requested, and not suggested, to ensure that the researcher did not instigate something that was not an ordinary group activity. After the fieldwork, it can also be difficult for researchers to adjust to a more regular pace of life when returning to academic institutions, and they may experience 'post-fieldwork blues' (Devereux and Hoddinoff 1993), when the job of writing up research is not as challenging or engaging as face to face interaction with participants.

4.13 Research in developing contexts: Power relations and 'Othering'

For researchers from developed countries conducting research in developing countries problematic issues can arise due to the inherent power relations between developed and developing countries, many surrounding the labelling of development/developing regions and the 'development project' (Escobar 1994). In conducting research, it is

important at least to be conscious of these power relations, and mediate them or include critical self-reflexivity (Kapoor 2004) and explicitly include in the design of the project practices and methods that allow the voice of the 'subaltern other' (Spivak 1989). Chambers (1997) states that it is important that the reality of disadvantaged groups is expressed, and that they are allowed to express their own voice, rather than having others from more privileged backgrounds create an interpretation of their reality.

Participatory methods have been interpreted as one way to redress power issues in research in developing countries, and were adopted here as one way to mitigate these power issues. Yet others warn that they do "not offer panaceas for all the ethical, political and practical issues of field investigation" (Kesby et al 2005, p145). Parpart (2002) argues that not enough studies have been made of power in participatory methods, and that they often fail to tackle overarching power inequalities, either in society or the research process, and can still be influenced by local power structures. Clearly participants in this study are affected by the power relations in Botswana that make PLWHA disadvantaged, and addressing these issues in such research could be argued to help address these inequalities. However other thinkers, in particular Thapar-Björkert and Henry (2004) see power relations as being much more complicated and dynamic, and suggest that power is continuously renegotiated through the course of a research project. This fits well with the notion of networks used in the study, in which power is a two-way flow.

As this study was located in an African nation, it is advisable to engage with the development literature. However Botswana is generally considered by economists to be a middle-income country, with higher levels of economic and social development than most 'developing' countries. It has a GDP per capita of \$5,280 (World Bank 2004), a literacy level of 79.8% (CIA 2005), and decades of peaceful democratic political process, all signs that Botswana does not fit the label of a 'developing' country. Thus considering it in this way could be considered a form of post-colonialism or 'othering', where it is assumed that because the dominant culture and ethnicity is black-non-Western, it should be labelled differently. However Botswana evidently shares strong cultural similarities to other countries in the region, and some sections of the population have economic and social levels more akin to developing nations, for example some 32% of the population are undernourished (FAO 2005). The inequalities in Botswana mean that neither a blanket description of developed or developing adequately describes the complexity of society there, and one could argue this applies to many 'developed' countries too. Jones (2000) suggests it is only a popular dichotomy that separates the kind of research done on disadvantaged groups in 'First' and 'Third' world nations. Houtum and Naerssen (2002) describe this process as 'bordering' – the creation of borders that separate people of different development levels, similar to the use of 'othering' to distance people from other cultures. They argue that inherent in this is a tendency for ordering, describing one group of people as being superior, or closer to the dominant society. This could be considered a post-modern critique of development labels, but also an attack on the obsession with difference in post-modern research (Houtum and Naerssen 2002) and also ranking or hierarchies (Marston et al 2005). These issues have strong implications on the reflexivity and positionality of the researcher, and how they conduct research. However, it is also important to note that racial, class and gender issues may not be the most important barriers to successful research, in fact Moser (2008) found that universal qualities of social skills, politeness and genuine interest, in other words personality, were much more important factors. This was certainly the experience of the researcher in Botswana, where commitment and respect to participants was the key to facilitating successful partnerships.

While the research took place within a context in which there are many development projects, the aim of the project is not to align itself with a development approach, but consider the research as being primarily a social support issue. Even though Botswana may have a great level of inequality, the state certainly has enough resources to provide strong interventions, unlike many developing nations. To adopt a proper post-development stance, the research must acknowledge the development paradigm and its influence, but design an approach, that while culturally appropriate for the context, is not demeaning and tries to address power balances. Some authors have specifically noted contradictions in the terminology and approach to HIV/AIDS epidemics in the West and developing nations. The HIV/AIDS epidemic in Africa is often blamed on the pure 'Africanness' of people in the continent (Chabal 1996), where the concept of African over-sexuality has become an unquestionable truism devoid of its cultural context (Jarosz 1992). Most importantly James (2004) has noted that research, on the provision of care and support for PLWHA in developing countries is lacking compared to the focus in the West

Dyck (1999, p243) speculates that "new debates and intellectual turns in sociocultural geography... [are] calling for more nuanced accounts of the contextual shaping of health and illness". Research needs to shift towards considering how cultures and landscapes affect HIV positive individuals themselves, and reflect in developing nations the cultural turn in Geography (Cosgrove and Jackson 1987). As Parker (2001) notes, the HIV epidemiology has shifted from looking at the behaviour of individuals to examine the cultural and societal forces that facilitate the spread of the infection, especially socially constructed notions of sexuality and deviance. The next logical step would be to go beyond epidemiology to recognise issues affecting the quality of life for people infected with HIV/AIDS, as is the norm in literature focusing on developed countries. This, at least in terms of the boundaries of this research, can be seen as a practical way to move beyond post-development critiques (Nustad 2001). It could however be argued that this is possible because the remit of the research does not directly address the traditional development project areas of economic growth, food security, formalised education or Western health provision (Escobar 2001).

Respecting the culture and especially religion of participants was very important, and the researcher has taken great care to ensure that the discussion reflects the importance to the participants, and not the beliefs of the researcher. A good example of this is importance of the church and God to many participants, a factor not properly anticipated by the researcher's own assumptions. The feedback process, including the production of a provisional report and workshop to stimulate discussion with participants was one safety net to minimise bias, and the participatory methods another, but as previously stated it is impossible to completely remove the influence of the researcher from such an emotive and personally engaging project.

4.14 Feedback

Giving information back to participants and the host community is an essential practice of ethically considered research, in both developed and developing settings. Feedback in research could be considered to be more critical than in policy consultation, because research rarely produces direct benefits to those who take part or give their opinions. Feedback can also be a useful method of gaining greater understanding and a more accurate insight, especially if initial conclusion documents can be produced for

discussion before the period of fieldwork ends, and comments gleaned from this material (Twyman et al. 1999). Not only does this improve reflexivity, increasing the accuracy of conclusions made by the researcher, it may stimulate more debate on wider issues that had not been considered before. Thus the whole research project was designed to have a component that would enable reciprocal comment, and give participants a sense of inclusion.

To achieve this in the context of doctoral study it is important that materials are created that are in an appropriate form for the participants, who would not have the time or inclination to read a 80,000 word thesis written in academic prose. Crosswell and Curtice (1994) recognise that without this dissemination stage, there is a risk, especially with health based research, that the findings do not reach the audience that the research studied, especially considering the lack of public access to academic journals which are sometimes the only point of dissemination for research. Flaskerud and Anderson (1999), advocate a two-fold strategy for dissemination, one addressing the professional field; through the standard production of journal articles, books, and conference presentations, and the second addressing the community field, through workshops and visits to relevant community organisations.

To address these issues, summaries and diagrams representing key findings and issues were created for this study, in a language and format that was appropriate for direct dissemination by the people who took part in the research. This included verbal as well as written materials, by conducting a feedback workshop for participants, where a short report, written in non-academic language with diagrams and illustrations, was used as an opportunity for the researched to comment and influence the conclusions of the study. Beyond improving understanding, it was clear that participants appreciated this process as valuing their contributions, and having something tangible to take away from it. The report was printed and presented to all individuals and organisations that took part, and also made available on a website that summarised the research project (www.danireak.net/research). All participants were also given a copy of the research proposal, written in both English and Setswana in general, non-academic language. This included contact details, and encouraged participants to contact the researcher if they had comments arising from the research, or from the findings of the draft report. The final thesis will also be submitted to the Botswana Ministry of Health, as well as the University of Botswana as stipulated in the research permit. This is an important policy which helps ensure that research conducted by foreign academics does not remain overseas

4.15 Ethics

In all research projects there are ethical issues which can affect the design, execution and final outcomes of the project, and these are especially apparent in studies such as this which deal with disadvantaged people. These ethical problems arise because “the researcher is ethically and morally responsible to his/her participants, the research sponsors, the general public, and her/his own beliefs” (Kitchin and Tate 2000, p35). One should perhaps also add academic institutions to this list, as universities in particular are making ethical review procedures and guidelines compulsory for all new research. Ethical problems or dilemmas arise when there are conflicting needs between two or more of these parties, and the researcher must use his/her judgement on how to proceed, often having to balance the need to complete the research and protecting the interests of those involved in the research. Laine (2000 p1) states that “ethical problems and

dilemmas are a necessary part of fieldwork” and are inevitable in social research that necessitates a level of proximity to subjects, especially when researching sensitive areas. The assertion that the researcher is always at the centre of ethical issues made in the definition by Kitchin and Tate (2000) is also echoed by Soobraya (2003, p1470) who states that especially in qualitative research, researchers must acknowledge that “truth and politics in research is in effect a confrontation with oneself” and thus that rules and guidelines for ethics can only go so far, considering the dynamic nature of a research process the notion of self will always have to be the yardstick by which ethical decisions are made.

When conducting field research in foreign countries, there may be additional ethical conflicts for political reasons, the researcher will also have to abide by guidance from local or national government, and this may be in contrast to the best interest of the researched population, or the successful collection of some data. This is especially relevant with marginalised groups who may be under-represented in political process, or in conducting research in states with oppressive regimes. This could lead to pressure to water-down conclusions from some research areas, or even to feel obligated to present findings in a certain way that is beneficial to marginalised people. Governments may also not value certain qualitative methods, and may be sceptical of conclusions that disagree with their own research or official line. This did not seem to be the case in this research project, government employees were happy to co-operate, and freely spoke on the record about problems in certain projects.

Historically, people living with HIV/AIDS have fallen into the category of marginalised people, not just because they have an illness that may make them practically disadvantaged, but also because they are a stigmatised group. Ansell and van Blerk (2005) have noted that research on PLWHA can be stressful for participants who are sometimes encouraged to discuss difficult personal and emotional issues. They suggest that some researchers even try to avoid addressing emotions in such research, but that a better approach is to make the focus on a specific issue, in their case migration not AIDS itself. This was the approach taken during much of the research, where the focus was on support systems, not directly on HIV/AIDS. In some group sessions people still shared personal and emotional stories, for example discussing support from spouses was difficult for people who had lost a partner to AIDS. As Ansell and Van Blerk (2005) acknowledge, ethical problems often arise in such research, and the researcher should not attempt to ignore the emotional aspect of the study.

Issues of confidentiality for participants in this research were very important, because in many situations people do not make their HIV status public knowledge, and protecting this secrecy must be a key ethical concern of the researcher. Therefore detailed ethical guidelines were constructed before fieldwork began, and approved by all relevant parties: the researcher, the universities of Sheffield and Botswana, local government in Botswana and during the research, the participants themselves. To go some way to ensure that participants have some control over the research, careful effort was made to ensure that the research is a two way process that continuously informs both the researcher and individuals and groups. This itself helped to mitigate potential ethical issues by ensuring that participants are aware of their rights to make suggestions, and not participate in discussions they feel are inappropriate. The research tried to fully respect the rights of individuals and groups to privacy, confidentiality, consent and the ability to participate in the research voluntarily and without having distress or harm caused to them. Participants were made aware of these rights, the purpose of the research, and of their right to opt out at any time by a briefing before the start of group

sessions or interviews. A consent form (Appendix v) detailing these rights was made available in Setswana and English, describing the purpose of the research, use of the data and what was expected from participants. A voice recorder was used to acknowledge verbal consent for groups, and where individuals were unwilling or unable to sign the written form. In the end there was only one participant from a formal service organisation who decided after seeing details of the research that they did not want to take part, seemingly because they were unable to obtain the consent of their superior.

To protect the identities and HIV status of participants, the data in this project was kept confidential and secure, especially the diary entries, which even when anonymised, may contain a level of detail that could enable identification of the subject. To combat this, it was suggested that participants did not use the real names of people and places they discuss in the diary, but they were also aware that all names would be changed on transcription. The participants were assured that no extensive or complete extracts from the diary would be republished, and told that the diaries would be analysed for themes in content, and only small quotes were to be included in published reports where necessary to illustrate key findings. The same precautions were made for transcribed interviews from focus group sessions, and semi-structured interviews. The names of individuals and organisations who were interviewed at an official level, group participants and support groups are all anonymised.

4.16 Conclusions

This chapter has outlined how a multi-method qualitative research strategy was designed and implemented to answer the key questions posed by the study. To start, theories of knowledge and research, especially the impartiality of researchers was discussed to ensure that the research was planned, executed and analysed as accurately as possible within the limits of epistemological theory. The selection of several inclusive research methods used in the project was justified, including the use of semi-structured interviews, focus groups, and participant diaries. Considerations for the practicality of collecting and interpreting data in this way was detailed, examining the potential role of researchers and translators in imposing their prejudices on research in a different societal context, especially when translation is required. Steps taken to address these issues were detailed, including a positionality statement which attempted to make the prejudices of the researcher clear, and a discussion of the influence of the researcher during participant observation. Some problems with fieldwork were explored, such as negotiating access to organisation and building trust, obtaining a research permit, and how initial findings of the research were disseminated in a workshop to inform the community.

The fieldwork period, although as always slightly different from the original plan, was generally successful. However fewer focus groups were conducted than hoped, 5 in total, mostly restricted by the collapse of two support groups during the course of the study, and the lack of alternatives in the field locations stipulated by the research permit. However these focus groups were all with extremely enthusiastic participants, and covered much more depth than had been initially anticipated. Sheer quantity of group representation was more than compensated for by the inclusion of a transcribed research workshop conducted at PLWHA Week 2006, which included contributions from 12 support groups across the country. 9 diaries were collected, providing valuable insights from urban and rural locations, as well as support group administrators and ordinary members. 11 fully transcribed semi-structured interviews were conducted with a variety

of formal service providers, including counselling groups, hospices, volunteer organisations, church leaders, funding bodies, and government departments for home based care and the Masa anti-retroviral programme. Volunteering with organisations for several months also contributed a wide number of insights into the operations and difficulties of support groups. Finally, bringing together participants from all levels to a workshop to discuss the results of the project became itself a valuable source of information on networking, through discussion and debate with donors and recipients that in some cases had not met formally in five years.

Having set out the aims and approach of the project, the next chapter will introduce the support groups as a critical feature of the landscape of care, and start to draw a picture of the different sources of support available for people living with HIV in Botswana.

Chapter Five

Support groups

5.1 Introduction

This chapter will introduce the support network by exploring the role of support groups in Botswana, which are an important source of support for people living with HIV/AIDS, and the wider community. Their role and structure as support providers will be examined using data from focus groups, diaries and participant observation from 3 support groups in the Gaborone region and one from a rural location in the north of the country described in chapter 4. The opinion and experience of formal support services and government departments will be used to build a picture of how support groups are seen from the formal sector through semi-structured interviews and material from official government documents and policies. Lastly the role of formal support networks of support groups will be described, to introduce issues raised in chapter 7, which describes the decline in networking and co-operation between support services. At all stages support and resources will be examined in the context of a network, describing the flows between individuals and organisations, as well as factors that are hindering co-operation between support groups, with a particular focus on communication problems.

First of all, the chapter will attempt to define support groups in Botswana and lay out the stated roles of the groups, and compare these to the services they currently offer, and how their members and officials see them. It will also show how different groups offer different services. The balance between providing practical and psychosocial support varies between groups, and many are becoming more like businesses by starting income generating projects to fund the group running costs, or to give money to needy members. Several factors that influence which services groups provide or are needed by their members will be considered, including the availability of other complementary support systems in each area. Secondly the function of support groups will be examined, essentially how they run, and how they meet their aims. The last section will look at the problems that support groups are having, both functionally in terms of access to flows of information, skills and financing, as well as limitations of individuals and groups which includes personal conflicts and aspects of trust. Leadership and governance are also shown to be issues which many support groups and other organisations need to address to ensure they are providing useful services to PLWHA, and to ensure

sustainability.

5.2 Support groups in Botswana

Defining the role of support groups is difficult in any context, but as described in section 3.12, they all offer a peer-led support mechanism for people with a particular common illness or concern, in this case people infected with or affected by HIV. However, the services they offer, and the way in which they are run vary greatly from group to group. Formal service providers, including representatives from NGOs, donors and government departments, were asked about how they saw the role of support groups, and despite many mentioning problems that they saw with group operations and undefined roles, they all saw them as being very important for service delivery

“They are definitely a very important resource... in some of the districts the information gets to the communities through the support groups. And the fact that some support group members have come up come into the open to say I am living with HIV/AIDS, that in itself has given the epidemic a face” {Funding Body, 81}.

They also had clear ideas about what functions they felt the groups could perform “Most of the support groups like that are having the PLWHAs they give each other support in that they share experiences, but they can also... depending on the skill... take care of each other, they take care of those who are helpless, depending on what they can offer, they have been trained as peer educators by the Ministry of Health in collaboration with the councils, they have been trained... as counsellors, in basic skills,” {CHBC: 167}. One government official felt that support groups should be seen as a key player in maintaining adherence to ARVs “Because they are more closer and live with them and know and experience some of the things that they would be able to share with them and... I think adherence is part of the support they could provide for their counterparts” {Masa, 73}. Clearly these formal organisations recognised that support groups helped to meet both the practical and psychological needs of PLWHA, and in the case of both Masa and the Funding Body saw them as partners in improving adherence to anti-retroviral therapy. There is a clear indication that government departments and donors saw support groups as strong potential partners for service delivery, and an important part of the support network. Yet as we shall see later, they also see several problems with the leadership and sustainability of some groups that restricts the co-operation between the official and community level. Another issue raised in the interviews was that support-groups rarely have a process for their members by which they leave the group {Former NGO: 180-189}. It is almost implied that people would stay in the group for the rest of their lives, a model which fits when patients are critically ill, and explains the importance of integration with the home based care system. However, in the era of anti-retroviral treatment, this respondent suggested that groups should be taking an approach where PLWHA are educated, given the skills they need on positive living and peer education, and encouraged to go out into the community, effectively no longer needing the support of the group. No group member went through a process of this sort during the participant observation: at the end there were the same members as at the beginning. This raises an important question: what are the roles of the groups in serving their members?

In Botswana, support groups are generally affiliated to a networking NGO, the Botswana Network of People With AIDS (BONEPWA), which provides advice,

guidance and training for support groups that register with it. In the USA, Powell (1990) found that self-help groups can provide their members with greater benefits if they have the experience and guidance of a national network. BONEPWA estimated that support groups had around 40 registered members on average (BONEPWA Annual Plan 2006), a figure on a par with the numbers found in groups that took part in this study. One thing that immediately became clear during the participant observation was that most groups had fewer active members than members registered. This is not surprising, as one might expect most types of groups to have more paper members than people who actively take part in meetings and events at any one time, as other time commitments and personal interests shift priorities. In addition these support group members, a high proportion of which



Figure 5.1: Example support group meeting

will presumably have HIV, will have high levels of absence due to sickness, drug side-effects, doctor appointments, caring for other members, and even a higher rate of mortality than general organisations. Thus while Group 5 claimed at one point to have some 80 registered members, the number of people attending meetings at the time of the study was closer to 6. In each group it was generally a few original founding and committee members that turned up regularly, with a small turnover of others that varied somewhat week by week {Research Diary}.

This study only examines 4 support groups in depth through the use of focus groups, diaries, and an approximately 3 month period of volunteering with groups which allowed an extensive investigation of the activities of the group, utilising an informal participant observation approach (Kearns 2000), with an emphasis on 'hanging out' and 'building rapport' (Russell 2006, p368). This approach allowed a critical insight of who groups worked with, and problems they encountered, as well as providing an opportunity to give back time, transport, and experience to the groups in exchange for their trust and participation in the study. Figure 5.1 shows a fairly typical meeting of a rural support group which was not involved in the study. This group is fortunate to have a plot of land for a vegetable garden and a Portacabin used for meetings and income generation projects. The poles in the foreground were donated to build a frame to support netting over the vegetable plot, which will provide group members with fresh food and goods to sell.

5.3 Case study: Group 3

To give an impression of the typical activities of a support group, an in-depth account of

Group 3 will be given, comprising of data collected from volunteering with the group over a 3 month period. Information comes from the research diary, official documents of the group, and letters and materials that the researcher helped the group create in the course of organising events, applying for funding, and requesting donations from local businesses. The specific details of the group location and partner organisations will not be revealed to protect the identity of the group and its members.

Group 3 is located in a poor urban district, mostly surrounded by low income homes, that are mostly rented. The group has been established for over a year, and is formally registered with the government and umbrella NGOs. During participant observation perhaps 10-12 regularly active members used the site, of whom 5 usually volunteer daily at the drop in centre, most of whom are also committee members. In general these are women in their 30s and 40s, and at least two older men, but there are also a few younger volunteers in their early 20s. There is a larger number of members who come to meetings and occasionally visit the centre, but are not involved in the running of the group. These numbers are difficult to estimate, but the group had around 30 registered members at the time of the study. Most of the support group members live within walking distance of the centre, but it is clear that group members make home visits far enough away that they take a local bus there and back. Although technically the support group is for members of the local district, their coverage area, estimated to be about 2km² of quite dense detached housing plots, is not exclusionary, for example at least one committee member no longer lives in the area, but still comes to the centre daily. There is also one other support group that could be considered to serve this area, although in reality the geographical overlap is small. This other group also offers very different services, with a focus on psychological support. Members probably choose the group by activity, personal association or reputation first, and proximity second. In smaller rural areas this level of choice is rarely available.

The group recently acquired a small plot of land with a three room building, which serves as an office, drop-in centre and kitchen for feeding group members. Depending on demand, volunteer group members typically prepare two meals a day in a small kitchen with very basic facilities. There is electricity, running water and bottled gas, but no toilet, which combined with the lack of space makes the premises impossible to use for the care of sick group members, or clients from the home based care programme. Thus much of the group members' time is taken up by home visits, partially to care for sick community members, but mostly to check on the conditions of people who may have been out of contact with the group for some time. This is done in partnership with the community home-based care (CHBC) programme, so the group keeps detailed records of visits and clients. These visits check on the health of the patient and provide meals, but also consider more general welfare, including psychological well-being. They ensure the patient has a clean living environment and a regular source of support from a family member. Even so, members reported some patients may go for days without any visits at home, even when sick. While many clients and volunteers have mobile phones, it is difficult to find money to buy credit for calls and text messages, so communicating that a client needs a visit is difficult: the carers usually work on a flexible rota system to get around everyone every few weeks. Should a client become very sick, the carer will try and call for an ambulance, but again this requires credit. Often a friend or neighbour is asked to make the call. Clients who have a regular prescription for medication, especially ARVs, can have their drugs collected for them by a carer from the clinic. In the event of the death of a group member or client, the group may also get involved in funeral arrangements, or conduct a memorial service. Some groups also help out with money for burial costs if the group member was not

contributing to a burial association, a co-operative in which members save towards the cost of a funeral

Promoting education and awareness of HIV in the local community is a key part of the group's activities. The group's constitution and official documents express an aim to provide education to community members about HIV and transmission, increase uptake of testing for HIV, to encourage the public to be supportive towards those with HIV and to reduce stigma and discrimination. Many group members have received training in public speaking, and are well versed in providing information to the general public on these issues, as well as other related topical issues that arise, such as legislation calling for employment of PLWHA, a debate widely covered by the media at the time of the study. They are invited to speak at local meetings and businesses, and organise unique community events in which public education is the key function. Members of the support group also regularly visit clinics and testing centres where they provide informal advice to the general public, as well as more confidential meetings with patients undergoing testing for HIV to provide counselling, support and information about the support group and other services that are available. The group also sees the promotion of the Prevention of Mother to Child Transmission (PMTCT) programme as very important, and actively encourages expectant mothers at antenatal clinics to enrol in the scheme, and also does follow-up visits to make sure women are adhering to their PMTCT medication. Aside from work at the clinics, the group also offers drop-in counselling at their centre, and occasional meetings for group members to educate them about adherence, or nutrition for example. Sometimes a health worker such as a nurse will come to run a meeting.

The group has weekly meetings which are for group members to come and share experiences and counsel each other, although these are also concerned with planning and awareness of future projects. Compared to other groups, counselling and psychological welfare of members is a smaller part of the services offered; this group has a much higher emphasis on the material needs of clients in terms of food and income generation, no doubt because the area is of low income, and urban so that most residents do not have plots of land for growing or rearing food. The large amount of outreach and education to the local community is not uncommon for support groups in the study, and has prominence in the aims of the group constitution. This is significant, as it reflects the ability of support groups to be dynamic and in tune with the unique needs of their members and community in each area. Male involvement in HIV testing and support has been identified as another area the group wants to promote. Although this group has several active male members, which is more than some, most are women. One project observed during the fieldwork period was a outreach day centred around football, including members of the national football team, an event specifically designed to appeal to men.

As with many others, this support group also provides services to orphans and vulnerable children in the local area, a service which is not just restricted to children of group members. Funding is perhaps easier to obtain for child services than adult care, helping to support the running costs of the group, and increasing the visibility of the good work done by the organisation. Children are encouraged to take part in traditional singing and dancing practice, and perform at special events at the support group and in the local area. This is an important focus for the children considering the lack of play equipment, and also a potential source of group income through bookings to perform at larger HIV/AIDS awareness events or private parties. However most money made from this goes back to the children, buying them food or small gifts for taking part. Some of

the more vulnerable children, or those closer to group members are also fed at the centre, and they have plans to open a day care centre with play equipment to expand their respite care facilities for family members looking after many children.

Already there are several areas which show the difficulty of defining and confining the activity of these support groups: they perform many different roles, both for members and the wider community. Collinge (1999) defines these boundaries of scale as being 'the forceful imposition of territorial limits that are essential to the viability of regulatory apparatuses' (Collinge 1999, p567), here the regulatory apparatuses are the need for groups to define their services and reach to secure funding, obtain a legal status and to meet the remit of the umbrella organisations that assist support groups. Even so, defining the role of support groups is important for the research project to situate them within the network of support. Yet there are many characteristics of the groups which make it difficult to impose scale or bounding upon them in the three aspects of scale which Howitt (2002) describes. First of all, the size, or spatial extent of the group is not clear. They certainly have a spatial area in which they operate, and have a demarcated base of operations. However, they provide services outside of their official premises, their spatial extent is the whole of the community, to a boundary which while not clearly demarcated, is defined by the varying levels of resources, physical and human capital that restrict how many clients they can manage, and how far they can afford to travel. Secondly there are also other organisations offering services within and beyond their spatial extent, this is the relation component of scale which Howitt (2002) discusses, and the part where organisational networks influence processes. Thirdly, the level of services is also difficult to define, including who the services are offered to, for example those infected or affected by HIV, children of clients or all vulnerable children in the wider community. Certainly, as the literature in chapter 3 suggested, the size and level of group scale is difficult to demarcate, and it is important to acknowledge here the criticisms of scale and bounding that Marston et al. (2005) and others recognise. Later, we will examine the extent to which these groups are part of a global network of flows and connections, which further make the scale of actions of these groups difficult to define. Yet it will be argued in chapter 7 that the relational and network component of the groups is still privy to hierarchies and power relations that make a total abandonment of scale problematic. It will also be shown that group operations, and the corresponding networks of support are constantly in a state of flux, particularly dependent on the financial resources of the group.

The constitution states that Group 3 is established as a charity, and as such non-profit making, but to raise money for projects, activities and to cover running costs, the group is developing many income generating projects, including sewing and jam making, for which they have received training sponsored by local NGOs and even some local businesses. The major challenge with these projects is to reduce the cost of raw materials so that they can be profitable, and also to find a larger market. At the moment the group sells to occasional visitors, mostly from international NGOs, but has not managed to find a proper outlet. The group also has plans to create more service based businesses to support the running cost of the group, such as a laundry service, for which they have approached a foreign embassy for funding. The group has also applied for funds to cover running costs of the home based care and OVC services, special educational events, as well as expanding community outreach and education programmes. Applications have been made to the local government District Multi-Sectoral AIDS Committee (DMSAC) for funding, as well as some of the NGOs that have small grant funds available. These applications can be quite technical, requiring detailed costings, measurable indicators of progress, and must be completed before

certain deadlines. Even if the application is successful, it often takes a long time before money is released to the group.

Much time is taken up by the group in trying to secure donations from businesses, especially for food, which is a major expenditure. Most businesses require written letters on headed notepaper to request donations, which must be written, printed and then delivered, often by hand, which uses time and bus money. This becomes a great burden in the run-up to a big event, as donations are also needed for equipment and promotional materials, and letters must also be delivered to invite politicians, key community members and other NGOs to the event. Money is donated from wealthier individuals, including local politicians, but much seems to come from the pockets of group members who have sporadic access to income. During the fieldwork period, the major source of income for the group came from a large research project looking at PLWHA, which involved many group members and the wider community. The research required several workshops, and the group was paid by the researchers for providing catering to participants in the form of basic cooked meals and refreshments.

The support group budget for one year totalled approximately P5,000 (£400), excluding training courses for income generation projects which were paid for by the local DMSAC. More than a third of this was rent for the centre, and the second biggest expenditure was food. The group also mentioned the cost of running public events for which they received sponsorship, but details of expenditure were not forthcoming, despite a note of thanks to listed sponsors. The budget is clearly not complete in many ways, several large outgoings were not included, such as bus fares, phone calls and small payments given to volunteers during events; a common expectation considering most of the group members are unemployed. The randomness of details included and omitted from the budget is suggestive of oversight and a lack of thoroughness rather than deliberate manipulation, but still highlights the difficulty that small groups have in accounting for money they receive and spend, and the lack of training in providing reports which frustrates donors and government departments. After the fieldwork was concluded, this group was accused of financial irregularities involving the misuse of funds, which has had a considerable impact on the group activities. It is not immediately clear if this resulted from actual misappropriation of funds, or perhaps more likely, an inability to provide records and accounts for donations and purchases. While some operations related to the group are apparently still operating from much smaller informal premises, a major loss of capacity means that fewer services can be provided to members and the community. The collapse of groups, although not always in such circumstances, is reasonably common, and will be discussed further in the next chapter.

Compared with others, Group 3 has made more effort to establish links to certain businesses who are regular donors, but has less input from the networking organisations BONEPWA and BONASO. This particular group does not have connections with any churches, or seem to have members who are actively involved in a congregation. There is a good flow of information with one other support group, which seems mostly due to a personal friendship between committee members, as there are few official collaborations between the two groups, or any obvious sharing of resources or equipment. The lack of a fax machine, while not uncommon, is a serious hindrance to obtaining information, especially from official channels such as larger NGOs or the local DMSAC, and were it not for this informal link with a larger support group, it is plausible that the group would not have been aware of certain events and opportunities. This is a key issue which challenges the notion of abandoning hierarchical scale introduced in the framework of chapter 3 (eg Marston et al. 2005), as if the group is

effectively isolated by a lack of communication resources, how can it be able to influence a global network? Surely the group is directly impacted by the actions of global movements that decide funding and strategy for PLWHA, but at first glance it seems as if working back against the power structure is more difficult. Has the increasingly globalised HIV/AIDS movement become isolated from small groups of PLWHA who have been left behind as Altman (1994) suggests? These issues will be explored in greater depth in Chapter 7. First it is necessary to compare the characteristics of this group to others, and to examine a larger number of groups, to try and examine typical characteristics of support groups, and common issues in communication and networking that hinder or facilitate the provision of support for PLWHA

5.4 General group characteristics

During the course of the study the researcher also had the opportunity to be involved in the organisation of a national conference of PLWHA, which brought together support groups from across the country. This provided the opportunity to run a workshop with 9 support groups from different regions, and for them to share information on their activities, plans and problems. A representative from each group was asked to introduce his/her support group, and provide detail on some areas that were of interest to the study, including:

- 5 What does your group do?
- 6 Who do you work with?
- 7 What do you have?
- 8 What do you need?
- 9 What problems do you have?
- 10 What plans does your group have for the future?

With their consent the session was transcribed, and together with information collected later from 3 other groups that were unable to attend, a broad picture of support groups across Botswana emerges, summarised in Table 5.2. This table shows key information about support groups and serves as a good introduction to the differences and similarities between groups, as well as a first look at the common problems that are mentioned

The first point of note is the commonalities in the roles described by the groups, especially terms such as support, love and care, and education. From this we can quickly see that a supportive psychological element is a key role of support groups in Botswana, as is education of group members as well as the wider community. Interestingly no groups listed welfare of their members as a specific goal of the group, when many of the projects and daily activities are clearly geared towards this, as will be shown later. However it should be noted that this table really represents the view of an individual group member, and not a written constitution, so while this is not an official line, it is still interesting to show what roles members perceive their groups to have.

Projects frequently included some aspect of Home Based Care, either with the CHBC project including clinic referral of people who need medical assistance, or home visits to clients or members on their own initiative, and counselling, reflecting the availability and need for counsellor training. Youth outreach, and especially care programmes for Orphans and Vulnerable Children (OVC) are common, perhaps due to the funding

Location	Role	Registered	Partners	Premises	Equipment	Projects	Income Generation	Needs	Problems	Plans
Caborone	Support, love, sharing experiences	Yes	HBC, Hospice, counsellors		Sewing machines	HBC, referral, support, education, counselling	Sewing	Plot, equipment	Accommodation, proposal writing	Porta-camp, proposals income generation
Tlokweng	Care, support and youth education	Yes	BONASO, DMSAC, Barlays	2 x porta-camp, plot	Computer, phone, combi	Counselling Miss Stigma Free, referral	-	-	Getting vehicle insurance, male involvement	OVC
Old Naledi	Help infected and affected	Yes	BONEPWA, BONASO, BONELA, Clinic	New Office, rented	TV, cooking, chairs	Counselling, OVC, meals, HBC	Lam, knitting	Chairs, tables	Stopping HIV	Male involvement, outreach
Bobonong	Love, help and support to infected and affected	Yes	HBC, DMSAC, counsellors	Plot	-	HBC, referral, support, counselling, education, outreach	Garden, poultry	Income generation, members	Members, independence from HBC	Plot, income generation
Hukuntsi	Youth education and orphan care	-	Social and Community Development, BNYC		-	OVC, youth education		Solidarity with elders and parents	Young people do not commit to the group	-
Mabutsane	Calming emotions of infected and affected	No	Schools, churches, ACHAP, DMSAC, S&CD	Electrified caravan	-	Education, awareness, positive living	-	Leadership, furniture	Lack of awareness of HIV	Educate about HIV
Moshuoa	Gain knowledge about HIV	Yes	DMSAC, BONEPWA, BONASO	Plot, porta-camp	-	School and business outreach	Pots, garden	Electricity, furniture	Selling pots, patience, responsibility	Counselling
Kang	Home visits	-	DMSAC, BONASO, Global Func	Plot	Car, stove, oven	OVC, HBC, cooking	Yes	Funds	Male involvement, official assistance	-
-	Care for orphans and sick	No	Clinic, nurses	-	-	Orphan, ill	-	Plot, training	No assistance, finance	Poultry rearing, care
Mochudi	-	Yes	Clinic, hospital, SG, shop	Porta-camp, plot	Furniture	Condom distribution	Beads	Transport, electricity, water, money, volunteers, gas	Volunteers, sharing resources, lack of awareness	Street bash, income generation
Kagalagadi North	-	No	HBC, DAC, health department		-	-		Registration, transport	Registration, new group	Garden, registration
Nata	Support and education	No	Social Workers, Peace Corps	-	-	Micro-lending, income generation, education, outreach	Garden, stall	Registration	Registration, transport	Plot, registration, build centre

Table 5.2: Self description of 12 support groups for PLWHA across Botswana

available from the government for OVC activities. Just over half the groups in the survey were involved in some kind of income generating projects, by which groups aim to raise money for the operations of the group and even for the direct welfare of their group members. Many groups had vegetable plots or gardens where they grew fruits and vegetables either for sale to raise money, or directly for their members. Other activities included sewing and knitting items, from AIDS ribbon badges to pillows and clothes, again for sale wherever a market can be found.

Groups had a variety of equipment and accommodation available to them, but nearly half of them had no equipment or premises. In terms of other items, a few groups had basic equipment such as sewing machines, furniture and cooking equipment, but most did not mention their group had any possessions, although for both equipment and premises, most groups stated these things were needed, and formed part of their plans for the next few years. The five groups that were fortunate enough to have a base of operations generally had a 'portacamp' also known as a 'portacabin', a temporary one or two room office, some with electricity and water. Some also had their own land, or government donated plot, which usually provides space for the accommodation and land for growing vegetables. However many groups are still without a plot, and of those that did, only a few had sufficient buildings for their operations. This is an important point to note when considering the notions of the 'landscape of care' outlined in section 5.6. It was postulated that in developing areas there is a stronger focus on networks of support through people and systems networks than through physical spaces which are sites of therapeutic care (Parr 2003). Since many support groups are unable to afford a physical presence, yet clearly still provide support, the network of support provided is more than the physical evidence suggests. Regardless, it may still be the case that groups with a physical place of care are able to provide more or better services than those without, but considering that groups with premises tended to be established longer, and have access to other equipment, it is difficult to ascertain how important premises are to the quality of support that groups provide. As Smyth (2005) recognises, places of therapeutic care are not always obvious, and it is important to have an approach that considers non-Euclidean networks as well as place and space.

In terms of institutional networking, it is interesting that more support groups listed BONASO as a partner than BONEPWA, the organisation that networks support groups. Most groups stated that they worked with local clinics or hospitals, and many had good links to their local DMSAC, although other groups expressed difficulty in working with them or the District AIDS Co-ordinator (DAC), as will be discussed later in the problems section. Only one group in this session mentioned links with other support groups in the region, although it should be noted that most of these groups come from small isolated villages, and the feedback from groups in Gaborone suggested that some

Group	Location	Regular participants	Associations	Key activities
1, 4	Urban, semi-poor	10	Local Hospice	Psycho-social care for clients
2	Semi-urban, middle-income	6	Part of a major NGO	Youth education, outreach, counselling
3	Urban, poor	8	Independent	Home based care, cooking, income generation
5	Rural, poor	5	Independent	Home based care, counselling

Table 5.3: Key support groups in focus group analysis

do have links with other support groups, although mostly in an informal rather than formal manner

The analysis of support groups will now focus on four key groups, chosen to provide a wide range of different group philosophies, experiences, and locations. Specific details about these groups must remain omitted to protect the confidentiality of groups and their members, so the organisation and also location cannot be named, since there are few support groups in some of the rural locations. However Table 5.3 outlines some of the key characteristics of the different groups. Two focus groups were conducted with one support group, as it was too large for one session. Thus quotes attributed to Group 1 and 4 come from the same support group, but are two different focus groups comprised of different members. Using detailed focus groups, opinions on wider support, as well as the functions and problems that support groups face were collected in participatory sessions. In addition the researcher spent time volunteering with each group to build a picture of activities and problems over a longer time frame that were not mentioned by members themselves

5.5 Support groups as seen by members

It is worth noting that in all these focus groups the chairperson or leaders of the group are present, and in some cases, especially in Group 3, they provide many of the comments on the discussion about support groups, obviously from a biased perspective. They are unlikely to criticise their own group or think that support groups are not useful, or they would not be involved in the creation or operation of one. Again one must realise that the focus groups as a whole will also be skewed in favour of support groups, as obviously the group does not represent people who do not use support groups, or have not benefited from them, as such individuals are unlikely to remain in the group. This is why it is important to consider the comments here in tandem with the diaries, in which group members should have had more freedom to describe the activities of the support group, as well as interviews with other service providers who give a perspective of support groups from the outside. Ideally opinions of people who were HIV positive but not using support groups would be included as well, but for reasons of confidentiality it was not possible to openly recruit these respondents. While this limits the ability to impartially evaluate support groups themselves, this does not mean that their position in the landscape of support cannot be assessed, nor that their functions and role cannot be detailed. Group comments must be considered together with the opinions expressed in the semi-structured interviews with service providers, which take a much more critical slant. In fact, considering the small body of literature on support groups for PLWHA in Sub-Saharan Africa, a detailed immersion study of this kind is very valuable as a groundwork for a further study.

For many people, their first experience of help from the support group is when they are diagnosed with HIV, and people told how it had helped them overcome desperation and stigma.

“At first when you start realised you are diagnosed with HIV, you start having variations of thoughts... Then you [are] compelled to look for support, and hence it was there, formed already... It was easier for me to join it because we were advised to do so however, by the care supporters there as nurses and counsellors.” {Group 5: 184-5}

This comment also shows how many people first hear about support groups, when recommended by counsellors or nurses at clinics or hospitals. A counsellor from another group also mentioned the same path of entry, and this suggests that individuals find out about support groups as part of the formal network of support they have already entered. Support groups do not seem to be the first step in people seeking help with a possible HIV diagnosis, but since some groups, especially Group 2, offered HIV counselling at a local clinic, they are often the first source of psychological support. People seem to enter the support network through local medical services, and due to close links (both physically and co-operatively) with clinics, the services of support groups are immediately available for those that choose them.

Not all focus groups discussed the role of support groups in detail, but those that did described them as offering benefits that were either practical or psychological. It was clear that groups had different underlying philosophies that dictated the balance of physical and emotional help. For example Group 2 was involved at a very formal level in education programmes and with providing counselling at government clinics, while for Group 3 the role of the support group was to provide practical support in terms of food and income generation, by providing daily meals for members and a variety of craft making activities. On the other hand, Groups 1, 4 and 5 all stressed the importance of love, care and emotional support more than physical needs and services. Yet all groups mentioned both emotional and practical assistance, albeit with a different balance, so it is not the case that groups only provided one of these two functions. Participants from all groups were very aware of the emotionally supportive role support groups provide: "A support group encourages people infected with HIV not to get discouraged [sic]. They make them aware of the fact that they are human beings like everybody else. They encourage the infected people not to give up on life" (Group 4: 53); "we give each other love, care and support and counsel each other, we visit each other at our homes, we encourage people to go to the hospital" (Group 5: 15); "We have to support each other and other people... most of the time you will find that if you get support from someone whose situation is similar to yours, like for instance, counselling... you will notice that people who have been counselled by an HIV positive person accept their status better" (Group 3: 467). Clearly this was the most important role of support groups to some members.

For others, overcoming stigma was a key goal of the support group "there was a lot of discrimination... towards people living with HIV and AIDS. And we thought among ourselves, that how can we get rid of this stigma and discrimination, so then we decided that we would form a support group, whereby we would be having meetings whereby we will be giving each other love, care, support" (Group 5: 189). A participant from another group agreed that "Reducing stigma and discrimination" (Group 1: 351) was a key role. Support groups were clearly a forum for outreach work, to educate the public about HIV and reduce stigma and discrimination by providing a public face to the epidemic. But as a pre-condition for this, group members must be comfortable and public with their HIV status, before they can give talks to large groups as HIV positive people. Thus many groups encourage their members to overcome stigma by first getting members to accept themselves, thus overcoming the internalised shame which is often felt in persons with stigmatised conditions (Goffman 1963) and specifically those with HIV (Fife and Wright 2000, p53). Members must accept their identity as HIV positive persons; "we are practising to accept our status" (Group 5: 192) and then have the confidence to talk in public about it. "as the support group members, we are not afraid or ashamed of telling others about our status. We just tell [them] that we are living with HIV" (Group 5: 165). While this is an important step for members' welfare, it is also a

vital step to enable them to talk to others and the wider community about HIV: “I could not speak openly about my status and I could not talk to my family about the life that I was living, but I am what I am today because of a support group. I have been able to talk openly because we share experiences on how we used to live our lives at these support groups. Since then I have realised how important support groups are because I have been able to go out into the community” {Group 2: 7}.

No attempt was made to quantify the numbers of support group members who were public with their HIV status, since it would have amounted to directly asking members if they were HIV positive. Even so, in group discussions and participant observation slightly less than half the members of each group made clear indications that they were public with their positive status, by either discussing their medication or outwardly saying they were HIV positive. However it was clear that most members were still reluctant to disclose to many people, especially certain friends and family members, and thus that they could not do public outreach as an HIV positive person in case word spread to friends and family. Studies in different countries suggest very high rates of disclosure for PLWHA, all around 90% (Kaleeba et al. 1997, Nachtega et al. 2005, Skogmar 2006). However these figures are for disclosure to any person, not public disclosure, with Skogmar (2006) showing that many people only told their partners and less often members of their family. Although a potentially awkward topic to add to group discussions, in retrospect, gaining a further insight into how many participants had disclosed their status, and to whom, would provide a good way of showing trust in key support providers, and by showing how many were fully public with their status, the extent to which support groups had persuaded members to take up public speaking and outreach. It would also illuminate individuals’ networks of trust. Of course it also would indicate the level of stigma in the community, by inference of the fear of public knowledge. Qualitatively, it was clear that while some members, especially from Group 5 were used to public speaking as a PLWHA, and within the group slightly more talked freely about their HIV status, most group members were not widely public with their status.

Yet support groups in the sample also have members that are not HIV positive: “it’s not only the HIV positive living people who can form a support group. Even us who are not HIV positive need to support them, help them with some ideas because we could be in the same situation as them and end up being the same kind of people” {Group 2: 11}. Although some groups had more than others, all of them seemed to have members who were HIV negative, at least publicly. A clear advantage to allowing HIV negative members is that it protects the confidentiality of the group, as association does not automatically equate to HIV status, and also that members who are not comfortable revealing that they are HIV positive can join and gain trust and acceptance before they tell group members their status:

“They come in as volunteers. And when you see this person, you ask yourself... ah... why do you really want to volunteer. And in another, another group sessions, those informal ones, when everyone is talking and there are a couple of them who are very public and they talk about... when they tested and all that. And the person slowly... shifts from the group of being a volunteer to being a member.” {Former NGO: 150}

Having a policy that allows HIV-negative carers, the affected as well as the infected can clearly make it easier for people to join, especially those who are not ready to reveal their status. At least one group seemed to have a different approach, their group seemed

much more concerned with providing confidential psychological support, and very little education of the wider community, or encouraging members to be public with their status. One member said “that status is mine, it is confidential” (Group 1: 218) and it seemed to be the only group currently not doing outreach. In this respect it can be considered to be closer to groups like Alcoholics Anonymous, where therapy is behind closed doors. Group 1 does not have a remit to provide income or food for group members, but is associated with one of the hospices, so it might be considered that the hospice takes care of clients' physical needs, such as food and shelter, and the function of the support group is purely psychological wellness. This again illustrates the different philosophies that underpin different groups, and how geographical proximity may not be as important as the type of support offered, justifying the lack of catchment areas and overlaps for most of the groups in urban settings. But one group member also mentioned that the urban setting of the group limited their activities “You see gardening and all that, goat rearing, chicken rearing, poultry, orphanage and all that... In [an urban area] you will find that the problem with support groups... there is no space” (Group 1: 890).

Sharing ideas and information with group members was frequently discussed as an important role of support groups: “We can also give each other advice on how one can live their lives without losing any hope” (Group 4: 61), and “sharing knowledge is very important” (Group 3: 548). One even gets the impression that to many, this flow of knowledge is one of the key functions of the group: “we come together, discuss their experiences, discuss their views, share whatever they have and also come up with ideas” (Group 1: 888); “when we join a support group, we try to share ideas so that we can learn from each other” (Group 4: 322). Another group member put it succinctly, “we get educated at our support group” (Group 2: 343), suggesting that the knowledge gained in the support groups is empowering, and something group members are proud of. Within groups, there is clearly a tight network of trust, in which information and support flows freely. This would be expected, since regular contact and a supportive environment facilitate trust and friendship. However, the potential flip side of this is that the networks could form a clique – tightly clustered, but exclusionary. During participant observation, there were surprisingly few instances where new members became active members of the group, although many others occasionally attended group sessions, but did not actively participate. It is difficult to distinguish how much of this was due to a perceived exclusion from the group, discomfort in talking openly about a sensitive subject, or just not having the time or inclination to regularly attend.

For many members, there seemed to be few other places to talk openly about HIV, or before joining a support group they did not have the confidence to do so: “I could not speak openly about my status and I could not talk to my family about the life that I was living but I am what I am today because of a support group. I have been able to talk openly because we share experiences on how we used to live our lives at these support groups. Since then I have realised how important support groups are because I have been able to go out into the community to express my feelings” (Group 2: 7-9). Many group members were involved in such community HIV/AIDS awareness, which other research found was “either to prevent further infections or to challenge AIDS-related stigma, or both” (Paxton 2002, p562). So paradoxically, support groups seem to be somewhere where people come to gain knowledge, but also to forget about the stigma which exists in the outside world. “You even forget that you are HIV positive, you won't even think you don't have money at home to buy food, you won't even think that you [don't] have accommodation” (Group 1: 321). “I don't even think my man will run away from me or he is going to hit [me]... I don't think of anything... I just keep

myself laughing here, for that time it's very nice for me" {Group 1: 322}. Fun and laughing was one of the cards used in the focus group discussion, and members of this group all agreed this was an important thing for PLWHA, and was clearly associated with their support group. "People who are never serious on what they are doing, in the support group, you laugh yourself out because they are never serious" {Group 1: 332}. While this group may not have provided formal counselling services like some others, they certainly had a strategy for improving members' emotional and psychological welfare.

The diaries of support group members, in combination with participant observation, give an insight into the day to day activities of active support group members, as well as the operations of the group over a series of weeks. Examining the diaries in terms of official instances of support, as opposed to personal events, shows a very clear delineation between the group members who are heavily involved with the activities of the support group, and those that are mostly just users. Diaries 2, 3, 4, 5, 7 and 9 are written by committee members of their respective support groups, and show a good range of work done in terms of administrative work for the running of the group, as well as participating in group activities. Participant observation revealed time largely split between writing funding proposals and planning outreach events. During the week the diaries were written, all these authors mentioned being involved in multiple community education or outreach activities for HIV/AIDS, indicating that this takes up a good deal of time for active group members. Four participants mentioned doing counselling, often at clinics, the group drop-in centre, or at home, and these same four also all conducted home visits to sick clients. Only three of the diaries indicated that the writers were involved in the administrative tasks of the group during this period. The group member who wrote Diary 1 was heavily involved in doing outreach, much of it seemingly on their own initiative, despite being a junior member of the group. However home-visits and counselling require more training and thus it seemed that fewer support group members provided this kind of support. The researcher also observed fewer members doing these more involved activities, with the exception of Groups 2 and 5 in which several group members were providing formal counselling at local clinics. However some groups which perceived stigma as being a critical issue in their local community had many group members doing public speaking about HIV/AIDS.

Home visits often involved visiting sick clients to check on their condition, "I went out around my community checking on my clients" {Diary 8} and calling for medical help if their condition had deteriorated. "I gave help to a terminally ill patient by phoning the hospital car to come and take him to the hospital" {Diary 9}, "I went to check somebody who is sick, she wanted to go to the hospital but she don't have Money for transport I offered him P10-00 (80p) so that she can see the doctor" {Diary 2}. Providing counselling was also an important role for support group members, many of the problems seemed to be with couples who were struggling with HIV diagnosis. "There was a lady who was HIV positive and having a man who has not tested. As the event has targeted men, I happened to be called upon by the lady in question to do them counselling so the man can test and know his status. I did a long couple counselling on them and finally the man agreed upon undergoing for a couple testing" {Diary 8}. "Counselling for un-married couple who are [blaming each other], that who brought HIV to the other one. But at the end of the session they were understanding and willing to visit me frequently" {Diary 3}. Encouraging patients to adhere to their ARVs and medication was also mentioned several times, "Provide adherence counselling" {Diary 2}, which for some clients was quite a challenge:

"At the hospital I helped the patient to adhere on her ARV because she defaulted for three months, I heard the scenario from the support group member, then I did a follow up until it was discovered that she used to throw the pills in the toilet. She came for her refills properly but she never took the drugs (drank) she believe that they gave her diarrhoea" {Diary 9}.

The same group member also helps ensure people take their medication by collecting it for them from the dispensing clinic "I collected the drugs for two patients who reluctantly go for their refill in due time. They are my neighbours so I keep on checking them if their refill dates are due so I managed to give a great help since I noticed that the other one was running short of pills." {Diary 9}. The home based care activities of the support groups in Botswana seem to be similar to other groups in Southern Africa, for example the Hillcrest AIDS Centre in South Africa also has volunteers who provide basic care and also refer clients to a team of nurses if they need medical attention (Hillcrest 2007). In these circumstances group members are providing much more of a formal service to the community, indeed some are even paid for it. This does blur the boundaries between volunteer members and professionals, however it is important to note that receiving peer support from someone who can empathise is likely to be well received by clients. Here, the network of support has expanded to the community level, but the strength of ties is potentially weaker than between support group members, and the client/care worker language used by participants reflects this more formal professional approach.

Perhaps the most frequent activity for diary writers was a variety of community outreach and education projects, many of them organised by government departments or businesses, but relying on testimonies from HIV positive group members. "Attend the Botswana 40th anniversary Independence events which was held at the bus-rank. The activities was done by non-governmental organisation, what we doing in our organisation [was] passing the message by music and drama" {Diary 2}. "I went to a local prison and spoke to one of the wardens to find out how much the prisoners knew about HIV/AIDS" {Diary 1}, "I was called or invited [to speak at a mine]. The invitation was all about giving a testimony or motivational speech to the employees" {Diary 8}. One group member once mentioned that government departments were always demanding PLWHA speakers for events and internal awareness programmes, but were not always willing to pay speakers for their time or expenses, a sentiment echoed by a global sample of AIDS activists, who stated they sometimes felt exploited by some AIDS organisations (Paxton 2002, p563). While group members with HIV/AIDS clearly want to see stigma and discrimination reduced in their communities, it was frequently stated that a key aim of the outreach projects was to prevent new infection, and that groups were dedicated towards achieving the ambitious government target set out in the National Strategic Framework of having no new HIV infections by 2016. Clearly the government sees support group members as being a strong resource in tackling stigma and the spread of HIV, but seems to have not recognised their need for compensation. This could be seen as another example of the uneven power relations in the support network, where individuals and smaller groups are seen as subservient to national programmes.

5.6 Issues and challenges

When looking at all the different sources of support available, and considering that less than 10 people regularly attend each support group, it seems that support groups are

actually not widely used. This becomes pertinent when one considers the large number of people that seem to use clinics, social work counsellors and churches for support, even the hospice had more patients than most support groups had active members. The counsellor interviewed for the study stated that awareness of groups was not the problem: "Most of the people know that support groups are there... I guess they are not too comfortable with support groups. I think it's because they don't really understand what support group do" {Counsellor: 323}; "but we try always to explain... only encourage them... Come, if you don't like it, you can even stay, if you like it you can join us. If you don't... it's even up to you. Come and just see for yourself, it's just a bunch of lovely ladies... [that] share experience, support." {Counsellor: 325}. Several group members also commented that there was a problem with people not understanding the role of support groups, "I think they don't see the importance of a support group, they don't know why they should join a support group and they don't know what they can gain from a support group, what help they can get from a support group" {Group 4: 81}. Once people have entered the network of support, it seems that they are aware of most of the different sources available, perhaps since these are promoted by official channels, such as counsellors or nurses. However examples and experiences of support are not being shared in the network as well, otherwise people would probably have a better idea of what groups did, and how they could be of benefit. Addressing this lack of information in the wider community could have a great impact. In Burkina Faso, Issiaka et al. (2001) found that women were keen to get involved with community support organisations once they were aware of the services they offered. There is also a perception that one's presence might compromise confidentiality, "Maybe some people don't join a support group especially those who are affected by HIV... because when you are in a support group maybe you share your status" {Group 4: 108}. However group members seemed keen to spread the word, "they need to be encouraged and be told what a support group is really about so that they can be members. If you keep telling them what a support group is all about, what we get involved in, in a support group, that person ends up understanding and ends up [joining]" {Group 4: 321}. Overcoming this first hurdle of trust for new members is an area groups need to recognise and work on.

A clear perception from both group members and officials is that support groups are misunderstood in the community, and this is a serious problem restricting access for many to this form of support. When most people "aren't aware of the services they can get" {Counsellor: 289}, it is clear that their supportive possibilities are limited. However it is almost certainly not the case that everyone who understood the role of a support group would join one, it is obviously not for everyone. Considering that many people living with HIV are not open with their status, and just try to get on with their lives, it is possible that support groups consist of people who are less able to cope than others, perhaps because they have no other source of emotional or practical support, especially finance. On the other hand, some research suggests that PLWHA who choose not to join a support group are more likely to use avoidant coping strategies rather than engage with their problems (Kalichman et al. 1996). Yet it needs to also be realised that in the network of support, many people will have joined a support group because in some way they feel they are not getting enough support from their existing social networks. Although examining the context of bereavement support groups, Levy and Derby (1992, p658) found that the main reason why people did not join support groups after a stressful event was that they felt they had "enough friends to talk to without going to a group". While PLWHA groups in lower income countries clearly offer a much wider range of support than just counselling and companionship, perhaps most people diagnosed with HIV can get the support they need from their existing social

networks.

Many groups talked about problems with transportation, which seemed to fall in three different sections, firstly the need to reimburse volunteers for transport money, the standard bus fare being P2.50 (20p). This was also a problem for group members who did home visits, and there was also difficulty in getting a sick patient to hospital or the clinic. "Transport is really important because if you have your own transport, we would be able to take patients when they are due for their check ups. We will also be able to check our patients' records and be able to keep track on who is due for a check up. The same applies for getting quotations, etc. We have to walk a long distance. Imagine having to walk to industrial sites... asking for donations" (Group 3: 347). Several members of this group expressed concern that impoverished patients might be isolated at home because they could not afford transport from neighbours (Group 1: 36) "people have come to check up on how you are doing, they are chatting with you and for a second you have forgotten that you are not well and you are confined to your bed. Your visitors have noticed a deterioration in your condition and are even suggesting that you be taken to the hospital. We need transport to take you to the hospital" (Group 1: 69). Only one of the support groups had a vehicle which had been donated to them, but because they could not afford road tax and insurance, it had been out of use for several years (Research Diary). However CHBC and the hospice have vehicles for home visits, "if I am ill at home and my friends, counsellors or even social workers have come to check up on me and they have come with their private cars" (Group 1: 89) and in critical cases it should be possible to call an ambulance should a patient need to be hospitalised, although this phone call is not free.

One group member noted that volunteers doing home visits had to walk a great distance: "it is very painful for them to be walking around... making the patient follow up. Showing the spots on her feet." (Group 5: 416). The problems seemed mostly to be in doing regular check-ups, clinic visits, which were essential not just for check-ups, but also for collecting medication, and for the day to day operations of the support group. Conceptually, transport raises two issues, the first is the spatial extent of a group, particularly for Group 5 which is in a rural area, this can be physically large. Participant observation showed that roads in the area were usually dirt tracks, ideally requiring an expensive 4x4 vehicle to reach rural members. However one member had great success visiting clients on a bike that had been donated to the group. This raises the second issue, that the physical scale at which groups can operate can be constricted by resources, and an increase or reduction here can change the scale of operations of a group, potentially stranding outlying members. This was probably less of an issue for the groups in more urban areas, where at least there was public transport and other groups operating in nearby areas. The combination of both physical factors and flows of resources can mean that group activities are often in flux.

While volunteering with groups for the participant observation, providing transport was one of the most valued services, since the researcher was able to drive group members to meetings, and to drop off letters for sponsorship and grant applications. The idea of a communal vehicle for support groups, at least in Gaborone was suggested, and apparently there was one available at BONEPWA, however during one observed incident when members of Group 3 wanted to take a sick group member to hospital, they were informed that BONEPWA would have to charge for use of the vehicle, an amount that was greater than the taxi fare (Research Diary). This incident demonstrates that a 'cost-recovery' attitude imposed on NGOs can limit the services they are able to offer to the network. Membership or affiliation fees charged by NGOs have also had a

similar negative effect on support groups, and will be discussed in the next chapter.

5.7 Gender, age and membership

The research showed that at all levels there was a lack of male involvement. This was manifested in officials at a government and NGO level being mostly women, some entirely female support groups, and home based care services largely being run by women. Even in support groups, while there was not an absence of men entirely, most members were women. This does mean that research participants were largely women, however this could be indicative of support users and providers in general and at all levels. Of more concern is that this demonstrates a landscape of care in which men were a minority. Most officials could only speculate about the reasons behind this, "it's a very difficult area to work on... there hasn't really been any study to find out some of their reasons for [men] lagging behind in the health care system" {Masa Officer: 43}, but it seems to be part of a masculine culture that expects men to be independent, and not seek health care or support. "Guys think for you to go the hospital when you are sick, you have to go at the point when you think your heart is about to break. You are dying... you think it's not macho, you know, to go for [treatment]" {NACA officer: 88-90} "I just think it's their nature... I would say it's worldwide" {NACA officer: 82, 84}, a contention that seems is backed up by research in Western countries, including the UK and USA, where male use of healthcare lags significantly behind women (Banks 2001). Research by Hardon et al. (2006, p111) found that people in Botswana thought that men were more reluctant to talk about HIV compared to women, and less likely to accept an HIV positive status. Another possible reason expressed for the gender difference is the social norm that responsible women use health services, especially when pregnant, but for men seeking medical help is less culturally acceptable: "If I'm a woman [and] I'm pregnant. And I have to go for antenatal care, I go alone... it's expected that, it's me who is pregnant, it's me who needs the service, so I go without my partner" {Funding NGO: 118}. This finding is confirmed by another study in Botswana where participants commented that a man accompanying his partner to the antenatal clinic would be unusual in Setswana culture (Kebaabetswe 2007).

The effect of this is that men in Botswana are not participating fully in prevention, testing, treatment and support services for HIV. "Male participation in prevention of mother to child transmission, is still very low. Male participation in terms of enrolment of ART [Anti-Retroviral Therapy], or even to HIV/AIDS testing is very low" {Funding NGO: 115}. Another official recognised that this is also the case for other health issues, such as TB, cancer and heart disease: "I don't think [HIV interventions are] the only programmes where men come out at a lower percentage" {Masa Officer: 45}. This officer also said that men account for only 29% of participants in the ARV programme, with approximately 10% children and 61% women {Masa Officer: 33}. This should be considered against the rate of infection for men and women which is 16.9% and 24.2% respectively, estimated from the 2004 BAIS II survey, in which samples came from all hospital and clinic users, not just antenatal users. Unfortunately, these figures may be skewed because they do not show people who have never used health services, which include the men who do not seek help that we are so interested in. However the rate of male infection, while substantially lower than that for women, is not as low as the figures of male enrolment in ARV treatment. Extrapolating this data shows that HIV infection rates for men may be 30% lower than for women, but *twice* as many women than men are enrolled on anti-retrovirals. This indicates a clear problem in getting men onto the Masa programme, and consequently this would suggest that more men than

women are dying unnecessarily from AIDS.

However there was a recognition that men had not been targeted in the right way, and that policy was to a certain extent to blame for targeting women rather than men. "You see them now, taking responsibility and saying, Hey, You leave us out. Maybe even when you design some of these programmes" {NACA officer: 78}, "we have created that culture to say it's women's issues. We don't bring our men along" {Funding NGO: 118}. Other research has also identified that HIV/AIDS programmes in Botswana tend to focus on women, and noted that there is a need to include men in prevention and treatment, as well as wider gender issues (Datta 2004). There was concrete evidence of this approach to include men during the study, for example groups had been encouraged by the local DMSAC to conduct activities to educate men, and one group was organising a football tournament, at which they would promote HIV awareness. Increasing the perception of the 'masculinity' of support groups was considered very important in research by Lyttleton (2004) who noted that in Thai support groups for HIV/AIDS, there was the same dominance of women that is found in these groups. The Botswana government was engaging with this problem by targeting the 'men's sector': government departments dominated by men, namely the police, army and prison services. "They are trying to work with the men's sector to try and involve males and they are trying to find different ways of involving men." {Masa Officer: 41}. There was also a perception that the situation was improving, and some districts had seen a greater use of services by men; "Usually it's like women are the ones who are leading, but with the intervention of community mobilisation, of male participation, educating the wider community, we can see that now all of them are on board." {Funding NGO: 119} however this officer noted that in her district until recently "There had never been a man boldly saying, I'm living with HIV" {Funding NGO: 109}, although there are openly HIV positive men in other districts, for example the director of BONEPWA. Yet despite this, one quote from the diary of a young man showed that most people still thought that HIV was more of a women's issue: "The prison warden was so impressed and also shocked that a man could be well versed about issues concerning AIDS" {Diary 1}. Since creating a supportive community relies so heavily on the input of support group members to speak in public, it is clear that a lack of male role models is hindering acceptance and awareness of HIV. There may also be an effect where the predominantly female landscape of care in Botswana is exclusionary towards men, even if unintentionally, and that entering the support network is difficult, or unappealing to many men in such female dominated area. However, during the participant observation period, there were no incidents in which men seemed to be excluded from groups or particular activities, and this attitude extended to the male researcher himself.

In terms of the age of support group members, there was a very wide range, most people were in their thirties, not surprising since this is the group with the highest rate of infection (Ministry of Health 2005). Yet there were also many people in their twenties, and over 50. In general it seemed that the youngest and older members were mostly there as affected by, rather than infected with HIV/AIDS, they typically had relatives they were looking after, and needed support as caregivers. This finding is supported by Linsey et al. (2003), who found that older women and young girls were the main providers of care for PLWHA in Botswana households. However some older women clearly just want to help others and the community, especially members of the Botswana Retired Nurses Association, which recognised a need for skilled healthcare workers during the HIV epidemic, and set up a society to provide respite, palliative and home based care to the community. "We said, well, we have the expertise, we have the experience we have the knowledge, why can't we make a contribution?" {BORNAS: 1}.

This group, entirely comprising women over 50, some well into their 70s, shows the positive impact which people of all ages can make. At the other end of the scale, CEYHOHO, the Centre for Youth of Hope, aims to include young people in tackling the epidemic, using peer education and encouraging children to produce plays to educate the wider community about reducing stigma and discrimination. This organisation also runs a support group, with a true mix of older and younger members, who support and encourage each other, and have found a common issue which brings them together.

Many groups expressed concern with retaining active membership, as groups have few facilities and services to offer, and with low levels of income, the costs of giving up time for the group are significant. It was also necessary to make people feel as if they are an important part of the group, by taking care to include new members in activities, and resist the forming of exclusionary cliques, especially of older members, or between committee members, a problem which was quite apparent in some groups. Wituk et al. (2002, p360) noted that new members of self-help groups must be made to feel useful, and be able to take part in offering support to others to ensure their continued involvement. Another issue already discussed was that many people do not consider joining a support group because they are unclear about what the groups can offer them. One group previously had lots of members, when social services had offered enrolment on the food basket programme, which provided basic goods and food to people judged to be in a vulnerable situation. "Every member who joined the support group... had the opportunity of getting the food basket... We were around 85 by then... So they came because they heard if you are a member, you are going to get the food basket." {Group 5: 288}. But once this programme was stopped, membership fell suddenly, and people felt that they had risked being open with their status:

"Members of the support group were known, they were easily identified because they were members, the social workers knew them... So they said, see, we exposed ourselves, we are well known and, they just cut us because they know us. Then they say if any opportunities come then we are easily identified." {Group 5: 298}

However this did not stop people from using the group services, in fact they initially became even more important: "they came in large numbers to be counselled for that, because most people they were relying on the food basket. Even their health status, relies on that" {Group 5: 299}. Without this source of food, many people were forced to spend time finding jobs or working in the fields, which is why only 5 people were able to take part in this focus group. A consequent lack of labour is one reason that the plot of land belonging to the same group remains undeveloped despite building materials waiting on site to be used. Thus we can see that there must be a reciprocal relationship between a group and its members, a group cannot function or carry out plans without active membership, and PLWHA will not engage with the group unless they can see a direct benefit for them that is worth more than the risk of having their status exposed. This example seems to suggest that for many the expected benefits are mostly material. This is also noted in The AIDS Support Organisation (TASO) support groups in Uganda, where 34% of interviewees stated that they expected material assistance when joining the group (Kaleeba et al. 1997, p23).

During the participant observation period, the researcher saw the collapse of two support groups, with a further support group described in this study effectively shutting down after the fieldwork was completed. In the two observed cases there were several important factors noted, first that both had largely been decimated when the larger

organisation they were part of lost funds, or had management issues. This shows that groups which are affiliated to organisations may be more vulnerable than independently peer run groups, if they prove too dependent on the larger body. In both these cases, the support groups were able to run a greatly reduced service for several months, with the intention of hopefully finding new sustainable sources of income, and also ensuring that vulnerable group members were not left without support. However, one of the groups was unable to keep the support services going, even when former employees and counsellors gave their time pro-bono out of concern for the welfare of the members. The other group still operates, but at a greatly reduced capacity, and has lost many regular attendees. Again, important issues are illuminated by these examples: both the importance of interdependence in the network, and how in some situations obligations of support exceed professional obligations, and the boundary between personal friendship is blurred, questioning the level to which the employees in professionally assisted groups are members or peers. However Nixon (1997) notes that this process may happen, and is not necessarily inappropriate, since counselling must be a mutually agreed partnership, and should only end when both partners agree that the process is finished.

Social networks are a key factor affecting the membership of other organisations, for example political or social groups, as word about the experience and benefits of joining a group will spread through networks of friends or family. Eventually individuals become an embedded network of group members, which makes it difficult to leave a group, and encourages people to keep attending (Porta and Diani, 2006). However in this context, it is important to note that joining support groups for HIV is usually a confidential decision that is not discussed with one's social network of friends and family. Therefore most individuals are not likely to have known anyone else who is in a support group (Levy and Derby 1992), and the outreach work done by many of the groups can only help spread information about the role of support groups, and encourage new members. Despite the confidential status of individual group members, Wituk et al. (2002) note that for groups to survive it is crucial that they maintain a high level of public awareness, even through media and advertising.

5.8 Funding and income generation

Income generation was seen as an important way for support groups to provide services while maintaining sustainability, gain some aspect of financial independence and provide for impoverished group members "It's important for us, as a support group. We need to know how we are going to generate income, being trained on how to generate income than just sitting and not knowing how we are going to generate income." {Group 3: 174}. There are currently large pressures on support groups and other NGOs to become less reliant on government and international donors, partly due to a reduction in available funds since Botswana no longer qualifies as a developing nation. A gradual shift in government strategy since 2005 slowed the bankrolling of large NGO projects after perceptions of poor returns, inadequate reporting and misappropriation of some funds. This also hit smaller groups hard, either directly, or through a reduced capacity in the network bodies that are supposed to support them. The researcher observed that these effects took some time to impact down to the level of small groups, but when the organisations supporting them were unable to provide funds, many support groups were unable to find other sources of funding from the network. This could either have been because funds were already scarce, or they did not have wide enough links in the network to seek alternative sources of funding in time. These dependent groups were

not able to adjust to becoming self-sustaining, and were observed to either totally collapse or severely reduce their services and became reliant on the goodwill of volunteers

Group members seemed keen to learn a skill and gain a source of income, either for the sustainability of the group or themselves.

Unemployment is high in Botswana, estimated officially at 17.6% (Daily News 07/02/07), but is likely to be much higher in practice. Despite the law generally preventing employees being fired purely because of a positive HIV status, the Botswana Network on Ethics, Law and HIV/AIDS (BONELA) is involved in several legal cases where HIV positive workers felt they had been discriminated against (Daily News 17/02/04), and it is assumed that there are more cases that are not publicly reported. Some support group members were well aware of the risk of being fired for being HIV positive, and that they could seek legal advice in such situations “You might end up losing your job because of your status, you might be discriminated against so legal help is important. You can even seek help from BONELA” {Group 1: 234}.

It should be noted that most support group members seemed to have no formal employment, and a study of PLWHA on ARV treatment in Botswana found that 42% were unemployed (Hardon et al. 2006). Therefore income generating projects are important for many group members as a source of immediate income, and a potential to develop skills to lead to financial independence. Groups had a variety of activities, including growing and selling vegetables, sowing and making crafts, shown in Figure 5.4, making pots, and even running small stalls selling sweets. Craft projects and growing vegetables were common activities across all groups, and are also common income-generation projects for groups outside Botswana (eg Hillcrest 2007). Some groups had even been sent on workshops to teach members to make jam and bread, sometimes organised by BONASO for their members {BONASO: 22}, or by applying for funding from the local DMSAC. However groups had big ambitions for money making projects, for example Group 3 applied to an international embassy for equipment to set up a complete laundry service, and Group 5 wanted industrial machines for mass producing envelopes {Group 5: 437}. Group 1 on the other hand only had plans for an additional sewing machine. This raises an important issue, are the support groups charities or businesses? Certainly at the level of selling sewn HIV ribbons for extra income the issue is unlikely to be controversial, but this becomes different if groups start running manufacturing businesses to support the running costs of the support group. Some groups see income generation as part of a process to individual independence, and in terms of gaining a skill: “this was started because a lot of the clients, you know, maybe after they were ill, didn't have a livelihood. So it was basically to support the clients, you know in terms of getting a skill, and being able to



Figure 5.4: Sample income generation goods

get money for that. So the goods and things that were produced, [we] would provide the material, they produced the goods, and a certain amount of money when the goods were sold would go to the client that produced those goods" {Hospice: 27}. Similar schemes have been detailed in Ugandan support groups for PLWHA (Kaleeba et al. 1997), with the notable availability of micro-loans to help start projects, which are not available in Botswana. There is a government assisted scheme called CEDA, but this tends to target extending larger business operations, the application process is complex, and default rates are high (Durham 2007).

Income generating projects had problems related to feasibility and proposal writing, but the biggest problem for most projects seemed to be finding a suitable market to sell goods, and also competition from other groups. "In fact we can say that there is no market locally here. We had to go to Botswana Craft to go and sell our things. At first they were not able to take them, but I think for compassion sake... they took them... Most of the tourists visit Botswana Craft [a large souvenir shop]" {Hospice: 49}. This group recognised the need "to innovate and move from producing what everyone is producing locally, and produce something new" {Hospice: 52}. Another group had also struggled to sell their wares, "Sometimes a clay pot can stay 2 months without being bought. We don't have a place where we display our clay pots yet... We are still looking for a market where we can sell our clay pots, but we are still hopeful because the co-operatives have asked us to bring our clay pots to them and hopefully they will find buyers." {PLWHA group: 134}. Support groups themselves recognised the need for training in business and marketing, as well as learning new skills, and to their credit, BONASO has been organising training and workshops with a major business college in Gaborone {Research Diary}. Other research has found similar deficiencies in the sustainability of support groups' income generation projects in Lesotho due to a lack of experience in business management, and suggested that groups partner with local businesses to gain working knowledge (Seifert 2002). This approach had not been adopted by any of the support groups in this study, which is perhaps surprising considering the Public/Private Partnership (PPP) approach to HIV/AIDS intervention advocated by the African Comprehensive HIV/AIDS Partnership (ACHAP) in Botswana, and the government policy to include business in the fight against HIV/AIDS

Support groups give their members an opportunity to take part in training and workshops that equip them with information about HIV and treatment, public speaking skills, advice in running the group, as well as learning how to start new income generating activities.

"Training is really important. Nowadays you will notice that we experience a number of difficulties. For instance, if I have HIV and I need to be taken care of, how will the caregiver know how to take care of an HIV patient without being given proper training? I may be having open wounds. That caregiver would not know how to handle an HIV/AIDS patient if they are not properly trained. The other thing is that, in support groups, we do different things. We need training for things like how to prepare proposals. Attending workshops is also a form of training" {Group 1: 586}.

This quote shows that PLWHA are able to receive training on a wide range of skills, and this education is highly valued by group members. This group member also seems to understand the limitations of what groups can achieve if they are not properly trained. However the number of workshops seemed to have declined

before and during the fieldwork period, in part due to the reduction in activities of two networking organisations, COCEPWA and BONEPWA, which will be highlighted in chapter 7.

In looking at support groups in terms of flows of resources, such as information, equipment and volunteers, one must also consider a sense of efficiency, the factors that let groups make the best use of what they have to offer. At some level this comes down to strong governance and training of the individuals who run the support groups. Another government official described the problem.

“the challenge is in terms of... organisational skills, you have these people with a passion to do something [but] they don't have the expertise to run some of the organisations... So this is one area that we need to address, like for instance we have BONEPWA... they have a passion. But they need technical support to come up with viable programmes... They try, but because most of them are not educated [trained], they are limited” (NACA, 284-286).

This was a common opinion expressed by donors and official organisations, and was even acknowledged by an administrator that used to work for a major NGO: “There is need for capacity. Of the directors. But you know... a lot of people question the qualification[s] of these people... the directors. But they forget that these are the people who have initiated [the organisation]” (Former NGO worker, 327). Democratising small NGOs and support groups is a common issue across charities and NGOs, to be discussed at length in the next chapter. A key issue is that the founders sometimes see the organisation as being their own, and there is a need to shift to a member owned perspective “I know the director loved the power, of being a director. But maybe... they will understand the need to have someone else who is more empowered” (Former NGO worker, 331). Wituk et al. (2002, p362) noted in a wide study of self-help groups in the USA that sharing responsibility in a group helps retain more active members, as well as reducing the risk of burn-out for the group leader. The issue of power sharing within and between groups and NGOs will be discussed in the next chapter.

Aside from general governance, there are many other operational skills that many of the support groups lacked, specifically financial management and accounting, writing proposals to acquire funds, planning, and project management skills, especially creating reports and evaluations. While these skills are not essential for the primary aim of the groups in providing support, as well as competent counsellors, group members must also be competent administrators to acquire funding to keep the group and projects operational. Setswana society is very formal with respect to law and regulations, not surprising since the country was founded by a lawyer (Transparency International 2007). While this means that business and government have low levels of corruption, it does mean that society often operates in a very bureaucratic way. Before a support group can do work with the local DMSAC or be the recipient of any funds or donations, it must be registered with central government. Groups are usually incorporated as a legally binding trust, in which responsibility for the organisation rests on a board of trustees, with a binding constitution and management committee. This ensures that legal action can be taken should the organisation deviate from the constitution, or if members of the committee or management deviate funds, and also sets responsibilities for disposal of debts or materials should the organisation be dissolved. However this also creates a high start-up cost for small organisations, such as the hundreds of support groups across the country. This is not just in terms of time and finding committed

trustees, but also in legal costs and advice. In addition groups need to also decide if they will affiliate with any of the network bodies, BONEPWA, BONASO and BOCONGO, each of which has different requirements and membership fees: "you need to be affiliated to them. So we don't have the P300 for affiliation. There is no [way] they can help us if we are not affiliated to them, that is the main problem." (Group 3: 53).

To examine the difficulty of setting up a charitable group in Botswana, the researcher spent several months with a group that was trying to set up an orphan care centre. Although the centre had been running informally for some time and had been promised equipment to help it expand, this could not be donated until the organisation had a bank account, and for this registration was required. This process took over 6 months, and over P2000 (£180) of legal and application fees, not counting phone calls, time, photocopying and frequent trips to Gaborone, as the group was from a distant rural location. This is a difficult 'chicken and egg' scenario, groups cannot get funding because they are not registered, but cannot get registered because they have no funding. Getting over this first hurdle usually requires donations from the community, group members, or wealthy benefactors, who may prefer their money to go towards a more tangible asset, rather than to a solicitor. Conflicting with this was advice from BONEPWA who stated that if a group affiliated to them, they could apply for funds through them, which was not the case for some donors, and some groups were reluctant to trust a middleman. However it seemed that small groups who were not officially registered were still operating and providing services to their members, but could not apply for funding from government or NGOs, nor were they privy to advice, training and information from the network bodies.

Once registered, groups must then apply for funding, which may come from a variety of sources. The government generally provides grants through the DMSAC at a local level, or directly from NACA for larger national projects. Indirect funding comes from the network bodies, especially BONASO and BONEPWA who administered the small grant programme of the Global Fund, although some organisations get money directly from international NGOs, churches and embassies. Most groups also ask members to pay a small subscription, typically only P10 (90p) a year. But applying for funding from official channels requires detailed proposals, which are time consuming to create and usually must be typed in English. The proficiency in the formulaic and technical language required for successful grant applications varies greatly between groups. It is not insignificant that two of the groups in the study asked for assistance in writing proposals, and letters to solicit donations from businesses: "We've got a problem with proposal writing... We have problems in letter writing and all that." (Group 1: 95); "We want proposal writing... We are stuck because we don't know what to write." (Group 3: 96-97). This clearly limits the activities and sustainability of support groups, takes away time from giving support to group members, and represents a high entry cost for new groups looking to establish themselves.

5.9 Networks of support groups

In declaring a 'war' on AIDS in Botswana (Guardian 8/7/02), the government set out in the National Strategic Framework a comprehensive strategy for tackling the problem (NACA 2003), of which a key aspect was establishing a network of community based (CBO) and non-governmental (NGO) organisations to relieve pressure on the government departments and also as an independent voice for PLWHA to call on the government. One government employee testified that before this intervention, the

concept of community organisations such as NGOs and CBOs for HIV was unheard of in Botswana {CHBC: 30}, and it was specifically the government programme that started the movement that now has hundreds of registered charitable organisations assisting PLWHA and OVCs {CHBC: 144}.

Key to this strategy was the establishment of networking organisations to co-ordinate NGO activities, and provide advice, and guidance. The first of these is BOCONGO, the Botswana Council of Non-Governmental Organisations, which provides assistance to NGOs operating in all fields. Acting parallel to this is BONASO, the Botswana Network of AIDS Service Organisations, which as the name suggests, offers affiliated members in the field of HIV/AIDS guidance, educational workshops and also acts a source of finance from INGOs. Last in the trio is BONEPWA, the Botswana Network for People Living with AIDS, which has a remit to support and act as a voice for PLWHA across the country, and especially to support and encourage the creation of support groups. At a local level, each district has two bodies in the Ministry of Local Government which provide assistance and guidance in HIV/AIDS work, the District Multi-sectoral AIDS Committee (DMSAC), which consists of government, business and PLWHA representation, and the District AIDS Co-ordinator, the DAC, a government officer who works closely with the DMSAC on local issues. If this description seems to reflect clearly defined hierarchies of scale, this is no doubt reflective of the way that government policy and procedure is designed. There is a clear attempt to define bounded hierarchies of scale, with the President and government departments at the top, and community organisations at the bottom. It is difficult to see this structure as being deliberately totalitarian, especially since individual PLWHA are represented at committees at the highest levels. Yet it is significant that during the feedback workshop one participant from a community organisation made an offhand remark that they were always placed at the bottom of diagrams, a charge the researcher was also guilty of. This structure was designed to facilitate the flow of power from government to organisations, and information about problems and possible solutions to flow the other way, with the government preferring to deal with a few network bodies rather than hundreds of individual groups. While a logical structure in terms of functioning, it does facilitate inadequacies in power relations, and as will soon be demonstrated, when the network bodies are not functioning correctly, there is poor communication between government and the grassroots.

More details about the formal institutions in Botswana will be given in the networking chapter, but for now it is worth briefly noting the level of support that groups in the workshop receive from these groups. Only two mentioned having links with BONEPWA, four with BONASO, and five with their local DMSAC: all of these were from rural locations. Since the NGO networking bodies (BONEPWA and BONASO) do not have offices outside Gaborone, this trend is not surprising: most groups are networking with organisations closest to them. A more detailed discussion about the networking of overseeing bodies and support groups will follow in the next chapter. But it is worth noting that groups can network outside official channels. There may be members or even leaders of different support groups that have good links, due to personal or other professional ties. COCEPWA had trained many people to start support groups, and there still exists a certain camaraderie between these former members, many of whom are still running active groups. Participant observation showed that this was a strong network, providing many advantages and connections to members, that had outlasted the COCEPWA organisation itself. This seems very similar to the network benefits Hanson (2005) describes from alumni in Ghana, but notes that such networks often form exclusionary cliques that can prevent access to outsiders. For support group

leaders these informal links certainly acted as flows of information, but rarely of resources

To receive assistance from the networking organisations BONEPWA and BONASO, groups had to pay an annual affiliation fee, in the region of P100 (£8) or P300 (£24) respectively at the time of the study. While this may appear to be a small fee, many groups had struggled to find this amount of money from their membership, and so several were no longer receiving network updates or invitations to workshops and events. This also made them ineligible for funds that were channelled through the two bodies. In some cases membership fees had not been paid purely due to administrative error. Group 5 were under the impression that the CHBC co-ordinator had registered their group “the co-ordinator, she just kept on saying that she had affiliated for us. And so we found out that she didn’t... So we didn’t manage to affiliate for two years.” {Group 5: 367,365}. This group had also not managed to do the paperwork to register with BONASO, which maybe was in part due to their remote rural location. Members of Group 2 had complained about their problems in getting assistance from these bodies “We could not get any funds from BONASO because with BONASO, you need to be affiliated to them. So we don’t have the P300 for affiliation” {Group 3: 53}. Until recently, BONASO was responsible for administering a large number of small grants to HIV/AIDS service organisations, which were a primary resource for support groups looking to deliver services or buy equipment. This group had experienced a dead end in applying for the Global Fund grants as well.

“We are not getting any help from BONEPWA because we had applied to Global Fund and with Global Fund, BONEPWA is the organisation which is supposed to recommend us... Global Fund could not assist us financially because we had no place where we were operating from. Now, when we tried to ask for assistance again, we were told that global fund no longer gave out funds, but BONEPWA is not helping us in any way.” {Group 3: 43}

This was despite the group noting that “Two years ago, they trained two of our members to be counsellors” {Group 3: 45}. Interestingly Group 1 did not mention BONEPWA or BONASO at all, and when asked about organisations that lobbied or advocated for PLWHA, only BONELA (Botswana Network on Ethics, Law and HIV/AIDS) was mentioned. One member of group 4 tellingly thought that BONEPWA was not an NGO: “BONEPWA does not form part of these... you can group it under government institutions” {Group 4: 242}. Clearly, some of these groups are not fully aware of the role of the network bodies, both in terms of the services they offer groups, and the advocacy role they should play with government. There is even a sense that some groups only see BONEPWA and BONASO as potential sources of funding {Diary}, as many groups when planning events would only write to them to ask for financial assistance. However despite something of a personal rift between one member of Group 2 and BONEPWA, this group seemed well aware of the role and benefits offered by the networking bodies “in these organisations... you get the empowerment, you will be more involved mostly in many things even in planning... even networking with other PLWHAs, networking with other CBOs or other NGOs so for the best lessons you will get from others” {Group 2: 169}. Another group member stated how NGOs, including the support group she was a member of, had helped her. “When we talk of charity organisations and/or NGOs, I personally have benefited from them because I have learnt a lot of things that I didn’t know before. I never knew I would be where I am today. I am what I am today because of the NGOs. Since I tested positive, I have learnt a lot of

things. I have been for Peer Education training, I have been through JAB [Junior Achievement Botswana] training as well" (Group 2: 151). The official response from BONEPWA when accused of being inactive with certain groups, was that it did not have enough funding from government to carry out its operations (Mmegi 6/12/06). To a certain extent this was certainly the case, as government and international donors had cut general funding and shifted towards specific projects, and during the course of the study there was a visible drop in staff and day-to-day operations. Yet some group members felt that there were leadership issues within the BONEPWA committee.

5.10 Conclusions

This chapter has introduced the broad and varied role of support groups, which are shown to be an important source of support and encouragement for their members. It includes much detailed information about the operation of groups, necessary in part because there is so little in the literature on support groups for PLWHA. Groups showed a great variety in the support they offered, seemingly according to the needs of their clients, which in some case were more psychological and others more practical. Considering the wide range of functions they provided for members, the community, and by inference the nation at large, they serve an integral part of the wider network, and are clearly impacted by the funding decisions of the global network. Many people attending the groups are impoverished, and some groups spend a great deal of their resources in providing for the basic needs of members by providing food and money from largely unprofitable income generation projects. However, the groups were all struggling with several recurring issues, especially in raising awareness about the services support groups can offer to PLWHA, and finding sources of funding for running costs. All the support groups seemed to be mostly run by women, but there are clear gender issues in the whole landscape of care, with a burden placed on women as primary caregivers (Lindsey et al. 2003), and a lack of involvement from men at any stage of the medical or support systems. This problem is not just restricted to HIV or Botswana, there may be global cultural norms on masculinity which discourage men from using health and support services (Courtenay 2000), again issues are raised which are global and boundless. For support groups, this results in few active male group members, and a consequent lack of men giving and receiving support, and educating the community on prevention: a circle of indifference that is difficult to break.

Some of these problems seem to stem from a lack of practical assistance, especially management training for support groups from NGO/CBO network bodies or local government committees. There are also significant barriers to entry in the network for support groups, especially in terms of high costs of registration with umbrella bodies and a lack of basic communication equipment. These 'transaction costs' (Williamson 1985), exclude groups from flows of information, reducing awareness of training and funding opportunities that could strengthen their sustainability and service provision. Chapter 7 discusses in greater detail the collapse of the formal support networks for community organisations, the effects of bad governance, and the lasting impact both can have on the vulnerable people whom organisations are charged with serving. First the landscape of care needs to be expanded in the next chapter from the group experience to include the wider network of support from individuals and organisations, demonstrating the variety of experience participants shared in focus groups and diaries.

Chapter Six

Experiences of Support

6.1 Introduction

This chapter will widen the discussion of the landscape of care for PLWHA in Botswana from focus groups to the whole network of support, to include detail of support given and received through individuals and organisations. Through the use of focus groups and diaries with support group members, the voices of participants will be used to build a broad picture of both the different sources and forms of support available and utilised. These participants share detailed personal experiences of support as both givers and receivers. This will show the level of variety and commonality in service use at the level of individuals in different groups and locations. The analysis will start with individuals as providers of support, move on to groups of individuals, such as friends and family, and finally look at larger groupings, such as the community, church groups and NGOs. In this fashion the reader will be shown the importance of the many different scales of support provided, the different experiences they provide, and how many PLWHA use support at all different levels for different or overlapping needs.

Through the coding and analysis process described in chapter 4, using pattern coding of fieldwork data (Miles and Huberman 1994, p69), and triangulation of different data sources to validate topic areas (Brewer 1989), the voices of participants will be used to show what services individuals use for support, and what assistance they get from them. Differences of opinion will also be shown, and used as a point of discussion on access and use of different sources from the informal, such as friends and family, to formal institutions of support. Where applicable, examples from participant observation will be used to contextualise some of these issues. It is important to note throughout this analysis that, as previously discussed in the methodology chapter, selectively sampled qualitative data of this sort cannot be used to be make generalisations across the community of study (Howe 2004), instead the aim in this chapter is to show support at a detailed micro level, and the complexity of the supportive environment. Yet this approach raises the level of participant voices in the study, and shows different and conflicting views and experiences, as described by the experts: the people who live these experiences on a daily basis (Morgan and Kruger 1996)

	Family	Spouse or partner	Friends	Church & congregation	Home based care	Health & welfare professionals	Support groups
Emotional	2	2	1	2	1	2	3
Information	0	1	1	2	2	3	3
Instrumental	2	2	1	2	2	1	2
HIV/AIDS Care	2	2	1	1	2	3	2

Figure 6.1: Matrix of types of help received by support group members from different sources: 0 = none, 1 = some, 2 = most, 3 = unanimous

Using a categorisation scheme adapted from House et al. (1988), Table 6.1 shows an overview of how support group members described the level of four different types of support from different sources. The House et al. (1988) study focused on stressful events in the workplace, and provided a strong framework for examining social support for stressful events. Therefore some of the categories have been modified to better fit the context of this research; specific headings relating to the workplace have been removed, and replaced with HIV/AIDS specific categories. Along the top row are seven different sources of help for PLWHA which will be detailed in this chapter. The left column details 4 types of support. First, Emotional help, for example listening and other psychosocial assistance. Information includes advice, and instrumental care, which House et al. (1988) describe as practical help such as money, labour and time. An additional category was added, HIV care, which in this context includes help for specific HIV/AIDS issues, such as medical help, bathing and medication. Through the course of the chapter, each section will draw from the research which has been coded into each category, to demonstrate the level to which PLWHA obtain support from each source, and to what extent differences of opinion are expressed. This is summarised in the table, for example the section on family illustrates how few people mentioned receiving information from family, but more felt they had been given emotional support from them.

In participatory sessions with support group members from the same group, people were given a series of cards representing different sources and types of support. To promote discussion on each topic, groups were asked to put the cards in order of most important for PLWHA, and explain why they had ranked each card. If there was disagreement between participants as to the importance of each type of support they were encouraged to discuss different experiences, and come to a consensus. This happened often, and illuminates the different experiences of members of the same group in getting help from different people.

6.2 Individual self-help

In addition to the seven sources of support detailed in this chapter and the following, it is important to also deal with the notion of self, since self-support must be the starting point for all further attempts at seeking and using supportive services. Smith (1993) recognises a sequence of scales, body, home, community, urban, region, nation and

global (p101). While he recognises the difficulties inherent in bounding different scales in this way, and some authors (eg Jones et al 2007) would question this approach, it is a useful structure for describing the support network in a thesis which is to be written and read in a linear fashion. In feminist geography, the body is recognised as a spatial site, and an important unit of analysis, especially in studies of impairment and illness (eg Moss and Dyck 1999), and is a good place to begin an investigation of the network of support, with self as the first node. An involvement with the individual, and in particular the concept of self-efficacy introduced in the literature review, helps explain why some people are more reluctant to seek help than others, and the extent to which people feel able to tackle stressful situations themselves. People in the support group discussions were shown a card representing 'self', and asked how important they saw themselves as source of support. Members in groups 1, 2, 3 and 4 (see section 4.4) responded that they felt that it was important to help oneself, group 3 found the concept especially significant, noting that independence in particular was important for both individuals and the group. One commented "The most important thing is for us to be self supportive and not be dependent on other people" (Group 3 : 180) and that even though someone is living with HIV/AIDS, "We should be able to do some things for ourselves" (Group 3 : 396). Another group member agreed, "We are skilled and it's possible for us to do the things that we want to do" (Group 3 : 403).

Two other groups also commented on the importance of high self-efficacy, "Don't let your condition get in the way of what you had planned. You just need to tell yourself that you still are going to stick to your plans" (Group 1 : 286) and another respondent stated "I can take good care of myself, I follow advices and orders from the doctor ... and [by] telling myself that I am who I am because of me not because of what other people think. I know myself much better than anyone else" (Group 2 : 186). These positive comments on the importance of self were very encouraging considering the stigmatised and psychologically debilitating potential of a positive HIV diagnosis, and was good evidence that groups are encouraging their members to feel good about themselves, and attempting to reverse the effects of stigma in their community. Studies in Western contexts have suggested that high levels of self-efficacy increases the likelihood of PLWHA being open with their status (Kalichman, Nachimson 1999). This is usually discussed in the literature in the context of having an effect on risk reduction (eg Wullert and Wan 1993, Forsyth and Carey 1998), the attitudes expressed by PLWHA suggest that self-efficacy is also important to deal with a stressful situation, such as being HIV positive.

However, with the possible exception of Group 3, groups had members who seemed to have low levels of self-efficacy, and felt somewhat dependent on others: "There is no [way] how I could do something without having received any training or have the knowledge about something" (Group 1 : 583) and one group when asked what PLWHA can do for themselves answered "I can ask for help from my neighbours. I can help myself by asking for help so that I know what decisions I can make and which direction I can take" (Group 4 : 113). However the notions of self-efficacy expressed by members of Group 3 seem closer to a feeling of self-preservation. There is a definite feeling that the group and its members must look after itself before others, "I can't just go out, get things and then give to someone else. I reward myself first." (Group 3 : 581). While this may be more of a philosophy of the organisation rather than individuals, it may reflect the fact that this group (Group 3) is located in the poorest district studied, has had a history of members leaving when services could not be provided, and an emotional split of the group several years ago. Details learned during participant observation suggested this issue revolved around a conflict that arose

because the group was operating out of the house of one of the founders, due to lack of resources. This led to confusion as to when the house was a private place for friends, and a public place for group members, and whether donated goods were being misappropriated, or access to them was restricted. Here is another good example of the ambiguity of categorising the space in which groups provide care, in the previous chapter it was noted that groups enact support throughout the community, not just from a base of operations, here is evidence that the private/public nature of homes is also contested. This can also be considered to happen when members visit bed-ridden clients, enacting the clients own private space as a space of care, a process which is also becoming common in the West (Williams 2002).

Clearly in the case of Group 3, a certain level of self-sufficiency had been necessitated by problems in the past, and a situation in which independence from others had led to an increased emphasis on self-efficacy. Thus it is important to consider that self-efficacy is a factor in explaining the level of dependence on wider supportive networks, and that negative events in the past, which are also noted from other groups that have been let down by previous funders, can in fact promote sustainability. This balance between dependence and independence is crucial not just at the personal level, but also for the sustainability of support groups and NGOs, and this will be explored further in the next chapter.

One invisible aspect of self-efficacy is particularly relevant when considering the low use of health services by men, a factor noted in studies from many countries (eg Mustard et al. 1998, Marcell et al. 2002). Numerous officials and group members noted this problem accessing support, which will be discussed in detail in later in the chapter, but is worth noting here as in essence this comes down to a notion of self; that when one does not have an experience of using doctors or other health services, it is difficult to overcome this barrier of inexperience. This is especially common in men for two main reasons, first they may not have regular contact with doctors to the extent that women do for regular check-ups, for example cervical smears or pre and post natal clinics. Secondly, there tends to exist a bravado of self-sufficiency in many cultures which creates a social pressure discouraging men to visit a doctor (Singleton 2008). One could even suggest that cultural norms in some societies dictate that women have a role to look after their boyfriends/husbands, and so men without long-term partners in these situations have little influence on them to use health services, except when pressured by their mothers

Many respondents at all levels, both male and female, stated that low male involvement in support and preventative services was one of the biggest issues in Botswana, and this will be engaged with in the next chapter while discussing how people from different genders and locations access support networks differently, as well as a section later in this chapter on husbands and wives. It is important to note that the majority of care providers are women (Lindsey et al 2003), both at informal and formal levels, which may be another factor that excludes men from the realm of social care, or at least makes it less likely to be well targeted towards men.

6.3 Family

Of all the issues discussed by participants during the course of this study, family was by far the most controversial and sparked the most interesting debate. Far from being universally the closest and most common form of support as suggested by other studies

in Botswana (eg Lindsey et al 2003), respondents had very different experiences of friends and family. In general people seemed to fall into two camps, perhaps the majority got most of their support from family, while some had been ostracised by their kin, and had strong networks of friends. Few people seemed to have both, and at least no-one openly stated they had neither.

It is important to stress that extended family is important in Setswana culture, especially in providing care and health decisions (Shaibu 2007). In general, families have close ties with even distant cousins and relatives, this is evidence since the Tswana language has separate words for uncles, aunts, and cousins from the mother and father's sides of the family, and strong traditions, for example that certain uncles act as supportive patrons to nieces and nephews. In general most families in Botswana provide very close supportive structures, evidenced by one church official who noted that "most caring in this society... is done through families" (Church, 47), an opinion that concurs with one of the few studies undertaken on family caring in Botswana (Shaibu and Wallhagen 2002) on care of the elderly. Certainly many respondents in the study did have caring and supportive families, indeed some could not imagine a better source of support: "my family, they understand me much better than anyone else, they know what I need and what I don't need" (Group 2: 119).

However others had much less positive experiences. "You can't depend on your family that much. Family can end up deserting you and you could end up suffering on your own. I don't know about some of you but I have given up on my family. God is the only person who is looking out for me but my family, I've given up on them." (Group 3: 614). Most of these problems with family members seemed to stem from stigma and misinformation about HIV, "the family can sometime stigmatize you the first time but after knowing that HIV/AIDS is not a virus which can be transmitted through sharing food and so on, they would then start by giving you love, care and support" (Group 1: 429).

Even if they had supportive family themselves, many group members understood or had specific examples of some families who were not caring for PLWHA: "But it's different with other families. Others would stigmatise you after you have disclosed your status. Sometimes it's difficult for them to understand." (Group 2: 130), "I would not like to dwell much on family because you will find that families are different. There are some families which can isolate themselves from you. Only a handful number of families can support you, encourage you, some can even be ashamed of you" (Group 4: 211). The answer to this problem advocated by several groups was that family members need to be educated about HIV, and this was a task being done largely by social workers.

"We need counsellors to counsel the family... in our families you will find that if I am HIV positive, I have got my plate painted in red, my cup and my plate are washed differently from the other utensils though they are my family, so that is when you can call social worker and counsellors to sit with those people and unite them." (Group 3: 430)

"Still on the issue of social workers, if I am HIV positive and can't talk to my family about my status, social workers can visit my family but they would not direct tell my family that I am living with the virus. They could start by educating my family about HIV, how to take care of an HIV positive living person. In that way, they would be advising my family on how to take care of an HIV positive patient." (Group 2: 83)

Interestingly it was not considered a role of support groups to directly educate the family of group members. Groups had programmes of general public awareness, but the direct education of family members of PLWHA was considered to be a role of social services and government counsellors, and seemingly then only after there was evidence of some conflict or discrimination. As shown in Table 5.1, families were never mentioned as a source of information, and often needed to be provided with HIV education.

However, family members were clearly offering good support in many circumstances, "They give great help when you are ill" (Group 5: 87), "When I feel the pain, they realise it [more] quickly, than any other people" (Group 5: 88). Especially valued was the support group members got from their own children, one described how they were "doing laundry, cooking for you but what would count even more would be the passion, love and care that maybe your child would give you" (Group 1: 173). One respondent noted in her diary for one night "After hours, started a terrible diarrhoea the whole night on up to morning. Asked my daughter to make me SSS (salt sugar solution) for me. I felt a little bit better. I was helped by my daughter. Thank you very much daughter" (Diary 4: 8/10/06). Although other research in sub-Saharan Africa has considered the role of the family in care, it often considers the pressure illness places on the family, rather than if they will provide support in the first place. Oluwagbentiga (2007, p676) for example finds that most families support HIV positive members, but only notes in passing that some had discriminated against them, and sent them away. This seemed to be the case here, most families are supportive, but those that stigmatise tend to offer no support at all.

People described different experiences with their partners or spouses. There was also debate as to whether they counted as family: "if you are not married, your family are the ones closest to you, your friends are also the ones closest to you, then your family, maybe your spouse if you are not married and if you have got a girlfriend and you are not married, she is the one closest to you more than your parents" (Group 1: 673). It was a contentious issue because clearly in some situations, while being a major source of support, someone's husband or wife may have been the person that infected him/her. Finding acceptance therefore was sometimes difficult, although there were also some stories with good outcomes:

"She was married before, and the husband passed away, she, she tested herself before the death of the husband, but her husband gave her love. The husband shared love care and support before she was tested HIV positive, but unfortunately he died. But recently she's got a boyfriend, he told her status, he accepted her status. He can even remind her of taking her drugs, all the time he is giving her help." (Group 5: 67-68)

However some group members had very different stories about partners accepting their HIV status "My, my neighbour. Is a woman, a married one, the wife of someone. So she tested HIV positive and called the husband. You know what happened? The man started not sleeping at home, doing all the strange things under the family. He couldn't accept her, his wife's status, because he said where did you get [HIV]" (Group 5: 83-85). While these stories come from the rural group, similar comments on both sides of the spectrum were made in urban areas, showing that people react very differently on discovering the positive status of their partner.

Group members offered different views as to the type of help that supportive partners gave: "The wife or husband can give care and emotional help. That is love and care, that is adherence counselling also" {Group 4: 22}. Another group member agreed, "They can also be loving. A husband or wife can give love to an HIV affected or infected person so that this patient does not get discouraged in life" {Group 4: 33}. "They can give you support... they can care for you... for housework, [or] they can be there as our counsellors." {Group 1: 660}. But again, a difference in experience was common. "They are just like friends and family, they can be on both sides, they can be positive and negative" {Group 1: 662}.

Several members of one group expressed interesting views on the different roles of men and women in a partnership:

"If, for instance the husband becomes ill, his wife is the one who will take care of him." {Group 1: 704}

"Some of us have been lucky that our women have been very helpful to us by doing our laundry and doing almost everything for us." {Group 1: 703}

"In my own opinion, when you are a man and you're ill and if you have a wife, its very important for your wife to be next to you at all times so that she can take care of you." {Group 1: 696}

These quotes suggest that women are expected to be the caregivers in a relationship, and in the wider family, an opinion that echoes findings that in much of sub-Saharan Africa: gender inequalities lead to women, much more often than men, giving up their career or education to look after sick relatives or partners (Essex et al. 2002, p663). Comments such as "A woman can take care of her husband but a man can't take care of his wife," {Group 1: 708} suggest that this might be a cultural expectation, but whether the meaning of this statement is that men are not obliged to take care of their wives, or that they are unable or incompetent is unclear, although it is interesting that these viewpoints were expressed by both men and women in a largely female group. However, Group 1 was also observed to be the most religious, regularly holding prayers during meetings. These comments may therefore be indicative of them expressing a more traditional view of marriage. Unfortunately, no other groups or individuals expressed views about the role of husbands and wives as opposed to partners, but it seems to fit in with the general view gleaned from the data that men are not engaging in support as much as women. Of course this comes from a largely female sample, we are unable to speculate on the opinions of men who are not involved in support. Another study on family care for the elderly noted that women were expected to be general carers for their husbands (Shaihu and Wallhagen 2002, p145), and Datta (2004) found that while there was a expectation to find that women were better carers, in fact studies see little difference in psychological tests of social support (Burleson 1994). While some studies have painted a bleak picture of women's rights in Botswana (Langen 2005), this was not obvious from the research, which included a large number of confident and independent women, who were actively involved in PLWHA action. Yet of course, this data only shows participants in support groups, it does not show women who are hiding their status, too busy to attend, or afraid of participation in HIV related activities.

HIV testing and counselling for couples was an important issue for service providers at the time of the study, and this was reflected in many of the group's comments on partners, "there are programs like Netefatso [To Ensure], whereby a couple would go

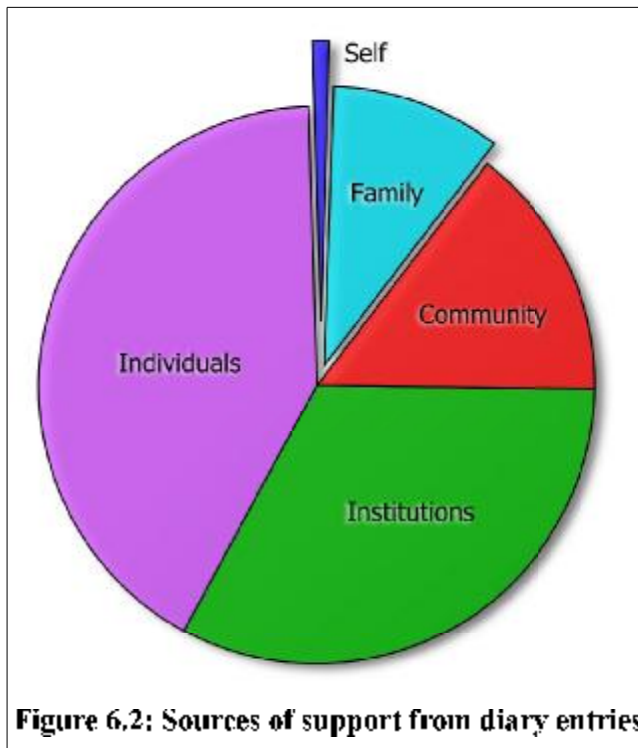


Figure 6.2: Sources of support from diary entries

for testing and if one of them tests positive, they both go through the post counselling sessions together” (Group 2: 73). One counsellor based in Gaborone noted that “most of the women come and test without their husbands, or their partners. Or their partners have this thing of saying if you’re negative, it means I’m negative. If you’re positive, that means I’m positive. It’s not like that. Because you know, you’ve been having so many discordant couples” (Counsellor Interview: 263). This counsellor also seemed to have had some negative impressions of many couples’ reaction to HIV testing, “Even those partners who have been supporting their girlfriends... when they they knew their girlfriend’s status, they end up

breaking up” (Counsellor Interview: 267). And despite their best interventions, “They do break up... I mean we do try our part, we do do our part... But but at the end of the day, it’s all about them, it’s their decision” (Counsellor Interview: 275). While counsellors like this one are in theory available at most clinics across the country, and with church pastors also providing relationship counselling, sometimes either the fear of HIV or pain of infidelity is too much for couples.

While negative experiences with family and spouses were quite common, there was also a sense from many people that “At the end of the day, they are my family, never mind if they like or they don’t like but at the end of the day, they are my family.” (Group 4: 216). Diary entries which logged each instance of support over a two week period for 9 participants noted that family was not a frequently used source of support (Figure 6.2), and this finding triangulates well with the numbers of respondents in the focus groups. However it is important to acknowledge that this graph only indicates the number of support instances, not the importance or significance of the support received, and the data is based on a small sample. Even so, combined with the evidence from focus groups, this finding is important considering the literature on support for PLWHA in sub-Saharan Africa tends to put an emphasis on the family as primary caregivers (eg Kipp et al. 2007, Lindsey et al. 2003). The findings from diaries and opinions expressed in focus groups suggest that family are just one part of the landscape of care for PLWHA. As a network of support, family can be a very tightly clustered clique, which can either be a strong source of support, or strongly exclusionary. While Figure 6.2 shows that diaries logged many instances of support from individuals, in the focus groups, there were perhaps even stronger problems expressed with friends than with family.

6.4 Friends and confidentiality

"Friends they are not trustworthy and comparing the family and friends, she doesn't stay with the friends, and the family, they keep her happy here, unlike the friends." {Group 5: 78}

This was a common issue expressed about friends, that they could not be trusted, especially with regards to confidentiality. "You need to choose [your friends], I would tell my friend that I am HIV positive and that they should not tell anyone" {Group 1: 372}. When asked what made a good friend, the immediate unanimous answer in this group was that they should "Keep secrets" {Group 1:377}; in another group, "Some friends... What can I call them? Spies?" {Group 4: 271} This was never mentioned as an issue when disclosing HIV status to family members, even the ones that had stigmatised group members.

Another respondent from the same group understood very well the fact that friends were part of a wider social network, through which information can spread. "with friends, I share with you what I have shared with somebody else... When I find out that one of my friends is HIV positive, I would probably tell one of my other friends about your HIV status. He or She is my other friend right? So we share gossips together, you see... I would probably tell one of my other friends about your status and that other friend had another friend, you see... it's just a chain." {Group 1: 395} "I can confide in my friend about my health condition... The next thing almost the whole community of UB [University of Botswana] would know about my condition" {Group 4: 275}. While families seemed to belong to a closed, and more trustworthy network for most members, friends are part of a wider social network in the community, which can cross levels of trust. While one may be able to trust friends, the same might not be true for friends of friends. Support group members expressed great concern about their right to confidentiality and spoke harshly of those that had betrayed their trust "They are back biters" {Group 1: 386}. Interestingly there were no such instances with families, they seemed able to keep secrets, be it by bond of kin or risk of embarrassing the family by revealing one of them was HIV positive. Still, as with families there was a great variety of opinion and experiences in the groups.

When asked to list what the qualities of good friends of PLWHA are, people listed a wide variety of examples.

"They would offer support, maybe... even sometimes resources like finance, they can give me money to go to the clinic for check ups... sometime they could even go to the extent of offering you food, counselling" {Group 4: 279}

"Also sharing experience. Maybe we are on the same platform so we can also share experience, we can also share ideas, find a way out and a way forward." {Group 4: 286}

"They give you advice, they take of you when you are ill, your friend can cook for you or even take you to the hospital." {Group 1: 379}

Another group began to discuss 'buddies': which may have referred to the formal adherence Buddy Scheme described in section 2.7, but their role could equally apply to a good friend. "a buddy can advice me not to take my own life, and they can also advise me not to discriminate myself from the rest of the community. Buddies can advise me to join support groups... visit social workers at local clinics and that way I would not have

to give up on life because of the positive advises that my buddy would have given me" {Group 2: 98} and another group member added "buddies can also help HIV positive people by reminding them about the times when they have to take their medication. They can also accompany me to the hospital to take my ARV medication" {Group 2: 100}.

Aside from the buddy programme, a few members shared examples of good experiences with friends after they were HIV positive, "when the nurses gave me the results, they told me that I was going to die. I didn't know what to do... My friend and I decided that we are going to stay in that church and pray for ourselves" {Group 1: 628}. Only one diary member mentioned help from friends, "helped by a friend with bread and meat for the day. A friend brought me a gift" {Diary 4 2: 11/11/06} and during a discussion on the merit of families, one member stated that "They help very much. But for me, from my experience, I got most of my help from friends." {Group 5: 94} "when I was terminally ill, she supported me with clothing, and for whatever I needed I had to phone her and she was there with the support. Even up to now, I know there is someone to rely on" {Group 5: 96}. This again concurs with the suggestion that people tend to have either family or a group of friends for support, but rarely both.

Many people in different groups all stated that since they were diagnosed HIV positive all their friends had left them. "The moment I test HIV positive and reveal my status to my friends, they are no longer your friends. I don't want to lie to you but that's a fact. I am not the only one who has experienced that. Friends tend to leave the moment they find out that you are HIV positive" {Group 2: 206}. One group member spoke quite directly "I don't have friends myself." {Group 1: 390} and another noted that "ever since I discovered my status I don't have a friend. All the people who were my friends just went like that" {Group 2: 196}. This shows that there are still problems with stigma, but it should also be noticed that support group members are more likely to be open with their status, and one can speculate that someone who was not public with his/her status might be more likely to keep friends. These findings reflect another study in Botswana, which found that 40% of people in the survey feared losing their friends should they test positive for HIV (PHR 2007, p51).

Participants also had mixed experiences with friends who were also HIV positive, a finding shared by studies of PLWHA in the West as well (eg Hays et al. 1990). "Like I said before, it falls on both sides, it can be good, it can be bad, it can be good to be friends with somebody who is HIV positive other than somebody who is negative, you see" {Group 1: 414} but in most situations this added an extra level of complexity, as so few people were open with their status to friends "at times I might come to you and tell you that I am HIV positive and then to my surprise you are also HIV positive so I might find you as the most appropriate person than anybody else because our status are the same" {Group 1: 400}. Studies in the USA found that friends are more often a source of social support than family (Kalichman et al. 2003), the opposite to findings from some parts of sub-Saharan Africa, where the family unit is considered to bear the brunt of care for PLWHA (Oluwagbemiga 2007). This may also be because literature on PLWHA in the USA tends to focus on heterosexual men, already a stigmatised group, and could be a reason for families to ostracise them further. In these situations PLWHA may turn to networks of friends, especially other PLWHA for help. Apart from this there seemed to be no obvious trend to explain why some people relied on friends and some did not, and one can only conclude that there is a mixed level of experience in Botswana, a situation recognised by many of the group members themselves "Some [friends] are important, some are not" {Group 4: 269}.

So before I went for my test, I wasn't a Christian. But after some, maybe, a year after being diagnosed HIV, er I started to hear the word of God... I went to test before, I became a Christian... I made a mistake. I was terminally ill. It was one night, it was on a Saturday. And I said, within myself, that I went to different places, seeking for healing. I went to the, the traditional doctors, I went to the, those, pastors who helped... help didn't come up. But that very night of Saturday, but I heard there is God. Believe in God. And I believe that God can help me in this situation.

The following day was Sunday. Then, when I woke up I felt I was, my body was a bit healed. I felt like walking fast, because before then I couldn't even walk fast, I was just walking like a chameleon, slowly slowly... Then I woke up, I bathed well, then I dressed... Then I found where Assemblance of God was. There I found the Christian there was preaching at the pulpit. And, eh, you know, a miracle happened. Then he called an altar call, that those that want to surrender their lives unto God should come forward. When I went there, I didn't go there thinking to getting healed, just to accept Jesus Christ in my life. So I went there and accepted Jesus Christ in my life. And from that very moment, my life changed completely. [laughs]

Then I started, I started socialising with the church members. Because, when I was there, very ill, I was afraid of looking at people. Because I had an experience that they used to discriminate me some of them. But after, after receiving that spiritual message, I was really encouraged. I was really encouraged, because I got the support there, I experienced love there, and caring amongst the church members.

**Figure 6.3: Testimony on God
from member of Group 5**

6.5 God and the church

In both the support groups and diaries, faith and religion was an important source of support for PLWHA, and of all the participants in the study only two openly stated that they did not believe in God. However one group noted that there was a distinction between the Christian God, and traditional Tswana beliefs in ancestors. In Botswana there is a wide range of churches, including Catholic, Anglican, and Dutch Reform Churches demonstrating a history of missionaries to the country. These are now joined by evangelical Christian churches, and independent churches more or less run by one pastor to their own principles and beliefs, which may include a mixture of Christian and traditional Setswana faiths (Heald 2004). There were mosques in Gaborone, and several other faiths represented, but official figures suggest over 70% of the population describe themselves as Christian (CIA 2008). However it is also clear that not everyone in the study was a practising church-goer, one diary participant described how he was visited by a gentleman who "taught me a lot about the bible. I knew nothing about the bible but after he gave me a few lessons, he took me to church and I will forever be grateful to him for that" {Diary 7: 14:01/07}. Other people shared stories as to how their faith had developed, including one that is worth repeating in full (Figure 6.3). A member in another group shared a similar story "I went for my HIV test in 1994 and when the nurses gave me the results, they told me that I was going to die. I didn't know what to do. I went to church. I received some prayers at the church. We were also advised to pray for ourselves. My friend and I decided that we are going to stay in that church and pray for ourselves. We were told that only God knows everything, he is the one who has brought this disease and that he will heal us, he will make us live." {Group 1: 628}.

It became clear after the first focus group that there needed to be a clearer distinction between God and the Church, as people would talk about both help provided by the

church as an institution in terms of support services, the pastor, or members of the congregation as well as the prayers, help and spiritual guidance they received from God. Indeed support from the church can differ due to one particularly helpful individual or group in the congregation, or an especially active pastor or priest. Even in later groups, once there was a separate card for Church and one for God, people clearly saw both as providing different and overlapping support: "Church is important. But then when you talk about the church I become a bit confused. We talked about God earlier on. I become even more confused because I don't even know whether you are talking about the congregation, the members of the church or are we talking about the building?" (Group 2: 287). When discussing both the church and God it was clear that most people felt the most important thing they did was to give hope, one respondent stating "It's all about hope, right?" (Group 4:132) Many participants in diaries and groups spoke of their faith, "God has been of great help to me. I was going through difficult times because I had even given up on life. If it weren't for God, I wouldn't have survived because my family really prayed for me and asked God to set me free in all the hard times that I was going through" (Group 4: 134) and even "everything you need your God will provide" (Group 5: 153). Clearly, for those that believe, God is an important source of psychological support, providing supportive feelings including comfort, strength and self-acceptance (Siegel and Schrimshaw 2002), and even a sense of purpose for some.

In addition to supportive feelings, one group also discussed the guidance that God can give to PLWHA, "God is important to a person living with HIV/AIDS for instilling the belief in you, that maybe he can hear you and guide you on what to do right or on what to do because as an HIV positive person you need to change your lifestyle" (Group 4: 138). "If a person is infected with HIV, they can ask for God's assistance through prayers" (Group 4: 129). In dealing with terminal illnesses, other research, again focusing on a Western context, has found that spirituality and faith have an important role for many people (Woods and Ironson, 1999). Thus it should be considered that in some way God acts as a source of information for some participants.

The community at churches was important, especially when there were supportive pastors "you meet people who you can trust there, most probably the pastor as a counsellor, who will give you encouragement, without looking you down. I am very thankful to churches" (Group 5: 181). Another participant wrote, "I received support from the church by the pastor's wife who preached the word which was full of encouragement. 'No matter HIV/AIDS positive, you must carry on doing righteous things before God' She noted" (Diary 9: 18/02/07). Crucially it was clear that this participant was also an active donor of support in the congregation, "I gave help to a terminally ill patient by phoning the hospital car to come and take him to the hospital, I prayed for him after inviting another church member to accompany me and also I gave him a 1 litre milk, encouraged him to trust in hospital procedures" (Diary 9: 13/02/07).

Support given by the church came in the form of both practical services, for example donations of food and money to NGOs and sick members of the congregation as well as psychosocial support. There were also sometimes formal structures, such as fund-raising events, or close links with hospices or specific support groups, as well as educational programmes, and orphan care programmes at some churches. Insufficient research has looked specifically into the role churches play in providing support for PLWHA, although it is noted that they can be an important vehicle to providing information for preventing infection (Surur and Kaba 2000). Some respondents also talked about the support they got from members of the church:

“The congregation plays an important role, especially for the people who are sick in the church... because they will just come and have hymns for you maybe at home, maybe at the church, they pray for you, they pray with you and you know it heals.” {Group 2: 290}

“Even if she's not feeling well, if she goes to church she becomes well, and she got all the counselling and support from the church.” {Group 5: 138}

This support included practical donations “The congregation at some other churches can even provide the sickly with food” {Group 2: 294}. Other donations included “food and toiletries so that you could look clean and not really give up on life.” {Group 2: 296} and it was also observed that “some [churches] have counsellors” {Group 2: 300}. Beyond material donations and formal services “the congregation can volunteer to take care of your children when you are HIV positive so that they give the HIV patient enough time to heal without having to stress about taking care of the children” {Group 2: 204}. Participant observation at several church events noted individuals doing home visits, especially visiting the terminally ill to provide spiritual support, donated food drives for sick community members, and monetary collections for the local hospice.

These examples show that beyond the facilities of the individual churches an important factor for PLWHA was a supportive group of people, clearly missing when so many had lost friends after their diagnosis. While God and faith are an important source of comfort and guidance, the congregation of the church offered a different level of support, and was an important network of support itself. We could consider this network to be quite closed, being clearly limited by people who regularly attend a particular church, but people expressed that within the congregation there was a strong level of trust. Thus this represents a tight, closed network of peer support, but also with an outward function, that offered services to the wider community, for example food donations, but without directly integrating those community members into the network of the congregation. This is quite similar to the support groups, who also have close ties between members, and a public function offering education and services to the wider community. In both cases the advantage to belonging to the smaller network is an increased level of mutual trust and emotional support, and the essential requirement of entry to the inner circle is to share a common quality, either a belief in the particular faith of the church to join a congregation, or to have been infected or affected by HIV to join a support group. The wider services are offered to people who may not explicitly share these characteristics, but in both cases there is the potential for recruitment.

A common theme across groups was that merely taking treatments was not enough to get better, one also had to have faith, either in God or yourself. This even applied to anti-retrovirals (ARVs), “Even if you can drink those ARVs but you don't have that belief of getting better, they can't help you anyhow. If, for instance, you have a headache, you go to the hospital and the nurse prescribes some paracetamol pills for you and all you do is complain that the nurse has given you paracetamol to be taken thrice daily, you will not get healed if you don't have that belief. So we get that belief from God and from the church” {Group 1: 570}. Other respondents had similar views. “One has to pray to God so that God... prolongs your life and also to help in having faith that you will get better by taking medication, having that belief of getting better” {Group 4: 131}. The testimony in Figure 6.3 shows how one support group member had been critically ill before she turned to God. However, it also notes that before she had been healed at the church, some members of the congregation had discriminated against her, presumably because of her HIV status. This shows that the networks of support are not

always homogeneous, and have the potential to have fractures, or cliques within the wider networks. It also raises an interesting question, was she supported by different church members to the ones who were discriminatory, or did the some individuals who used to stigmatise her only accept her after she had accepted God? Either way, this is another good example, in this case in a church, of the network of individuals within organisations, who have their own actions which are not always harmonious with the views of the group (see Fig 3.3). It also questions the bounding of organisations, showing that defining a group as being at a particular scale because of its level or structure hides the fact that organisations are also functions of actions at an individually networked level

Yet the majority of these quotes come from only a few participants, who clearly got much more from the church and God than others. Even these people were aware that, once again, people had different experiences of the church, and agreed that certain churches were better than others. The less helpful churches seemed to be those that drew heavily from Tswana traditions; in Botswana there are many independent churches that preach a mix of Christianity and traditional Tswana religion, and many participants were suspicious that some ministers ran churches to extract money from the congregation. Group members shared this view, ‘with some other churches, they don't do what we have been mentioning good about the churches... if she goes to the pastor and the pastor prophecies, that ah, my sister is HIV negative, it's only that people have bewitched you... [they say] I can get rid of this disease if you only give me [money]’ {Group 5: 181-185}. Another group member joked that the good churches were “Other churches, not our Setswana ones” {Group 2: 295}, those she called “Modern churches”

3	Those people are always after money and its very rare to find someone who will be honest with you and say NO! I can not examine you because of a slight headache, and that they should go for an HIV test.
6	That traditional doctor is going to cause some friction between the patient and the patient's care givers
3	They can even go to an extend of coming up with some story that one of my relatives is a witch.
4	I am not opposing what you have just said, like what my fellow speaker has just said. There are other traditional doctors who are not always after people's money. Of course they can advise you to go to the hospital, I have been to a few traditional doctors and lost lots of money...
6	Now you see why we are saying they are not important
4	But after visiting a few of them, I visited one who actually advised me to go to the hospital without charging me
8	Because they had already noticed that you had no money to pay them.
7	Let me give you an example of why I am saying traditional doctors are okay. When I fell ill to an extent that I could not walk and was bed ridden, I went to see a traditional doctor and after he gave me some medication to drink. I was able to get out of my bed and walk again and that was before I started taking ARV's though I had already gone for an HIV test.
3	You were healed because you had that belief.
8	It was you own personal belief that the traditional doctor can heal you.

Figure 6.4 Debate on traditional healers {Group 1: 512-532}

{Group 2: 306}. While it seems that most churches are very well educated about HIV and treatment, there was one example to the contrary “I have this experience very recently, whereby one [PLWHA] quitted her, her drugs, being told by one of the pastors that they should get rid of them.” {Group 5: 188}. The same comment was made about traditional doctors or healers, which in Botswana may either be Tswana doctors, or from many other African countries such as Malawi or Nigeria. “With the traditional doctors, sometimes someone will be administered at the hospital, they will do their things there, and encourage the patient to come out of the ward.” {Group 5: 33}. Again traditional doctors was a subject on which there was great debate within the support groups (Figure 5.4), with the exception of the rural support group, who were unanimously and vociferously against them “they are shouting they do not help!” {Group 5: 21}. The implication in this group was that they were only after money, and lacked accountability.

“You will walk away from them having given them money. The money you have been supported yourself and buying yourself fruits or something... [so you] go back to him again to say, no, it didn't work out. And he will say, ah you didn't use it properly. Or maybe you don't have faith, you don't have belief. You know? Then he's done with you.” {Group 5: 28-29}

It is interesting that this rural group were very strongly against traditional beliefs and doctors, which may be explained by comments from the District AIDS Officer in the region, who stated that there were a lot of problems in very rural areas caused by men following certain traditional practices {Research Diary, Feb 07}. This included beating wives as well as a reliance on traditional medicines. It may be that these well informed support group members have seen bad examples of traditional doctors, and have taken an extreme disregard to them.

In other groups, opinion was more mixed, but always caused intense debate, an example of which is given in Figure 6.4, and clearly illustrates the strong and opposing views that people had about traditional doctors. A similar exchange occurred in Group 2, where one woman said “my mother is a traditional healer so most of the time she gets visitors who are HIV positive and she is able to heal them. At times she can even help their CD4 counts to improve and that can also be confirmed by visiting the clinic” {Group 2: 216}, which did not stop another group member from saying “I am against the idea of going to traditional healers... There isn't any point of going there and being told that your relatives are bewitching you” {Group 2: 248, 260}. This respondent did admit that there were some herbs used by healers that were useful, another member even stated “The reason why I am this pretty is because of them [these herbs].” {Group 2: 231}. This group was the most positive about traditional healers, and had a more rural location on the outskirts of Gaborone. It is interesting that Group 4, the most rural, expressed the strongest opinions against traditional doctors, so this is not an issue where there is a clear urban/rural divide. It is surprising that two groups did not discuss traditional healers at all, as some research suggests that they are used by many people in Botswana (Chipfakacha 1997). That study also reached the conclusion that traditional doctors should be educated and integrated in HIV/AIDS, not just to provide better care, but also to prevent their own infection. Despite a growing opinion that traditional healers can form an important resource in providing HIV/AIDS education, treatment and support when provided with the right training (eg Homsy et al 2004, Burnett et al. 1999), official government engagement with traditional healers in Botswana is official policy in only a few local districts (NACA 2003). Thus support group members may have received training or documents that warn against using traditional doctors,

especially for those taking anti-retrovirals who should not be mixing medications, or stopping the ARV course to try an alternative remedy.

As in any society there was clearly a wide range of beliefs, but one specific example given when discussing faith and God was especially interesting.

“So this child collapsed at around 1.30pm, immediately after the students had their lunch and she remained unconscious until 5pm. I had this feeling that maybe if I could pray that the child may regain consciousness it would help. People were amazed when they saw me walking towards the child with a glass of water that I had said a short prayer for. I then gave that glass of water to the child so they could drink and she regained consciousness. Ever since that time, that child has not experienced that problem ever again. So I also believe in God.” {Group 2: 143}

One can interpret this story in different ways, some might say that it was God and the prayer that made the child better, while a sceptic would say that it was just the water that revived them, so how can we say what the source of support was? However it should be argued that in fact the real actor in this situation is of course the person who gave the water and prayer, whether it was the water or God that revived the child, it was the willingness of the speaker to pray and attend to the child that made a difference. This raises an important point about support, that the provision of supportive behaviour could be as important in some ways as the support given, because without an active desire to help, there is no support of any kind. Research highlighted in the literature review has shown that, perhaps not surprisingly, giving good support is better than just having the perception of being supported (eg Burleson 2003). Yet without a willing actor there is neither the action or perception of support. Thus we need to consider carefully what causes different actors to become supporters, be they institutions or individuals, because this is crucial to the debate on whether networks of support are based on altruistic behaviour or the expectation of reciprocity.

6.6 Community home based care and anti-retrovirals

As the previous chapter describes, Botswana has for many years provided a home based care service, which has become a valued and respected scheme, thanks largely to a very successful integration between clinics, community and NGOs. This is also a deliberate policy to provide treatment for all critical illnesses, which has prevented the service from being associated with just HIV/AIDS care, “some of the people have misinterpreted it as only looking after HIV patients... but since we have said that it is provided for all chronically ill patients... it has helped” {Masa Interview: 122}. A CTBC co-ordinator stated that

“This was introduced as a response [to the] HIV/AIDS epidemic. The community home based care programme in the country takes care of all patients that need care or support while they are at home or at the community level, regardless of their HIV status. And this has helped a lot, because the fact that... care was integrated for everybody, the programme was easily accepted by the community and by the client, it also helped a lot in addressing the issues of stigma.” {CHBC: 13}

The integration of government services, volunteers and community groups in the CHBC

programme means that many support groups were actively involved in doing home visits and referring clients that needed assistance. "In our support group we have already trained people for home support services. We call ourselves home support services providers not home based care providers" {Group 5: 191}. A different group was also involved in CHBC, but had some difficult experiences, especially when money given to volunteers from the support group was abruptly stopped after a major donor pulled out of Botswana. "At least if at all they could have thought of this and... getting all this support group members, and fitted together with home based care, to be taken care of by counsellors at least. That 124 [Pula £10/wk] could have made a difference... at the end of day, you know?" {Group 5: 396}. Many of this group's difficulties with the Home Based Care programme seemed to stem from a particular co-ordinator, who had broken promises made to the group but had subsequently left {Group 5: 369}. This is an important point, because it shows how much experience of the same system can vary because of particular individuals in organisations, an effect that is difficult to assess or evaluate at the level of a national programme.

In general, even groups that were not directly involved with CHBC had good opinions of the scheme, especially for those without other sources of support. "Home Based care is important in the sense that it helps in taking care of the sick who do not have any relatives who can take care of them or who have been neglected by their relatives" {Group 4: 255}. Clearly the home based care programme is important for people who lack a support network of friends or family, or when these networks of care are exhausted, or even physically distant. Since women are generally the primary caregivers in the Botswana home (Lindsey et al. 2003), the home based care can provide important respite, and care for carers. However there were clear examples, especially from Group 3, of clients for whom the home-based care visitor was the only source of support. "They help those who are infected with HIV... they do that by visiting these patients at their respective homes, try to find out the condition of the patient and how they can help that patient after they have analysed their condition, whether or not they will need any food baskets" {Group 3: 29}. Group members mentioned during participant observation several occasions when clients had been on their own for days, and had become ill. Clearly the support group volunteers are a very important part of the programme, and an administrator in the CHBC scheme noted that the government cannot afford to provide universal coverage without the assistance of community organisations {CHBC: 233}. This partnership approach is exactly the strategy suggested by Nsutebu et al. (2001) for improving home based care programmes in Zambia, where the government has even more limited funds. However, as discussed in the previous chapter, this raises some issues about independence and the separation of state and community services. The support groups seemed to be well trained in their roles, not only were group members well informed about the services the programme offered, some clearly understood the rationale behind it: "home based care helps to relieve carers at the hospitals so that the community or the family can also be involved in taking care of the patient other than being hospitalised and not being able to spend time with their families" {Group 2: 112}. While questions can certainly be raised about the level of financial and material support given to home based care volunteers, this CHBC programme is an excellent example of integrating community and government services, and is a good example of a very strong network of support.

The network of organisations which comprised the CHBC programme is interesting from a network and analytical point of view, since it includes close partnership with a variety of organisations at different levels and hierarchical scales. Perhaps Marston et al. (2005) would see this as a good example of a flat ontological network, in which it is

difficult to define the boundaries between the different institutions, especially as the services are enacted on the ground by individuals who may be from clinics, social services or support group volunteers. However, at the organisational level, the government sees a clear hierarchy where it is outsourcing certain operations to smaller organisations who must adhere to their standards of care. This is essential to ensure that clients are offered a good service and that volunteers are providing quality services, but it also creates a slightly subservient culture, where the government has power over what is offered as part of the CHBC programme. Even so, comments expressed by the CHBC co-ordinator in an interview suggested that they were open to groups trying new ideas and services, and recognised the importance of community organisations maintaining their independence. It is also important to note that this philosophy of partnership of state and community organisations is championed by the influential global network of donors, and thus is part of the global strategy of HIV service delivery.

Anti-retrovirals (ARVs) are obviously a very important source of support for those who have been put onto the medication, as well as a source of long-term hope for those who do not yet have AIDS symptoms. It is important to note that the support groups contain three groups of people, HIV negative caregivers, HIV positive persons who are not yet on ARVs, and those who have started treatment, and may have been taking them for several years. In most groups, while a few people talked openly about their ARV medication, this was unusual, and so it was difficult to tell how many people were currently on medication. However Group 5, from the rural field site, was the only group in which people were very open about being on anti-retrovirals. 4 of the 5 participants in this group introduced themselves by giving their name, and then how long they had been taking ARVs {Group 5: 11-21}, almost with a sense of pride. Clearly, they were lifesaving, and to some the most important kind of support.

"They are very important, they should actually top the list. They have really helped out a lot of people... Some of our relatives had even given up on us and thought that we were going to die but ever since taking medication, a lot of people have really survived" {Group 1: 486}.

However there were also some people who saw them as less essential, and as the last resort in what should be a more holistic approach to treatment.

"My opinion is going to differ from yours. I don't think ARVs are important because our problem is that we are not living positively but if you can live positively, eating well, I don't think there's need to take these drugs... You can live long, positively, if you are eating well without these drugs." {Group 3: 282-290}

This opinion actually represents the official medical recommendation, as ARVs are generally prescribed as late as possible, only once CD4 counts are below a critical level to prevent drug resistance. But it is also interesting to note that this group was the only one that provided regular meals to their clients, suggesting not only that their clients in the poorest region of the study would otherwise not have regular meals, but also that they understand the medical reasons for doing so. However, even when on ARVs most tablets must be taken with food, often three times a day.

The other factor that all groups were well aware of was the need to take the anti-retrovirals regularly, as many as three times a day. Many participants talked in the diaries about the adherence counselling they provided, ensuring that members and

clients in the home based care programme were reminded to take their medication, but also mentioned that even family members could help: “whenever I forget to take my treatment, that person would be there to remind me of the times that I have to take my medication” (Group 2: 128). There was also concern that many people did not understand enough when treatment should be started, and the side effects:

“Because most of the people enrol in the ARV treatment program with lack of understanding and in the end they end up realising that they could have just lived positively without ARVs and the it would be too late for them to stop taking ARVs. So we should be taught about these.” (Group 3: 296)

As was demonstrated in the previous chapter, support groups were an important source of both adherence counselling and education on treatment and ARVs, both to their members and the wider community.

6.7 NGO and CBO support

Assistance from non-governmental organisations (NGOs) and community based organisations (CBOs) can be grouped roughly into two categories, support for individuals and institutional assistance to support groups. The latter will be discussed in section 7.3 in the networking chapter, but it is worth discussing here the benefits that individuals have received from certain organisations for PLWHA in Botswana. Most of these came in the form of education or training, which was very well received by those participants that had been lucky enough to be invited for workshops or courses. “In these organisations, you will have the... empowerment, you will be more involved mostly in many things even in planning. You will have access to many things, even networking with other PLWHAs, networking with other CBOs or other NGOs so for the best lessons you will get from others” (Group 2: 168). Provision of information to the community and PLWHA was described as a key role of NGOs.

“Clinics do not hand out enough information to people. The time that they spend in educating people at the clinics is very limited because they open at 7:30am and there is very little time to educate people because the clinic staff also have to attend to patients. So with charity organisations like support groups always having enough information and if a patient does not adhere to doctor's rules, buddies will be there to remind you. If you are pregnant, there is always someone who will advise you to enrol in PMTCT (Prevention of Mother To Child Transmission). Advice on whether the HIV positive patient has enrolled in IPT (Isoniazid Prevention Therapy) are always there and whether the HIV positive living patient has enrolled in ARVs, and CD4 counts as well.” (Group 2: 178)

Just as with the community home based care scheme, support groups were providing much needed additions and extensions to the official government services, and what is illustrated from this quote is this support includes medical advice. Flows of information through the formal networks, were being added to by the community organisations, but they were also extending the network, but conducting educational and awareness events in the wider community. However, this time training was coming from NGOs, as well as government departments. Some group members had been on training sessions with NGOs on providing psychosocial support as well, “Two years ago, they trained two of our members to be counsellors” (Group 3: 45), and some subsequently won awards for

their community outreach work: "I've got an award again from CEYOHO... as a man who holds a key for stigma reduction" {Group 5: 178}. These quotes show that through training and empowerment, PLWHA are encouraged to become providers of support as well as receivers. It was largely such training that allowed them to become community outreach workers, and is not just beneficial to the government in reducing the costs of providing support, but also to the sense of purpose and independence that PLWHA have. As noted by Thomas (2006), AIDS sufferers feel better when they are not dependent on others, and clearly providing help reduces this perception. This was also evident from the diaries, as when looking at the direction of support in events recorded by participants, it was clear that there were slightly more events where participants gave support than when they received it (Figure 6.5). This is purely illustrative, but nevertheless an interesting observation, and certainly shows that support group members cannot be conceptualised as only being receivers of support in the network. The government also provides training on counselling to members of the community {CHBC: 254}, and also has a partnership with another NGO, Lifeline, which trains government departments in counselling skills {Lifeline: 214}. This is clearly not just a situation where government is supporting NGOs, the network of institutional support is multi-faceted and bi-directional

Individuals in the groups had received a great deal of training as well,

"When we talk of charity organisations and/or NGOs, I personally have benefited from them because I have learnt a lot of things that I didn't know before. I never knew I would be where I am today. I am what I am today because of the NGOs. Since I tested positive, I have learnt a lot of thing[s]. I have been for Peer Education training, I have been through JAB training... and counselling training." {Group 2. 151,155}

This participant even sparked a controversial exchange within the group, as she stated "if it weren't for the virus I wouldn't be having all the skills and knowledge" {Group 2: 165}. Another member was horrified by this statement: "What are you trying to say? Are you trying to tell us that you wouldn't have known all these if it weren't for joining the group or contracting the virus?" {Group 2. 166} But it raises an interesting point, that in quite a resource limited country, a lot of opportunities are being made to PLWHA that are not available to the general public, a situation recognised by some of the government service providers "I think the resentment is that there is given too much attention [to HIV], and then we tend to forget about other conditions" {Masa Interview. 158}.

Some specific NGOs were noted for the special services they offered to PLWHA, such as home based care, counselling and legal aid:

"She is referring to the likes of the hospice, they help people with a lot of things... some of these organisations have departments who always ensure that home based patients are being taken care of." {Group 4. 222}

"Yes, they encourage people and children especially if one of the parents is HIV positive and children are not being taken care of properly. They can take those children and keep them busy in their pre-school." {Group 4: 230}

The provision of these practical forms of support shows that some larger organisations,

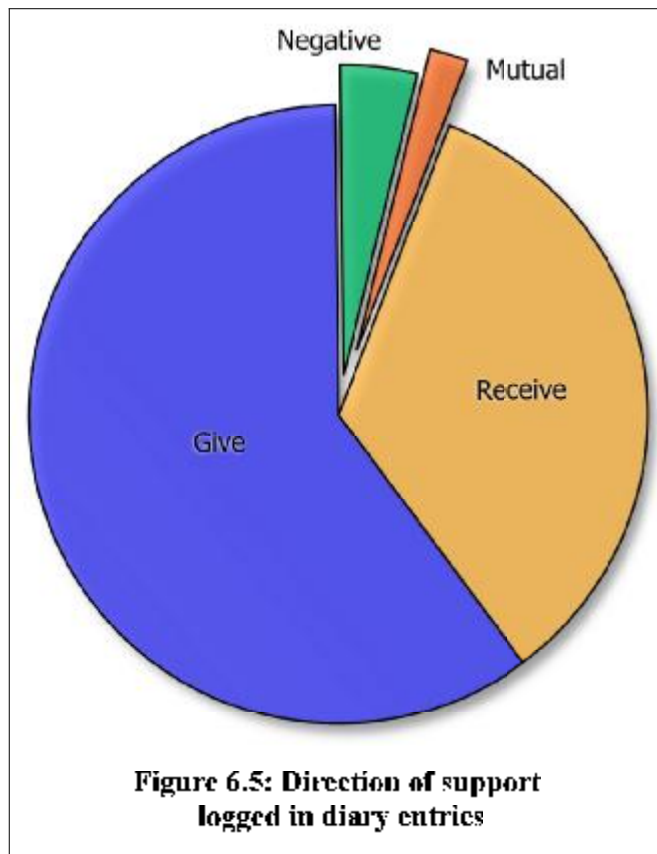


Figure 6.5: Direction of support logged in diary entries

like hospices, were taking a holistic approach to support, and providing both medical care, practical and psychosocial services. Clearly these organisations are providing both direct support to PLWHA, and as previously seen, sharing expertise with other community organisations.

The perception of what NGOs did for PLWHA was very varied across groups, with some listing personal support, and others only institutional help to the support group. Groups 5 and 3, interestingly both from groups with the fewest resources, stated that they had received no help from the two networking NGOs which have a remit to assist groups assisting PLWHA, because they couldn't afford the membership fees. These are the

Botswana Network of People With AIDS (BONEPWA) and the Botswana Network of AIDS Service Organisations (BONASO). "We could not get any funds from BONASO because with BONASO, you need to be affiliated to them. So we don't have the P300 [about £25] for affiliation. There is no how they can help us if we are not affiliated to them, that is the main problem" {Group 3. 53} "with BONEPWA... we didn't manage to affiliate for two years. So we took a long time without affiliating. So when workshops are there, when opportunities are there, we are not called because we didn't affiliate." This was a difficult subject for both support groups as well as the NGOs, due to the pressure they were under from government to try and be self-sufficient and cover their own operating costs. Again this is an example of the influence of the international politic, where neo-conservative cost recovery measures are often encouraged. Yet in applying for funds, there were other barriers that prevented groups from receiving NGO assistance,

"we had applied to [the] Global Fund and with Global Fund, BONEPWA is the organisation which is supposed to recommend us... So the problem was that Global Fund could not assist us financially because we had no place where we were operating from. Now, when we tried to ask for assistance again, we were told that global fund no longer gave out funds." {Group 3. 43}

This is a clear example of the breakdown and restrictions on the network of organisations, especially where opportunities rely on the functioning of other parts of the network. These conditions became difficult obstacles for groups to overcome, and as we shall see in the next chapter, became part of a situation of conflict that led to some groups being isolated from the formal networks of NGOs that were supposed to be in place to assist them, while others benefited from very close relationships. These

relationships are explored further in section 7.6.

6.8 Conclusions

This chapter has shown that from the point of view of the primary recipients, a wide range of formal and informal support is available from a variety of places. Yet for each source, there has been a wide variety of experiences, as demonstrated at the start of this chapter in Figure 6.1. Despite some patterns of dependency on certain sources for particular individuals, it is very difficult to say that there is one primary source of support for PLWHA as a whole, especially when some people have been ostracised by friends or family, while others seem to have them as their main source of assistance. This makes it difficult to draw conclusions based on the level of income, location or age of the participants in general, at least with a relatively small sample size, since so much seems to rest on particular relationships.

Yet important conclusions on the network can already be drawn. Participants in group sessions seem to have at least one source of support, and psychological support was considered just as important as material assistance by different groups. This is an important finding, as it vindicates the approach taken in the research to examine all forms and sources of support together, as it is clear that PLWHA seek and receive a wide variety of assistance. Had the approach merely focused on family support for example, it would not have been possible to show that those who do not get help from their families develop networks of friends instead (although the direction of this causation is disputable). Similarly if informal support had been considered alone, the study might not have fully shown that home-based care provides support to people who lack a network of friends or family to care for them, or the importance of the extensive government services that are provided. A joint approach has shown how PLWHA exist in overlapping networks of care, and that people rely on different sources for different needs.

Yet the limitation of the study in focusing on people who are actively involved in support groups also makes itself clear, as we obviously have no testimonies from people who have no networks of support available to them, or those that choose not to seek services geared towards PLWHA. Although this is partly due to the practical impossibility and ethical problems of recruiting people who do not want to be identified as having HIV/AIDS, and discussed in Chapter 4, it is not necessarily a deficiency, as long as no attempt is made to pass generalisations about support to all PLWHA. The research can only describe those who are involved in support as donors or recipients in this context. Yet as Figure 6.5 shows, the idea that support is mutual is borne out clearly: the diaries written by support group members show that they may give more support to others than they receive themselves, supporting the idea that the flow of support in a network is multi-directional. There are also examples of this at the institutional level in the CHBC programme, where government projects partner with community organisations and volunteers to provide support services.

The next chapter discusses in greater detail the collapse of the formal support networks for community organisations, the effects of bad governance, and the lasting impact both can have on the vulnerable people whom organisations are charged with serving. Investigating the problems with network bodies, it will also detail how official sources of support fit into the landscape of care, and how they integrate with the community organisations, and support groups.

Chapter Seven

Networking

7.1 Introduction

The previous chapter illustrated examples of community and government organisations networking together to deliver counselling and home based care services. It also showed how support groups relied on umbrella NGO networks for organisational assistance, such as training and funding opportunities. This chapter explains the role of official bodies providing support for people living with HIV/AIDS (PLWHA) in greater detail, including government organisations, networking bodies and civil society organisations including non-governmental organisations (NGOs) and community based organisations (CBOs). The emphasis of the discussion is on formal networks of cooperation and the flows of information and resources between these groups. This will be examined at multiple levels, between government departments, from NGO to NGO, between civil society and the state, and also between national and international funding bodies. It will also include a discussion of how these networks of local and global effect have an impact on services for PLWHA in Botswana, and form interdependencies which function at different spatial scales.

Using interview data on government departments and civil society organisations, discussions from a national workshop of support groups arranged for this research and participant observation, evidence will be combined to show the extent that different support providers interact, and what factors are restricting flow in the network. The functioning of these networks is essential to reduce overlap, increase co-operation and improve the efficiency of the network (Proval and Sebastian 1998), and impacts upon the level of support available to both PLWHA and caregivers. Evidence will suggest that when networking breaks down, there is a serious impact on community support services. A lack of trust and communication between organisations has been a major issue in the collapse of these networks, especially a lack of respect between donors and service organisations. Several key events will be used to illustrate this problem, and it will be shown that the same problems with governance and communication which have hindered support groups also affect the network as a whole. Finally the chapter will use the example of the collapse of two support group networks, including the Coping Centre for People With AIDS (COCEPWA) to suggest that networks can also have a negative influence, since a reduction in trust and strength in one organisation can impact the

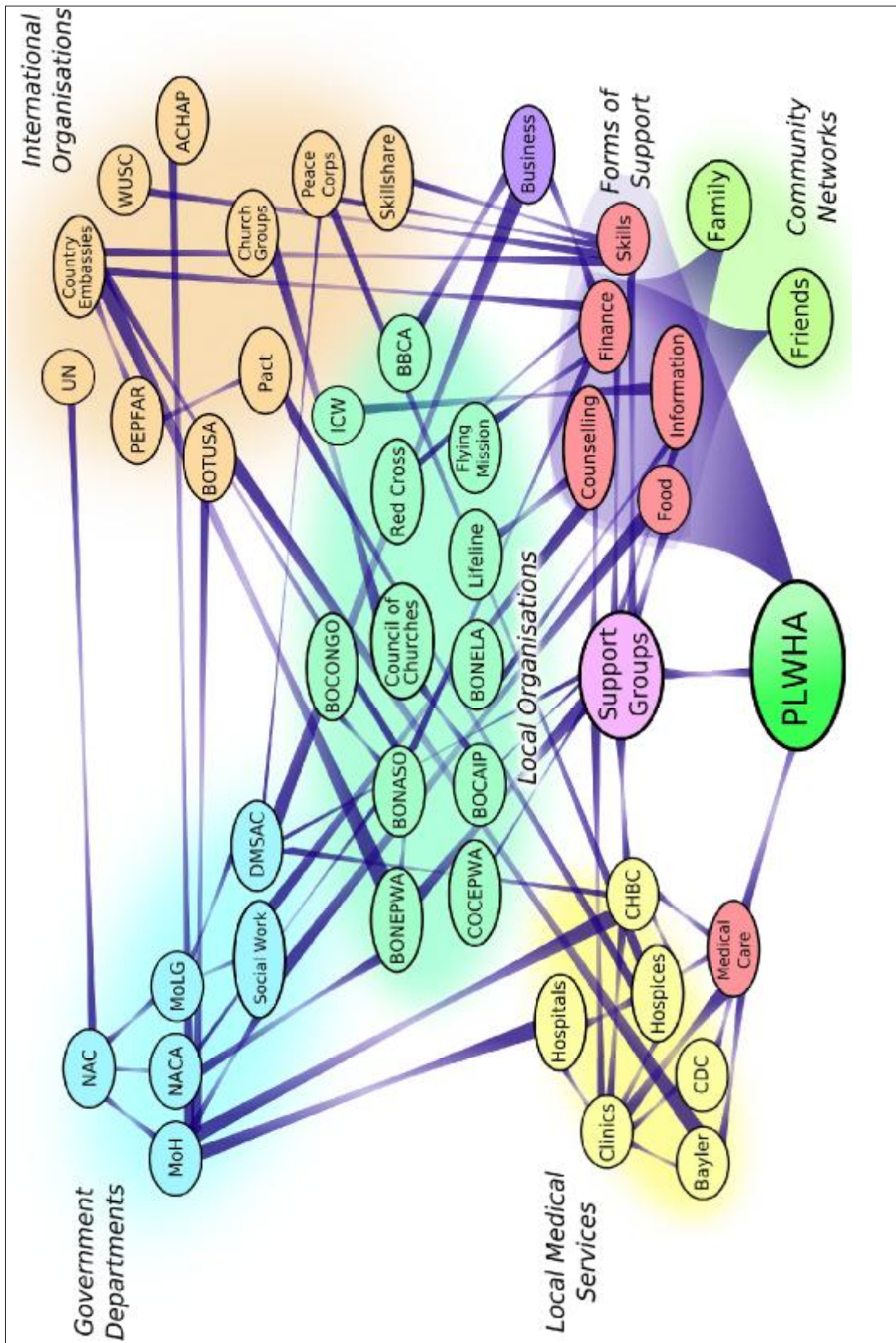


Figure 7.1: Network diagram of major AIDS Service Organisations in Botswana

whole network

Figure 7.1 shows a map of the support network for PLWHA in Botswana, focusing on the organisations which network together to provide services. The diagram was created at the end of the fieldwork period using information collected from participant organisation and interviews with service providers, and shows the major connections between most organisations which in some way assist PLWHA in Botswana. It was presented in a draft form at the feedback workshop, where participants suggested minor amendments. It demonstrates how national, international and local networks have many interdependencies, and how channels of assistance often flow through many partner bodies at the local level. It also shows how government services have many different departments and bodies which provide assistance to PLWHA or other community organisations. The diagram is complex, due to the large number of formal actors in the network, but this in itself is an important observation. It was clear that most organisations were well aware of the complexity of the network, and it was noted by other researchers working in Botswana that learning the abbreviations and affiliations of the almost 50 organisations shown here was something of a rite of passage. Not surprisingly, there are clear clusters between organisations at similar scales, especially between government health care providers. One interesting thing shown is the importance of clinics in the network, they provide direct services, but also have close links with hospices, support groups and the social services for counselling support and providing information. The networks of formal support services will now be discussed further, starting with reference to the relationship between the state and civil society organisations.

Now the level of analysis has shifted to focus more directly on the networks, it is worth recapping some of the conceptual frameworks introduced in Chapter 3 which guide how networks can be examined. A network approach was chosen because it can function at all levels. Support itself is defined as acting as a network in several classic texts (eg Durkheim 1952, Cobb 1972, Putnam 2001), and in the previous two chapters, the networks of support were demonstrated as families, the community, congregations, support groups and others: a direct network of actors who provide support and supportive services to individuals at a local level, with a high level of closeness. Now the more formal network of institutions and organisations will be examined, that have a strong influence through the network, but are further removed from PLWHA. It is hoped that this analysis will illuminate the multi-directional and complex interchange of power that influences the global and local levels of service delivery, showing that the local scales in which supportive actions are performed are as integral to the global network as international bodies (Marston 2000).

7.2 Government and civil society services

To consider the interaction between government and civil society service providers, it is first necessary to revisit some of the theory and background behind civil society organisations as actors providing services for People Living with HIV/AIDS (PLWHA). In the National Strategic Framework (NACA 2003), The Government of Botswana has deliberately facilitated an integrated policy to tackle the HIV epidemic with the contribution of civil society, especially in the form of Non-Governmental Organisations (NGOs) or Community Based Organisations (CBOs) as independent service providers and lobbyists. This attitude is forward thinking, but not unique:

“NGOs have always provided welfare services to poor people in countries where governments lacked the resources to ensure universal coverage in health and education; the difference is that now they are seen as the preferred channel for service-provision in deliberate substitution for the state.” Edwards and Hulme (2002a, p188)

NGOs are often considered to be cheaper, more flexible, quicker to respond and more akin to the needs of the people they serve than state based interventions (Edwards and Hulme, 2002a). Thus where resources are limited and quick action needed, governments can achieve some of their aims through the funding and support of NGOs with similar goals. However, more recently literature that is more critical of the role of civil society organisations has emerged (eg Zaidi 1999), and many researchers have commented that they are in some ways less democratic in nature than government based service providers (Uphoff 1995). More detail on this debate can be found in section 3.11.

Although it may have failed to prevent the spread of HIV in Botswana, the government is widely regarded to have pursued an active strategy to tackle HIV/AIDS, and to have started early (Heald 2005). Part of the reason behind this comprehensive intervention must be the history of good governance, coupled with prudent management of resources, preconditions noted by Taylor (2004). However what Taylor does not describe is how this combination allowed the government to create a comprehensive HIV/AIDS strategy that could be coupled with significant government expenditure. The government of Botswana has only had a policy to engage with NGOs and civil society organisations in key development issues since 1996 (Datta 2004), and as several participants testified in earlier chapters, the government actively encouraged the formation of NGOs to address the issue of HIV/AIDS. Webb (2004) recognises the rarity of the state facilitating NGOs, and suggests that in most cases NGOs are formed to address areas of 'state neglect' in which governments are failing to tackle or recognise societal problems. In general, the literature suggests that the increase in power of civil society through NGOs has come at the expense of the power of the state (eg Held and McGrew 2002, Rosenau 2002). Yet policy in Botswana fits better with the assertions of Woods (2002) and Risse (2002), who find that states often actively support, fund and outsource to NGOs. This can be seen as creating both recipient and donor processes. To gain Global Fund money, the Government of Botswana partners with NGOs to deliver services, while the US government's USAID money is distributed through PACT, an International Non-Governmental Organisation (INGO) to channel money intended for HIV/AIDS development projects to local NGOs. Clearly, neither the Botswana or USA governments have completely lost power through this process, but as Beniter et al. (2004) suggest, states have gained in some ways, as they can now claim a better representation of civil society, strengthening the legitimacy of the state on the international stage.

When examining official documents, the commitment of the government of Botswana to incorporate the community response seems low considering the rhetoric and number of partnerships observed during the fieldwork process. For example the National Strategic Framework for HIV/AIDS (NACA 2003) dedicates only two pages out of 104 to the role of NGOs and their umbrella bodies, however the tone of these statements seems positive and inclusive;

“Civil society has enormous potential to assist with the fight against HIV and AIDS and needs to be further enabled to address the growing needs of the National Response. These needs have overtaken the Government's

ability to deliver and civil society offers alternative mechanisms to assist the country to increase the scope and coverage of critical HIV/AIDS programmes.” (NACA 2003, p70)

Policy also recognises the importance of NGOs having an independent voice, they should “perform a 'watchdog' role, ensuring appropriate design and implementation of HIV/AIDS programmes” and “undertake advocacy and lobbying activities in support of prevention, care, support, and mitigation initiatives” (NACA 2003, p71). When evaluating these statements, it is important to note the influence of UNAIDS, who greatly influenced the formation of the national policy and subsequent evaluations in a technical advisory role. Certain facets, especially the language of community involvement, echo strongly the policy of UNAIDS: this is another example of the power of the international networks of governance, and is no coincidence.

Networking between government and NGOs is crucial to ensure the communication of goals and problems as well as accountability on both sides. “The evidence show [sic] that it is the quality of the relationships between GROs, NGOs, donors and governments that determines whether patterns of funding and accountability promote or impede the wider goals of all these organizations” (Edwards and Hume 2002b, p205). Clearly, good networking is key to achieving the aims of both the state and NGOs, if necessary through compromise and facilitation, and from the face of the government policy statements, we would expect to find strong network links between government and civil society. In fact, this policy of close partnership with NGOs for service delivery, especially in circumstances where the state is directly funding community organisations, raises questions about their independence, and whether they could be considered an extension of the government. Even so, government can decide whether or not to fund groups, and as sections 7.4 and 7.8 will demonstrate, it is possible for groups to find other sources of funding, either from local sources or the international network, which can aid their level of autonomy. However the ability of organisations to shift and use new or diverse flows of resources is dependent on their level of connectivity in the network

The District Multi-Sectoral AIDS Committees (DMSACs) act as coordinators for all activities related to HIV/AIDS at the local level, and include a committee comprised of representatives from business, government, PLWHAs and NGOs, as well as strong involvement from the District AIDS Co-ordinator (DAC). Regular meetings with the multi-sectoral representatives are supposed to ensure organisations at all levels are involved with HIV/AIDS education and prevention, and ensure cooperation and coordination between different community groups. Providing services directly to the community in terms of education or care to PLWHA is rarely done directly by DMSACs, but is achieved by providing some funding to NGOs and support groups in the region. Thus there needs to be a strong bi-directional relationships between the DMSAC office and committee and the NGO and support group service providers. Several support groups involved in the research had applied to their local DMSAC for project funding, especially for skills training, income generation projects, outreach events and providing meals or other care to PLWHA. These proposals needed to explain and justify projects by providing a detailed budget and costings for each quarter, indicators for progress with suitable regular targets, and an explanation of which part of the National Strategic Framework the project covered, all using forms that were unique to each local DMSAC

Completing these proposals was time-consuming for many small support groups who,

as mentioned in chapter 5, often lack the necessary training or equipment. "They tell you to go all over looking for quotations, they don't give you transport... communication wise, you don't have a phone" {Workshop: 152}. Proposals are considered annually by the committee, which often did not meet regularly, and money seemed slow to be released from government to DMSACs, and also from DMSACs to NGOs: "When you go back and ask for the money, [you are told to] fill this form. Spend two years filling these forms for nothing. You just hear of that money but you will never touch that money" {Workshop: 154}. Batsell (2005) noted that there was a tendency for a similar delay in Zimbabwe too, where local AIDS committees had not completed paperwork that allowed for dispersal of funds. Clearly in many countries, while networking and local government structures can include more participants in service delivery, this can come at the cost of adding many additional layers of bureaucracy, a problem that is surely no less true in Western nations. Wherever it occurs, it is a restriction, a frictional process that restricts actions and perhaps even trust, a challenge to the 'unlettered' flows which Marston et al. (2005) claim are inherent in network theory. Perhaps it is better to think of the connections between nodes as having a level of efficiency just as in section 3.6 where an analogy was introduced where connections were paths, some being smoother or wider than others. No process is perfectly efficient, there is always a loss of information or resources between nodes, or cost to the transaction. These funding processes create a cost in time and human capital to both the groups and donors, which hinders the flow of resources between them in varying amounts.

Comments made during the support group workshop which included representatives from groups across the country, showed that some DMSACs and support groups had much better relationships than others. "My DAC, we work very well with our support groups. When somebody calls [to say], we have a problem, we have to send a vehicle there. But it's not all DACs that do that" {Workshop2: 221}. While the previous chapter suggested that the rural group had stronger links to their DMSAC, some rural groups in the workshop had no contact with their DMSAC at all, and in each case it seemed that different parties were to blame for the lack of cooperation.

"Our [NGO] chairperson had really done everything in her power to ensure that everything was right on track but our main problem now is that DMSAC has not really welcomed us the way in which we would expect to be welcomed. We would write letters requesting for assistance, with all the determination that we have and our chairperson would even take it upon herself to deliver our requests or proposals stating whatever it is that we would like to do hence we request for their assistance but at the end of it all, they still don't welcome us at their DMSAC office." {PLWHA week: 245}

"Maybe the problem is that you do not attend DMSAC meeting, maybe your coordinator has not been to any of the meetings that have been held before. I remember at some point there were meetings... but no representative from your group was present. If only you could update DMSAC... when your proposal is being submitted, you will find out that there is not really enough information." {PLWHA week: 251}

This last quote could however also be indicative of the communication problems witnessed in groups which did not have a fax or telephone, there were several circumstances where groups were not aware of meetings. Even representatives from NGOs and support groups who had good relationships with their DMSAC recognised

that one of the problems was a lack of staff to coordinate and manage many community organisations, and understood the effect this can have on communication and networking:

"DMSAC has a very large mandate in the district. I am always wondering about that... Sometimes even if they employ people and they have small branches, they are limited by the funding that they get to be able to communicate with their member groups. Sometimes just having very few resources, including man power to communicate with people... can cause that problem [of communication]" (Workshop, 102)

"[At] the DMSAC, the people working in the office, one of them is a Peace Corps [volunteer], the other is full time employee of government... How is only 11 social workers or two people at DMSAC, to communicate with all the 300 and something NGOs in the area? So somewhere down the line there is going to be breakdown of communication .. because there isn't consistent interaction with the two people" (Workshop 100-101)

Again a lack of communication was impeding networking, as noted earlier between support groups and umbrella organisations, and inter-group relations. Whether the reason is lack of resources or lack of will, as quotes clearly show animosity between some groups and DMSACs, the effect is the same: a restriction in networking sometimes strong enough to cause a breakdown of the ties, threatening the common goals of providing services for PLWHA and education for the community.

Other government departments have connections with NGOs and support groups, for example some support group members had been invited to give awareness talks to government agencies, exactly the multi-sectoral response the government hopes to build. There is also representation of NGOs at the level of NACA and the National AIDS Council (NAC), and meetings between different stakeholders. Information on government priorities is certainly reaching NGOs and groups, who were reactive to new campaigns targeting male involvement, or care for caregivers. However it was not clear how this information was being spread through the network, it seemed to be just as much from media and local networks as from formal meetings or direct communication. While weak-tie networks such as these are clearly able to communicate basic levels of information between organisations (Hansen 1999), the technical detail may be lost; for example awareness of when the DMSAC was accepting proposals was well known, but the details such as the deadline and form required were not.

The quality of information here is a key factor. If information is informally communicated through many channels, detail can be lost at each stage. This echoes the previous discussion of the efficiency of flow between nodes. There is a clear risk of loss in the type of loose, clustered network that exists between AIDS Service Organisations (ASOs) and the government, as national bodies prefer to spread information and receive feedback through the umbrella bodies, who as we shall see, are not in regular contact with many smaller organisations, so information tends to cross horizontally in a sporadic way between the better connected groups. Even direct communication initiatives, such as newsletters from DMSACs, were not reaching all groups, and were not always published regularly. As Kiesler (1985) notes, while social support networks can be used in place of direct professional communications, there may be greater potential for misinformation from other informal sources. This is especially

dangerous if negative, and potentially incomplete impressions are being spread, for example about the effectiveness of the DMSAC, or about misuse of funds: both accusations were observed being expressed in this way. Even basic awareness is needed, support groups sometimes did not introduce themselves to DMSACs, and support groups must understand the role of DMSACs and other organisations: it was clear from the support group workshop that there was understandable confusion over the roles and hierarchy of the many different government agencies and umbrella bodies.

If groups had not cultivated a good, direct link with the DMSAC, they seemed reluctant to visit for advice or guidance. Just dropping off a form asking for money was not considered enough: "Do they really submit their proposals on their own or do they ask for assistance from their respective DMSAC? ... Do they really communicate with the DMSAC about the projects that they would like to get involved?" {PLWHA week: 252}. Conversely one support group member made accusations back the other way to DMSACs. "You have never been to our group... to actually find out what problems we have" {PLWHA week: 264}. Networks had clearly deteriorated in some instances. Where the onus lies here is not clear, should the DMSACs be actively going out and visiting groups to provide updates and documents? Or should groups be approaching DMSACs to obtain assistance? Clearly both sides have a lack of capacity with regards to communication, especially in terms of staff and phones, and need to cooperate better. But reversing a negative tie once trust has been lost can sometimes be much more difficult than starting a new one.

7.3 Networking bodies

Government documents, such as the National Strategic Framework, recognise four key umbrella bodies that are charged with co-ordination and networking of civil society organisations. These are BONASO, BONEPWA, BOCAIP and BONELA, (NACA 2003 p70), partly illustrated in Figure 7.2 which indicates there is a clearly defined hierarchy of networking described in government documents, with the three umbrella organisations (in blue) acting as conduits for sources of funding, and bi-directional flows of information. The civil society groups are represented by the smaller circles at the bottom of the diagram. The government relies on the umbrella organisations to

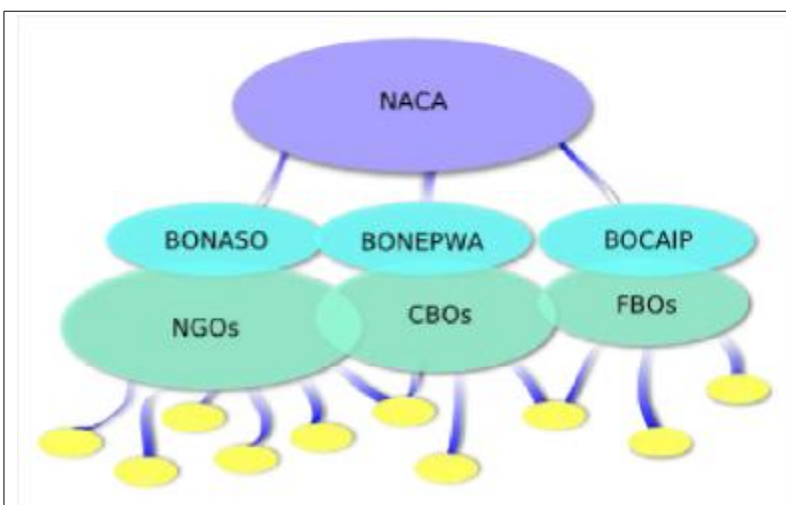


Figure 7.2: Hierarchy of HIV/AIDS organisations in Botswana

reduce the number of community groups it has to directly deal with, reducing time commitments and administration problems, as well as being a voice for the groups under them, maintaining manageable numbers at meetings and giving an overview of the requests from different groups. At least, this is the theory. However, later sections will show that not all community

organisations are heard equally through the network bodies, especially the support groups that cannot afford affiliation fees, while others such as CEYOHO were observed to have developed a direct relationship with the government.

The direct way in which the government has established bodies and processes to work at such a hierarchical scale, can be seen as problematic for any attempt to examine these networks without using notions of hierarchical scale (eg Marston et al. 2005). Indeed, it would be difficult to apply some other way of describing these these organisations when they consider themselves to exist and act as tightly bound entities. However it must be remembered that this formal government is itself a function of a society that is also very formal and hierarchical. Thus Marston et al. (2005) and others are justified in seeking an flat ontology approach, because it gives greater precedence to the 'local' societal and cultural norms which facilitate larger structures.

The government describes civil society groups as falling into three distinct categories. Non-Governmental Organisations (NGOs), Community-Based Organisations (CBOs), and Faith-Based Organisations (FBOs). Most organisations of all three types recognised the differences between the categories, although clearly there is some degree of overlap, for example the Holy Cross Hospice is an FBO, being initiated and supported by the Anglican church, but its scope is large enough that it functions like an NGO, including inpatient and home based palliative care, child care and income generation activities which serve clients regardless of faith. Some support groups had started at the level of CBOs, but now had much larger projects, and had grown to the level of NGOs, such as CEYOHO and COCEPWA. The difficulty of classifying NGOs has been discussed elsewhere (eg Vakil 1997) who details how organisations often straddle definitions of community based, grass-roots, national and international bodies. Perhaps partly due to this ambiguity, participants generally referred to all civil society organisations as NGOs, despite being clearly aware of the different categorisations.

One aspect of the categorisation of community organisations is the level of influence or geographical coverage an organisation has, which is difficult considering Botswana's small population, and the focus of activities around Gaborone. It may be considered that most organisations located in or around Gaborone are closer to NGOs than CBOs, purely due to their physical proximity to government. They are more likely to be asked to participate in NACA meetings, or be involved with networking with other NGOs in comparison to groups that are located further from the capital city. This effectively shifts power and influence over projects and policies towards Gaborone based HIV/AIDS groups. Rural CBOs will interact more with their local DMSAC, which is effectively the local government HIV/AIDS office, but less frequently with national government departments or NGOs. However this also works the other way: Gaborone support groups seem to have less to do with their DMSAC compared with their more rural counterparts, preferring to network directly with each other, or central government. It was clear during the study that there was a lack of national outreach from NGOs, especially from the umbrella bodies to other districts of Botswana, mostly due to the costs involved in travelling, setting up other offices, or finding staff time to make visits. Coupled with a lack of communication equipment, many groups felt isolated. For example many support groups were not informed about the National PLWHA Week in 2007, including a group that was located in the same district the event was held in. Before this event, that particular group, which came from a very isolated setting, had never had contact with another support group or NGO.

These network issues require important consideration, especially in light of literature on

the politics of scale (Brenner 2001) and reach of NGOs (Ars 2003) which suggest that in a globalised world, scale must be considered differently as increasingly detached from the limits of physical space. In the case of these organisations in Botswana, there is however a very clear level of local and national, and relatively little international influence. While this is partly due to the limited resources of groups, there is an important omission in Ars (2003) and other work on the politics of scale and NGOs: they are only considered as political issue groups, and rarely as agents of service delivery. When organisations are providing direct services, as is the case for PLWHA, scale is much more important, as at some level delivery must occur at the local level. While there are clearly organisations which straddle these boundaries, for example Oxfam which has a global network providing direct assistance to individuals, as well as global political pressure, as has already been noted, most ASOs in Botswana are not politically active, and certainly not at an international level. This raises an interesting question, does the contemporary literature on the politics of scale in a globalised economy not apply to service delivery in resource limited settings? Are service delivery organisations truly part of the global mosaic of organisations (Brenner 2001), or does the old standard of hierarchy still apply? Certainly the network shows that links are bi-directional, if not of equal weighting both ways, but here organisations are only connected to the global scale through other networks with the resources to communicate internationally, and as was demonstrated in Chapter 5, many support groups lack an ability to instigate communication even with other groups in Botswana, let alone international bodies. Yet the flows of power remain, these organisations are still directly affected by the decisions and resources of international and national bodies, which ripple through the network, especially as we have seen with funding.

There is clearly there is a need for networking of the myriad of AIDS Service Organisations (ASOs) operating in Botswana, especially for information sharing, but also to facilitate assistance from international donors, a fact recognised by participants in the study:

“When you look at the number of CBOs and NGOs it would be overwhelming for a development partner to be working because, let’s say 120 support groups, all of them are supported through ACHAP, and there are other NGOs, 120 contracts that you need to monitor.” {Workshop2: 92}

Renwick (2007) also recognised that the huge number of ASOs in Botswana was a logistical problem for coordination, an issue shown graphically in Figure 7.1. Tackling this is one important aim of the umbrella bodies, to act as facilitators and a point of contact between donors and recipients at all stages, from development and selection of a project, through to feedback and evaluation. BONASO was consistently rated successful in this matter, as noted by some support groups, who appreciated their insistence on accountability:

“BONASO is okay. What I like about BONASO is they give you money, they chase you [to] give them the report. Which is good.” {Workshop2: 25}

Groups also praised training that BONASO had provided for them, especially for income generating activities, although it seemed there was insufficient education on administrative skills, for example the ever crucial areas of bookkeeping and proposal writing. Yet especially with the support groups, it was not clear whether these were services that should be offered by BONASO or BONEPWA, which was the official

network of support groups in Botswana. It seemed that, perhaps due to a lack of communication in the matter between the umbrella bodies, there was confusion and even finger pointing over providing certain assistance to support groups or NGOs, especially when one considers that there is also a wider network of NGOs in Botswana, BOCONGO (Botswana Council Of NGOs), which, confusingly, may technically be a parent of the umbrella organisations. In reality BOCONGO had little direct involvement with ASOs, and although support groups and NGOs had attended some of their training courses, awareness of their services and activities was low. However for most support groups, the cost of affiliation for BOCONGO or BONASO was too high. "When you go to BONASO, the membership is 300 Pula. Which is for a PLWHA support group [is too expensive] and it's easier for a support group to go and affiliate with BONEPWA because it's 75 Pula" {Workshop2: 98}. This exclusionary process may even be deliberate, since neither organisation has the capacity to serve the hundreds of support groups, and each prefers to focus on assistance to larger NGOs. Clearly most assistance for support groups is supposed to come from BONEPWA, which during the fieldwork period seemed to be struggling to fulfil their obligations.

BONEPWA was founded in 2000 with encouragement from the government to create a network to support PLWHA, and especially support groups for PLWHA, for which it is the main networking body. It claims over 120 support groups are registered with it, and its mandate specifically details its role as "Facilitating the sharing of information, ideas, experiences and resources between and amongst support groups in Botswana" (BONEPWA 2006). They are also involved in promoting the creation of support groups, coordinating their operations to increase impact, and empowering PLWHA. One group said how much BONEPWA had helped them:

"BONEPWA is one of those organisations which can really assist you when you want to start a group of your own. If you do not have any idea on what you should do but having that idea of starting a support group, they are the right people who can give you the proper guidance. They can even help you every step of the way just to ensure that you are on the right track as a support group." {PLWHA week: 240}

NACA have publicly stated that they only provide assistance to support groups for PLWHA through BONEPWA, and by funding the umbrella body in terms of the "office rental, utilities, national co-ordinator salary, supervision, maintenance of office equipment, vehicle and institutional capacity building." (Daily News 17/01/06). In addition, their prominent position allows them to be able to negotiate for project funding with larger international NGOs, such as ACHAP, and they also have membership dues as a revenue stream. However, as with most umbrella NGOs in Sub-Saharan Africa, these provide only a token amount of their total budget, and this limits the influence of their members. Since their contribution is comparatively insignificant compared to the funding and demands of bigger stakeholders, such as INGOs and the government, the power of members in the organisation is weak, a common problem for NGOs in developing countries (Gariyo 1995). BONEPWA was clearly going through a difficult period during the course of the study, with many support group members expressing critical opinions of BONEPWA, stating either that they were not providing enough support, or that it was only going to certain groups. "We always write letters to BONEPWA in Gaborone but we hardly get any response" {PLWHA week: 258}, "We affiliate to them, but what do we get back?" {Workshop2: 103}. The official response of BONEPWA to this was that they were increasingly limited by a reduction in funds given to them by the government. (Mmegi 6/12/06).

This reached a head at the World AIDS Day commemoration when the director of BONEPWA made a passionate protest, interrupting the public speech of the health minister, accusing the government of taking AIDS day away from PLWHA, and noting that while ministers had come in cars and planes to the event, PLWHA support groups were not invited, and were staying in a local school without proper food or water (Gazette, 06/12/06). The support group workshop the researcher organised (Figure 7.3) took place in PLWHA Week running up to World AIDS Day, of which this protest was one of the outcomes. During the planning process for PLWHA Week there had not only been a lack of assistance from certain DMSACs and government departments, but a feud between BONEPWA and COCEPWA over ownership and leadership of the event.

“Who is responsible for facilitating PLWHA week? NACA is saying, I’m not the one. Ministry of Health is saying no. Who is? As far as I am concerned, I’m sorry to use the word, BONEPWA is supposed to co-ordinate the PLWA week!” {Workshop2: 112}.

Some members even felt that BONEPWA had tried to sabotage the PLWHA Week coalition, and start a rival event {Diary}. Clearly, networking between NGOs, government and support groups over this event was not effective, and even detrimental. The controversy played out in newspaper editorials for some weeks, with one commentator criticising the response of the health minister, which was seen as dismissive and insulting to PLWHA [Guardian 8/12/06]. By the end of December, formal apologies had been made [Daily News 21/12/2006], but the reconciliation process did not seem complete; during early 2007 BONEPWA received no funds to carry out activities such as the Mr HIV Positive Living Pageant [Mmegi 09/04/08]. The lack of government funding could have been for many reasons, inadequate reporting, concern over misappropriation of funds to other NGOs, for example COCEPWA, or even as Gariyo (1995) suggests, fear from governments that the NGO sector was growing too powerful. However that theory generally does not seem to fit the attitude of the Botswana government, and as this chapter will suggest, much of the NGO sector is currently not in a very strong position, especially financially. Yet the two examples of BONASO and BONEPWA show complexity in the system again, just as with the difference of experience between family and friends as support providers in the previous chapter, here groups described different experiences with their DMSACs, and with the networking bodies. Thus we cannot say that the umbrella organisations are failing all groups, or that this system is not working, rather, the network is in a state of flux. Here success is dependent on particular facets of the network, such as trust relating to funding from government, and the personalities of particular individuals that clash and create problems.

Considering the previously stated role of BONEPWA in assisting support groups, if relationships between the government and BONEPWA had deteriorated, a critical source of finance and networking for support groups had been disabled. Whether because of this, or in addition, there seemed to have been a breakdown in communication between BONEPWA and support groups: “The PLWHAs do not have access to the mother body. That is where the link is missing. And I think that if we can just close that gap where PLWHAs have access to BONEPWA. I mean, when last did PLWHAs have a conference? 2001!” {Workshop 2: 108}. Specific support for networking activities like the PLWHA conference, and PLWHA Week were clearly missing, despite interest from UNAIDS Botswana and ACHAP in facilitating, and funding such activities. Without the proper functioning of the network body, networking



Figure 7.3: Workshop for support groups at PLWIIA Week 2006

between support groups had deteriorated: few knew what other groups were doing, duplication of activities and application for funding that could have been undertaken as partnerships became competitive. During this period several support groups collapsed, and few new projects were started, ostensibly for a variety of reasons, but each in part through a collapse of the network around them. “All support groups are dying, because there is no support” (Workshop2: 190). This illustrates the importance of networking, especially for the smaller groups, and the consequences of poor coordination. Yet it also shows the importance of multiple redundancy: participant observation showed that some groups turned to rely more on their DMSAC, or made applications for project funding to foreign embassies. However, the sudden drying up of several important sources of finance made conditions very difficult for NGOs and support groups, and clearly many groups were dependent on the network or the network body for assistance.

7.4 Funding Issues

It was difficult for the research not to become completely sidetracked onto the issue of funding for NGOs and CBOs. It was clearly problematic for them, and was also a problem for the donors and government departments that were interviewed for this project. At every meeting funding was discussed to some degree, and it was almost always as a very emotive issue. Yet in terms of the aims and objectives of this project, funding is just one of many flows in the network, which cannot be seen in isolation from flows of other resources, such as skills, labour, other material goods and information. Proposals and progress reports are very important flows to understand, because as all parties understood these were required for any funding to occur. There were three main issues with regards to funding which arose from discussions; documentation, sustainability and perhaps most critically, relationships with donors.

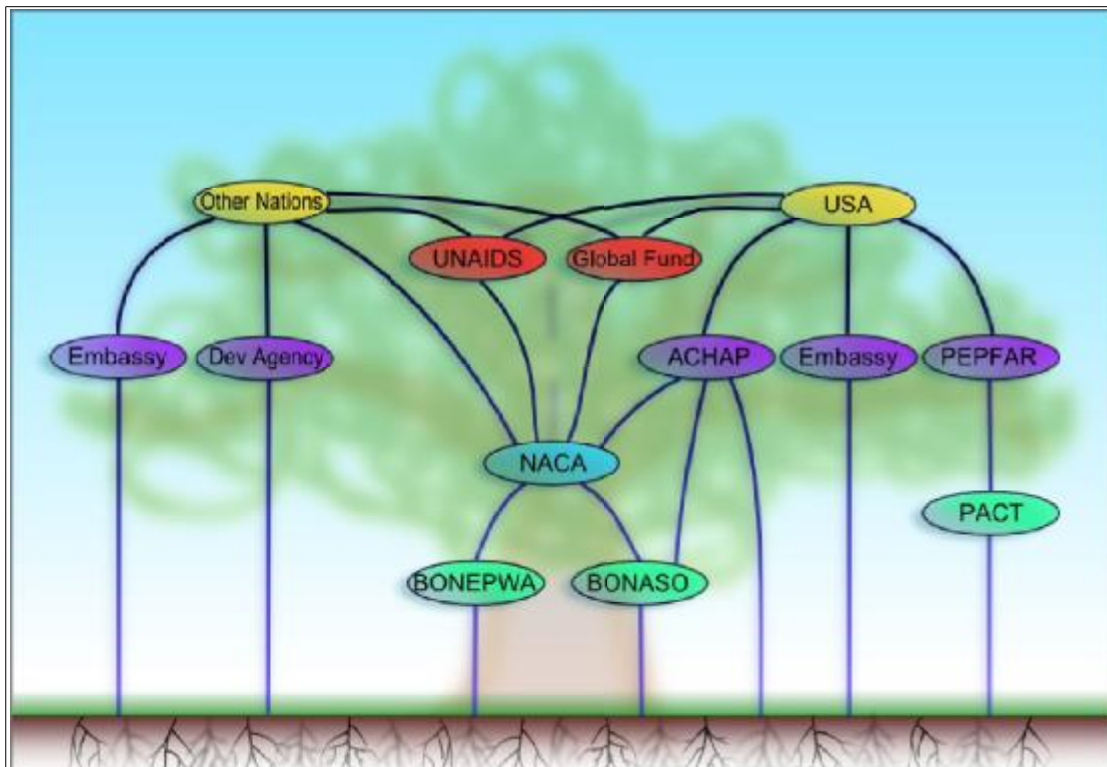


Figure 7.4: International and national flows of funding assistance to Botswana grass-roots organisations

Funding almost exclusively referred to money: either as grants or donations, which may come from a wide variety of sources. Some organisations, especially church groups, had international networks of support from congregations in other countries, which included volunteers, funds and a market to sell income generating goods. Donations from within Botswana are rare, especially financial, however many businesses donate food and goods to particular organisations with whom they have strong links. There are many sources and levels of funding, many of which are dependent on other sources further up the funding tree (Figure 7.4). For the most part, support groups and NGOs at the grass roots level are reliant on grants from government, or international sources, often channelled through local agencies (Purple) and national umbrella NGOs (Green) before they reach the grass-roots organisations at the bottom of the diagram.

Since Botswana became classified as an upper- middle income country in 1998 (World Bank 2007), levels of financial and technical aid to Botswana have fallen, as donor countries and NGOs have re-prioritised assistance to poorer countries. Consequently, FDI has decreased from 10.5% of GDP in 1980 down to a level currently just over 1% (World Bank 2007). This has had an immediate impact on some service providers who were funded directly by international NGOs, and also in terms of the general assistance from government, for example funds for specific projects run by NGOs and CBOs where funding came through official channels. At the same time, new avenues of funding became available to tackle the global HIV epidemic, such as the Global Fund for HIV, TB and Malaria: project specific money that was channelled through government and umbrella organisations. Additionally, the Bill and Melinda Gates Foundation provides funding administered via ACHAP, and the US Government President's Emergency Plan for AIDS Relief (PEPFAR), provides grant money administered through an NGO called Pact.

The National Strategic Framework for 2003-2009 lists 12 different international donors, of which a majority provide specific funding for increasing medical capacity, and 7 fund projects dealing with care, support and impact mitigation for those infected and affected by HIV/AIDS, totalling over US\$21 million over periods ranging from 1-5 years. This represents 25.2% of total funding from international development partners detailed in the framework, a majority of which, 52.8% goes towards prevention projects. It is important to note that while there is a significant contribution from ACHAP towards the Masa treatment programme, the Botswana government is paying most of the costs. This is obviously a huge part of the support for PLWHA, as the programme provides the drugs needed to extend their lives as well as regular check-ups and diagnoses.

International networking, at least beyond the realm of funding, is one area of which there was little discussion. BONEPWA is affiliated to the African network of PLWHAs, and COCEPWA, while operating, was reportedly very good at international cooperation. This was especially apparent in promoting their programmes, such as the buddy scheme, to NGOs from other neighbouring countries {Former NGO Interview}. However at a government level there was much evidence of sharing of best practice, especially through health departments from other nations visiting Botswana. But NGOs and support groups could not afford the expense in such travel, or even phone calls, and a lack of access to IT in the form of e-mails and regularly updated websites limited the potential for ASOs in Botswana to be networking at an international level. However there was some skill sharing, especially in the form of volunteers from Western nations, which some of the larger NGOs had been able to make use of. The hospice and BONELA had gained much experience in this way, especially through the twinning of church groups, and through formal structures such as the World University Service of Canada (WUSC), UN Volunteers and the Peace Corps who had placed experienced volunteers at BONEPWA and some DMSACs

International governments and donors rarely explicitly deploy development centred interventions, since they no longer consider Botswana a developing country. This is especially true of health related projects. While organisations such as the BOTUSA/Harvard partnership provide technical assistance to the Ministry of Health in improving health services, there are no organisations building clinics or hospitals. Strong health structures have existed in Botswana for decades, mostly built by government. The key difference here is the improvement of existing services to cope with the epidemic, rather than developing new services and delivery mechanisms. However one international funding body described its role in a different context,

“We are not in the business of creating NGOs. NGOs are in the business of creating themselves. We are in the business of funding for services, and training for capacity. So we are not in the business of providing training for NGOs, that's not the role, the NGO needs to exist, to be functioning, and then we come in to do certain activities. So that's not, not the role of development money, it's not charity, it's development money.” {Workshop: 139}

This comment is extremely interesting. It was perhaps the only time in the course of the research that any participant discussed 'development', other international donor NGOs had placed their emphasis on health and service delivery, but clearly this INGO had a wider scope that includes development projects. However it opens a conundrum, because most donors involved in HIV/AIDS in Botswana saw themselves as providing

assistance in an epidemic, be it funding medical or social support, but did not see these interventions as development projects. This is one reason why there is relatively little development literature in this study. PLWHA, organisations and government did not describe HIV/AIDS as a development issue, and Botswana is not a developing country, at least by official measures. The idea that providing health or support services can act as a 'pump-prime' development project, eventually leading to economic growth and sustainability, seems curious, regardless of the success of ancillary income generation projects by support groups. While having a healthy population certainly facilitates a strong workforce and economic growth, the major component of this, the ARV programme, is mostly funded by the government, as one would expect in a more developed country.

During the course of the research, a 'triple whammy' had hit ASOs in Botswana. First ACHAP changed funding strategies and decided to fund activities only in certain districts {ACHAP Interview}, removing one source of funding from many parts of the country, including Gaborone. Secondly PEPFAR funds were frozen globally by the US congress for a period over concerns that funds were being misused, accusations which were not related to Botswana. Lastly, and most importantly, Global Fund money to the Botswana government was frozen because monitoring and evaluation reports were delayed, with an admission by NACA that only half of allocated funds had been spent [Gazette 24/01/07]. Each of these national and international processes had a knock-down effect on community organisations, ripples of change in the network directly or indirectly impacted on every node. Thus some NGOs saw their funding expire with no opportunity for renewal, and others even had it suspended in the middle of a project, seemingly through no consequence of their own actions. In a system where successful projects are effectively 'rewarded' with funding for additional years, it was difficult for groups not to see this as some sort of punishment for the failure of themselves or the network bodies they relied on.

Another example of poor relationships between the government and the NGO community was the accusations levelled between the two sectors as to where blame lay for the failure to account for this Global Fund money [Mmegi 01/02/06]. NACA had accused NGOs of not providing them with reports in time, hence delaying the production of a national report for the Global Fund, while NGOs publicly stated they had provided reports on time, and were unaware that there had been a problem until funds were later denied. In fact the four NGO umbrella bodies; BONASO, BONEPWA, BOCAIP and BONELA issued a joint public statement to this effect: a positive piece of networking and solidarity. This event may indicate that there is certainly a lack of training in compiling reports and in accountability, which may exist in certain government departments as well as NGOs. While the Global Fund has been praised for not imposing strategies on governments and communities who apply, this also means they get little technical assistance, and the Global Fund itself is considered to be understaffed (McCarthy 2007).

Animosity had also grown between certain NGOs and ACHAP when they changed their funding process and stopped taking general project proposals. "Donors, funders, are the ones who create their own demons. Because they dangle the money and you are given the money and all of a sudden the money is gone" {Workshop: 29}. Despite making the change to funding rules publicly known, there were clearly some groups who were not aware of the change in policy. In addition, some groups that had previously been funded for a certain period were clearly anticipating that funding would be renewed. This raised issues about sustainability and the impact of termination of funding.

“What does it really mean when they are funding for three years, are they saying that at the end of three years they are not going to give us money, or are they saying that after three years they are going to review and see what we are doing and fund us again? Sometimes those things are not well understood.” {Workshop. 98-99}

“When you have a donor for 4 years, maybe 5, you tend to relax. You have that comfort zone and think, now I have money. You don't now look at others and think, how can I diversify my funding base so that if this donor exits the country, or decides to change their strategy of funding, I still have some funding at home.” {Workshop. 114}

Clearly it is important for groups to plan for the end of their funding, and have alternatives ready, not least for the health of the organisation and its employees, “Support groups and non-governmental organisations... employ people who have families to support. So that when funds are terminated [they are] leaving a whole community of people who are unemployed” {Workshop: 57} but also because the consequences for losing funds extends beyond the running of the NGO itself.

“We have been doing home based visiting, these are the, the people we have made some contacts with, they know we always come. We have the young ones that come to the centre for feeding for example. And then all of a sudden because the funding is not there, we have to cease. And I am really wondering if they go to that personal level... It's not just [the organisation], these people are really struggling as well. The impact goes right direct to the people that we help.” {Workshop: 123-126}

Compared to organisations in other research, most of these organisations seem fortunate to have funding for such long periods. Daly (et al. 2004) for example, found that the sustainability and effectiveness of NGO and CBO interventions in Brazil and Zambia were being hindered by short-term funding, typically on an annual basis. Projects in Botswana seemed to generally have a three year funding agreement, although as we will see later longer funding can also provide problems with restricting the flexibility of interventions

Groups were also aware that reliance on donors has implications beyond sustainability, especially the realisation that “The donor will come with their own agenda... and when you first start you have your own objectives that you wanted to meet. Then when they come with their own... interventions, we have to divert, because we need the money at the end of the day” {Workshop. 70}. Considering the previous debates on the ability of NGOs to react to needs by being closer to their clients, this practicality shows that power still rests with whomever has money to give and in general the preferences of the poor are rarely heeded (Bratton 1990, p90). Especially in countries where community and individual donations are small, such as Botswana, dependence on donors or governments will be an essential part of NGO responses, but where NGOs are small and lack power, this dependency leads to competition for funds, and bowing to donor priorities (Boone and Batsell 2001, p11), as workshop participants acknowledged.

Applying for funding from official channels requires detailed proposals, which must set out the need and feasibility of a project, provide detailed costings, including quotes, set quarterly and annual targets, set indicators of performance, and a means of evaluating

the success of the programme. Every donor has different requirements and guidelines for proposals, and in general there are few organisations that help with this process. One newspaper article stated that small organisations did not have the literacy or assistance to cope with complicated funding proposals (Gazette 11/10/06), a finding echoed in section 6.9. Support group members also mentioned the importance for training on proposal writing {Group 1: 586}. Groups were unable to afford administrative staff or consultants to write proposals, and lacked the training on competing applications themselves, and thus were either failing to get grants, or they were dependent on money allocated through umbrella bodies. For example there were heavily used sources such as the Small Grant Fund, provided by ACHAP through BONASO, or funds channelled through BONEPWA, including some from the Global Fund, but both sources had dried up during the fieldwork period.

Another issue is monitoring and evaluation, already discussed as a problem for both government departments and umbrella NGOs, but is probably even more difficult for smaller NGOs who rarely have qualified staff and have to rely on untrained volunteers. Even some larger NGOs were struggling with the reporting demands made for them by donors, for example one organisation spent 2,500 Pula (£230) on a consultant to write a proposal with which they acquired funding from Pact {Hospice2: 114}. However, since Pact demands monthly reports including quotations and receipts, the group was frequently missing deadlines, resulting in funds not being dispersed, and volunteers going without allowances on which they were dependant {Hospice2: 124-135}. This was even with a full time finance officer, as other factors, such as suppliers delaying an invoice, or e-mails not working (which was common) can result in a report missing the deadline. This can become a vicious cycle, delaying the next report as well, and increasing stress and reducing morale. Even smaller groups were affected by requirements on a less frequent scale. "The donor is expecting a quarterly report, and financial report on a quarterly basis" {Workshop: 112}. The requirements for monitoring and evaluation not only have implications for administration, but also the ability of NGOs to adapt to meet the needs of their clients.

"Demands for strict financial accountability do not allow for flexibility in switching funds between alternative uses. Second, the demand for continuous monitoring reports of programme activities, implementation and the evaluation of achievements is extremely time-consuming."
(Gariyo 1995, p133)

If one considers that most project funding lasts for at least a year, it becomes difficult to set up activities to address newly identified needs, and it is also difficult to get official funding for one-off events in this way, although sponsorship from businesses are more common for these activities. All these factors create a very complicated funding system, with a multitude of different organisations, procedures and requirements which NGOs and support groups are expected to navigate. With the network body not providing assistance, groups were increasingly left in the dark, not just about how to apply for projects, but also as to the role of the many different actors in the system.

"[Do] members of a support group really know how to come up with a plan of work like asking for financial assistance? Do you know the organisations that they are supposed to ask for money from, are they aware of the channels that they are supposed to follow when asking for assistance? Those are some of the challenges that groups find themselves in and they would not know how to overcome those challenges. At times

support groups would not even know that they are supposed to know all that information.” {PLWHA week. 234}

There is no single guide to funding for ASOs in Botswana, although donors have documentation for their own procedures, and it was clear that information about funding opportunities was only being spread informally through the network, often based on little more than rumour and outdated information: “Take for instance ACHAP, which is funded by Bill Gates. When people hear Bill Gates they smell money” {Workshop: 28}.

7.5 Partnership and trust between donors and recipients

The relationship between funding bodies and recipients was weak in most cases, with suspicion and mistrust seemingly the norm in the absence of good communication and partnerships. A good example of this was discussion of donors visiting projects, which arose at the workshop, sparked by one comment: “Having worked in a non-governmental organisation, I have never seen, except for one example in my life where a donor is coming to see where my money is being used” {Workshop. 31}. It seemed that in the presence of so much paperwork, funding relationships had become very officious and impersonal, and that they were rarely true partnerships. One donors stated that:

“We have a contract where you clearly lay down your terms, and you attempt to monitor the terms, or even visit the project, [but] people create barriers, so that you can’t even see what is happening inside.” {Workshop: 81}

This suggests that some organisations were not welcoming visits from donors, for which the reasons were not clear: either there was mistrust of their motives, or perhaps even a feeling of resentment that they were dependent on donor money. Either way, it represents a breakdown of trust and communication in the network. Donors working in Botswana also found the sheer number of ASOs daunting:

“We [a funding body] will not go down to [see] what they are doing. But because we work with the management office, with the secretariat office, we expect that we are supporting them, and within that support there are the monitoring and evaluation officers. These are the people that go down just to see what is happening, but we trust the mother organisation that is there.” {Workshop: 85}

Clearly, a lack of functioning of the network bodies was hindering this process, and had eroded trust between ASOs and donors. In a study of dozens of CBO-donor relationships in Africa and Asia, Brown and Ashman (1996) found that it did not matter whether it was the donor or the CBO who put the effort into co-operation and communication in the relationship, but either way, when a clear effort was made by either body, these were the partnerships which were successful. Where this effort had not been made, partnerships were having poor results, a finding that could well be true for Botswana organisations, although this study is not designed to judge the success or failure of particular interventions. However Brown and Ashman's (1996) focus does not allow them to see the effect that weak partnerships have on expectations on other relationships: here it is clear that there can be a system-wide breakdown of trust.

One participant seemed to imply that, with the exception of the feedback workshop, which was really only convened for research dissemination, there were few opportunities for communication in the network: "there isn't that forum where maybe the development partner and the implementer maybe come together to hear some of these issues" (Workshop, 76). Officially these structures and meetings do exist, but there was no evidence of them occurring, or any positive results from them. Lister (2000, p229) finds that it is very common to have this "disparity between the rhetoric and the reality of partnership", yet the solution to this is not obvious. International funding bodies, states and grass-roots organisations all have to build relationships that work between huge differences in "culture, power, resources and perspective" Brown and Ashman (1996, p1467).

It is important to stress the necessary partnerships of each body in the network, and realise that flows are not just one way. ASOs are dependant on donors for funds, just as much as donors are dependent on ASOs for evidence of results. The donors on the ground require some evidence of successful projects, or the initial source of funds, which may be governments or philanthropists, will take money elsewhere. One donor representative reminded recipients that "We are also accountable to the board, which comes here and says, we don't think we are getting the results, one two three. Maybe we should change our focus" (Workshop: 88). However there is ample literature that suggests that donor-community relationships are always uneven, and that "the donor can do to the recipient what the recipient cannot do to the donor" (Elliot 1987, p65), perhaps suggesting that the notion of a true partnership is unattainable. This does not echo Brown and Ashman (1996), nor all cases illustrated in the data here, but some relationships are clearly more balanced than others.

It is pertinent to remember through all these debates that all organisations at all levels have the same overall goal: providing services for PLWHA. Jones (2004) suggests that problems with donor/recipient chains can be minimised by adopting a unifying focus towards human-rights and health over other issues. However, as shown here and in other literature, it seems that quality of the relationship is more important than the rhetoric, it is difficult to see how agreeing on a rights based approach would in itself build broken bridges between donors and recipients. Yet the situation is certainly not hopeless, most projects in Botswana seem to be carried out successfully, albeit not as many as there could be, but more importantly there are signs that actors are willing to come together and rebuild relationships.

"There must be a way donors and government can come together. Establish a system that will continuously monitor on a regular basis, be [it] twice in a year, they have a representative, the government, and the donors, they have a team, a small team that can monitor. That can go down, right from the grass-roots, find out whether, according to the records that the money has been dispersed to the grass-roots level." (Workshop2, 137)

So how does one begin to conceptualise and analyse this lack of co-operation between civil society, global donors and the state? Is it best seen as a collapse of networking, or a collapse of social capital? In essence, is it the strength of the links, or the value of them that has declined? The different frameworks to analyse these questions, such as power dynamics (Lister 2000), social capital (Brown and Ashman 1996) and networking make clear comparisons difficult. Yet this research shares similar findings with other studies in suggesting a deficiency of the relationships between states, donors and civil society

organisations. Social capital, networks, or power are all ways of looking at relationships, and it is clear that this is where improvements need to be made, but it is not so obvious to whether the problem is transcending power differences, increasing capital or building stronger ties. As Hinton (2004) suggests, in such a complex system with so many layers and partners at different levels, the key to sustaining successful relationships is flexibility and fluidity between donors and partners.

7.6 Networking between groups

In the absence of effective networking bodies for support groups, a lack of cooperation and information had affected the functioning of groups. "We don't know what [a support group] is doing right now [for example. There isn't the networking that you just talking about, people are too much individuals]" {Workshop. 1}. Some groups were not aware of the role or even existence of a networking body, and even those involved in group networking realised that it was not working "Even here, in Gaborone there is a coalition of support groups. I'm the vice chair of this coalition. It's not working because... what we want is to call people and have a meeting, there is no way to meet. We have to call these people through our own [phone], because we don't have funds" {Workshop2: 208}. Jónsson and Söderholm (1995, p473) describe these issues as transaction costs, and note that for small NGOs the costs required to effectively network with other groups or umbrella organisations can be insurmountably high, especially if travel to national or even international networking events is required. It is clear that even the relatively small costs of telephony are too high a transaction cost for some support groups. Yet this is also coupled with some other tragic coincidences: for example while most NGO members in Botswana have a mobile phone, to prevent government employees using work phones for personal calls, in some offices staff are only permitted to call land lines. This means that for most groups who also lack fax and e-mail, government staff must use their own personal phones and money to contact some organisations. Obviously many individuals are reluctant to do this, not least to prevent their personal phone numbers becoming widespread in work related groups. Since Botswana also does not have a postal delivery service to houses or offices, one must rent a post office box to receive mail, again, a monthly payment which is liable to be neglected in lieu of more pressing costs, leaving some groups unattainable except by direct visitation, if they even have a plot, house or office. Groups in rural areas away from Gaborone are probably even less likely to get visited: this was certainly the case observed with Group 5.

At least in part because of these transaction costs, groups are rarely working together, "We are all competing... for the very little scarce resources that we have in the country" {Workshop. 2}, but there was little sense of animosity or hard feelings between groups, they even talked about the possibility of working closely together to prevent duplication:

"They will be networking, we will take care of the children, and you take care of the women. The money would be easier than the competition that is on-going as we speak." {Workshop2. 107}

"Every group starts with no idea of what is expected of them to do. The moment you begin to network, you will definitely get the knowledge of what there is to know about starting a group." {PLWHA week: 242}

However while networking and close collaboration was acceptable, one suggestion that groups could merge was more problematic.

"For instance in Gaborone there are about 10 support groups; is there an ability for them to be merging to become one NGO that has maybe different roles and different regions in Gaborone to serve the different areas?" {Workshop: 117}

"You will find that we can't be one support group. Because we are looking on different things." {Workshop2: 198}

It is critical to consider that just because networking is occurring, it does not automatically follow that it is efficient or successful. One NGO representative noted that even when there were meetings between ASOs, they did not always lead to progression: "Ok, so we have that AGM once a year. Now we have all this difficulties and challenges written down. Then the next AGM we meet, bring report, you report, you report, you report. There is no follow-up of what we reported last time, the challenges we were having, and you keep on reciting, over and over again" {Workshop2: 248}. Interestingly, similar problems were found in an assessment of a coalition started by the Bristol-Myers Squibb Foundation to improve capacity building in Botswana NGOs. Issues of trust led to breakdown between NGOs, and one organisation dropped out (Hartwig et al. 2008). Here again, the presence of a networking body, designed to facilitate co-operation did not automatically create functional relationships, perhaps a strong suggestion that network theory needs to include some consideration of trust, as has been done here, or even social capital to explain why some ties are effective, and others dysfunctional.

Networking systems perhaps also need to encourage good governance in NGOs, namely targets, transparency, reporting, appraisal and accountability (Hulme and Edwards 2002, p194). Most groups seemed knowledgeable about the concepts and benefits of networking, through the recurring mantra of cooperation and reduction of duplication. However there seemed to be a level of abstraction to this: groups did not discuss simple, practical examples of resource sharing, for example having a computer and printer or fax machine that they could all have access to. It could be considered that proposal driven funding systems actually encourage controlled ownership of equipment and services, there is no provision for example for groups to make joint applications for projects, or pay 'rent' towards equipment shared with another group, as funds have to be distributed to a bank account owned by a registered trust. Some of the neo-liberal development literature describes this process as healthy competition (Atack 1999). This seems a questionable notion, especially in health service delivery, where the consequences for the failure of an organisation to be competitive enough can include the waste of limited funds and a direct threat to the welfare of critically ill people. As already suggested, the failure of one NGO here seems to weaken the enthusiasm of donors and the government to invest in others, rather than risk any further loss of money. This is another strong example of the interconnectedness of the network: the failure or financial mismanagement of an organisation at a local level, can have impact on funding decisions for international networks of donors, which in turn can impact the funding and ability to deliver services of a community organisation in a completely different country. Clearly, this is one aspect where there is no clear distinction between the scale of what constitutes local and global impact (Escobar 2007), they are all interconnected as part of the network.

"One thing that is missing with the NGO movement is that we don't allow organisations to grow, you know to evolve so that they are strengthened." {Workshop 83}. This is exactly the problem recognised by much development literature, for example Carroll (1992) and Fowler (1992), who find that donors are more interested in short term projects with already proven organisations, rather than long-term development of smaller organisations, and by consequence, much of civil society as a whole. In Botswana, and no doubt elsewhere, this means that larger NGOs get larger, as they win more grants and projects, while fledgling organisations, especially CBOs, are rarely given the opportunity to learn project management skills and gain a track record. Fowler (1992) feels that this is in part due to the distance that INGOs are from the communities they support. Without local offices, and direct monitoring or connection with CBOs, it is more difficult to identify new or small CBOs, especially in remote areas, that may have a relevant or innovative mandate, or offer services which are unique to the particular needs of their clients. For example the support groups in the study were clearly providing a very varied mix of services, and trying new ways to increase awareness. It was clear from evidence collected from groups that most of them were reliant on the umbrella bodies for finding these sources of international funding.

These debates may at first glance appear slightly abstracted from the project aims of examining services for PLWHA, but clearly they took so much time and energy from groups, they were becoming detached from their main mission. "We have distanced ourselves from what we are supposed to be dealing with. We are looking at HIV as if it is something that is very far from us... until we narrow it down to us to understand what these people are going through, we will never be able to deal with it" {Workshop2: 238-240}. Whether this comment is directed at individuals, CBOs, NGOs or donors is difficult to say, but it is probably relevant for the whole network. It indicates that the direct consequence of problems in the service delivery network is a lack of focus towards meeting the needs of PLWHA.

7.7 Government networking

Cooperation across a multi-sectoral response is clearly a key part of the Botswana government's National Strategic Framework for HIV/AIDS (NSF), and it also seems to be genuinely enacted. However this does not necessarily mean that the networking is always as effective or as efficient as it could be: "It's more or less the same people. Tomorrow maybe it's the HIV/AIDS partnership forum, the next day maybe it's the country coordinating mechanism for the Global Fund, the donor's forum, and then you are like, wow. Maybe we, we need to kind of consolidate, so that there aren't too many so that we are stretched" {Gov Official: 202}. The large number of different agencies that the NSF includes is daunting from an administrative point of view, and responsibility for co-ordinating them falls on NACA, who were by their own admission understaffed at the time of the study.

The NACA official interviewed said that while many DMSACs were meeting and sharing best practice, there was less flow of this information upwards {Gov Official: 172-174} suggesting that NACA was not receiving information back from some districts, and thus could not act as beacon and spread ideas nationwide. However it is less clear whether the Department of Local Government was doing this role, another area where the overlap of government agencies can create confusion. In fact several participants noted that "there are too many of these committees and structures" {NACA: 208} and went on to detail the importance and difficulty of maintaining relationships

between so many stakeholders, "It's about relationship building, partnership building, collaboration, but... you need to strike a balance, such that you are not overdoing it... at the cost of maybe something else" {NACA: 226}.

This study is not the first to note that **the need** for better co-ordination between local and national levels, for example Renwick (2007) makes similar points, and NACA is also clearly aware of the problem itself, in both this interview, and official evaluation documents such as the Mid-term review of the National Strategic Framework. However, an effective plan to improve networking has not been so forthcoming. It could be another area in which parties are unsure as to where responsibility for improving communication lies. On the other hand, there are certain examples that show extraordinary promise, especially the government Community Home Based Care (CHBC) programme, which encourages and assists local communities to start care centres and support groups through which the home based care programme can operate. Previous chapters illustrated how support groups provided an important referral system for the home based care programme, and the specific design of the project to integrate community and government services is an excellent framework for integrated service delivery.

7.8 Governance

An important aspect of governance is accountability, an area which has become a difficult debate as NGOs have become more important as service providers, especially when defining their role between the state and society (Uphoff 1995) and as a function of this, who they are actually accountable to. Hulme and Edwards (2002) provide five pointers for good accountability in NGOs which this section will assess with examples from ASOs in the study.

"Effective accountability requires a statement of goals (whether in adherence to certain rules or achievement of identified performance levels), transparency of decision-making and relationships, honest reporting of what resources have been used and what has been achieved, an appraisal process for the overseeing authority(ies) to judge whether results are satisfactory and concrete mechanisms for holding to account (such as, rewarding or penalising) those responsible for performance" Hulme and Edwards (2002, p194).

They note that these processes may be formal or informal depending on the nature of the organisation. The first three pointers are responsibilities of management within the NGO, which was another debated and problematic area for some groups, and others that poor management affected.

In general, the first issue, a statement of goals, is well covered by most NGOs and smaller groups, who to register with any body must have a constitution or similar document outlining the aims and objectives of the group. However these may be wide aims, for example to assist PLWHA, which while allowing for flexibility, also permits overlap with other organisations, and a lack of clear focus to projects. This can be a common problem for NGOs: "Some of problems [sic] concerning NGO performance and accountability do seem to be related to an inability among NGOs to decide what they really want to do, or to a mix of functions and tasks that may conflict with each other" (Edwards and Hulme 2002, p207).

The second issue, relating to having open decision making and especially relationships, is where some organisations in the study were struggling. Note how closely these two quotes, one from the workshop, and one from the literature correspond.

"Some NGOs have even, themselves, at the initial stage, [decided that] one person is overall. The board has not been set up, and if it has, it has been hand picked" (Workshop2: 130)

"Many NGOs have a largely invisible board comprising a small coterie of friends and family, assembled by the founder(s), merely for the purposes of meeting statutory requirements on paper. The actual functions of governance are carried out by the founder(s), with or without the help of other staff in the NGO, and the board merely acts as a 'rubber-stamp'." (Tandon 2002, p216)

This accusation could clearly be levelled at least two of the support groups in this study, as well as some NGOs, in which there had clearly become a founder/leader who was largely responsible for shaping and running the organisation.

"A key issue in the arena of governance arises in situations where the founder is the leader of the NGO for a substantial period of time. By its very nature the NGO begins to reflect the vision and perspective of its founder; its culture and programmes imbibe the style and background of the founder too. Over a period of time, the NGO's identity becomes very closely linked to the person of the founder-leader. In such situations, the board is initially assembled by the founder, and most board members are individually known to and associated with the founder-leader. This has the potential to limit the autonomous identity of the board... On the one hand the founder-leader provides the bulk of the energy and ideas for the NGO, thereby building up 'sweat-equity'; on the other hand, the long-term sustainability of the NGO requires the institutionalisation of energy and ideas beyond one person." (Tandon 2002, p219)

However it is important to balance the problems associated with such an undemocratic approach to hand picking management relationships with the benefits: "Such a situation clearly provides the founder(s) with the ease of pursuing his or her vision with speed and energy, unencumbered by the usual hurdles related to paperwork and bureaucracy." (Tandon 2002, p216). This echoes exactly the perceived benefits of NGOs in general over the state. One should not be too quick to berate the energy, enthusiasm and hard work many NGO founder/leaders have contributed to the landscape of HIV/AIDS, especially as many of these people at the same time were also innovators in being openly positive with HIV. However these organisations also seemed to be struggling more than others, perhaps partly as over time their flexibility is compromised. Fukuyama (2001) suggests that trust and social capital between leaders of groups and NGOs can be strong enough to become exclusionary to other members of the organisation or the wider public. Perhaps this has occurred in this case because of the lack of trust or social capital in the wider network, illustrated by the example of poor governance in the COCEPWA organisation shown in Figure 7.5.

Where there is a breakdown in relationships between donors, the state and civil society, it may be that each facet of the network becomes more insular as a protective measure:

Figure 7.5: COCEPWA: A case study in collapse

The Coping Centre for People With AIDS was founded in Gaborone in 1999 as a drop in counselling and advocacy centre for people living with HIV/AIDS, which grew quickly and opened centres across the country. The organisation became a powerful lobbying force for the rights of PLWHA, and advocated that members try and overcome stigma by going public with their HIV status. They were extensively involved in providing peer support, training in public speaking, capacity building, public awareness, counselling and establishing a 'buddy programme' partnering newly diagnosed members with a trained 'buddy' who provided encouragement, support, and help with ARV adherence. COCEPWA created a strong community among PLWHA which provided hope, empowerment and a sense of purpose. Funding was provided from ACHAP, NACA and others including the Bristol-Myers Squibb foundation, including support for large and ambitious programmes. However, despite employing many skilled paid members of staff, financial accountability was allowed to slip, possibly in part due to an undemocratic culture of leadership. The organisation was involved in serious financial mismanagement scandals, which led to a lack of confidence from donors and a freeze on funds. Branches and the head office were officially closed, some as early as 2004, but dedicated volunteers have kept some centres open even without any formal assistance.

The circumstances of irregularity were extremely controversial, and blame was levelled at the government and the board and founders of COCEPWA, and highlights the effect of poor governance at any level on the sustainability of organisations and trust in the donor community. The repercussions were still apparent, the government publicly stated that the incident led to a reduction in general support for HIV/AIDS NGOs, and trust between all donors and NGOs has suffered as a result. This example graphically illustrates the importance of good governance and trust in a network, and how a vicious circle can reduce the strength and effectiveness of formal support networks. However, COCEPWA left behind an important legacy: many support group leaders today were trained at COCEPWA, and it was clearly an important motivator for many PLWHA, and the model for many current interventions at support groups, home based care and advocacy programmes

- based on interview with former COCEPWA employee, fieldwork and local newspaper cuttings

the cliques become tighter, and as an unintended consequence, leadership becomes more exclusionary and less democratic. Similar cliques form in networks where societal prejudice against homosexuals forces them into tight groups of trust (Sullivan and Leong 1995), or exclusionary cliques in businesses due to strong ties between a few individuals that can exclude new ideas and criticism (Edelman et al. 2004). This illustrates another part of the breakdown of networking, where trust and respect is lost, networks can fragment and divulge, affecting communication and integration, and leading to strong leaders dominating in parts of the network. This certainly seemed to be the case after COCEPWA collapsed, cliques had formed between former members and groups affiliated to COCEPWA. Trust in NGOs across the whole network was diminished, and correspondingly co-operation between NGOs and the government.

One other example of a support group network collapsing was observed during the fieldwork period, again in a case where a large organisation ran several support groups, but funding problems at the top level of the organisation filtered directly down to the local groups. Several of these small groups were subsequently shut down due to lack of resources, and an inability to pay wages. In this case there was clearly a lack of networking and trust between some of the local groups and the head office; for example

the employees of the group were dismayed to receive the news that their group was to be closed by fax, rather than face to face discussion. However, there is evidence that communication in the network had obviously been strained for a while. People involved in the group had suspected their office would be closed for some time, due to informal information and rumours that came from the wider network. Here, when formal channels of information had dried up, participants had used wider informal networks to replace the information loss, and accurately assess the health of the organisation. This demonstrates how networks can be flexible, and compensate for the loss of one part of the network by relying more on other wider links. It also shows that governance issues impact throughout the network, and it is important to consider the causality of these flows. For example, poor governance in securing the sustainability of the national organisation after funding for one project expired, had an impact on the local groups, that even when well governed, could not be mitigated against. The situation and impact on the network was the same between this organisation, even if the root problem was lack of forward planning, not direct financial mismanagement. Yet again, the same slow death was observed as with the COCEPWA groups, former employees volunteered their time to keep the groups running, or at least gradually wind down services. It was clear from participant observation that the work in providing support to PLWHA was not being done purely for money, people gave their time freely for as long as they could before their own needs necessitated finding other sources of paid employment.

Mitchels (1915) argued that leaders and their organisations inevitably tend towards oligarchy, although his study was on socialist groups in the early 20th century. Uphoff (1995) suggests that one can see leaders of grassroots organisations as being in a similar situation, as far as they would be comprised of members of the 'lower classes' who through gaining a first taste of power and prestige, are reluctant to release it. Yet Uphoff (1995 p21) himself finds counters to this argument, and it seems that 'oligarchy' NGOs have appeared in Botswana regardless of background and privilege. Yet even if Lord Acton's (1887) maxim "Power tends to corrupt, and absolute power corrupts absolutely" is true, there must still be a level of governance, in the form of checks and balances, and crucially observers of those procedures, and ultimately repercussions to prevent abuse. These are the last two issues from Hulme and Edwards (2002, p194), and it seems that some of these problems had been recognised by some participants. "Somebody tried to hand pick the board members. What is that? When you look at the constitution, it says the board members must be picked by the AGM" {Workshop2: 165}. It is not clear if any challenge had been made about this, but if so it seems to have been brushed aside. More likely is that members of the NGO and PLWHA communities had not raised such issues loud or high enough. "We have raised complaints with BONEPWA, with BONASO, but... have we gone beyond those two organisations? Because BOCONGO is the overall!" {Workshop2: 261}. One participant felt that responsibility for this inaction lies with the NGO or PLWHA community. "We will still be pointing fingers at ACHAP and NACA, and it is us! Us who should be blamed!" {Workshop2: 175}.

There is an interesting cultural point here; that in general, Motswana are rarely vociferous protesters, they tend to prefer non-confrontational discourse. Two examples illustrate this. Renwick (2007) describes Motswana in a slightly patronising way. "polite 'personality' (placid, undemonstrative, unwilling to display open displeasure)" of Tswana people, "epitomised in a peaceful, non-violent approach to attaining independence" (Renwick 2007, p146). The other example, mentioned previously in this chapter is the reaction of the health minister to the protest at World AIDS Day in 2006, who said that the interruption was inappropriate, as Motswana are supposed to be 'well-mannered' (Guardian, 8/12/06). Workshop participants agreed that during two recent

controversies, where the government had removing food basket subsidies and stated that PLWHA should not be allowed to have children (a crucial reproductive rights issue) they had not spoken out {Workshop2. 266-277}. A suggestion made by the researcher that PLWHA should have been marching in the streets over these issues was met with laughter. This is an important cultural difference, especially considering the very public outcry by gay men over inaction on HIV in North America in the 1980s, a difference that may weaken the ability of civil society in Botswana to put pressure on government or NGOs that are failing to meet their needs, and hold them accountable.

7.9 Conclusions

This chapter has shown the way networking can assist or hinder the provision of services for PLWHA in Botswana, and in general seems to have painted a bleak picture of a lack of co-operation. The reasons for this are many, and it is not clear whether the problems are endemic to the donor/civil society network in general, or the result of certain instances of poor communication or governance. Yet it seems more likely that echoing Seckinelgin (2006), the whole system is actually tightly incorporated, even dependent on other actors, and it is not possible or productive to see fault at one place in the chain. Rather the research has shown frictional surfaces in the ties between organisations which hinder communication, and lead to mistrust, poor governance and an eventual restriction on the supportive services offered to PLWHA.

Yet it should be considered that some organisations, although acting undemocratically, are not automatically acting for selfish reasons: each case must be considered to assess whether the leaders or board are still following their mandate to serve PLWHA. It is especially impractical with small groups of a few people who are often also close friends and comrades to impose democratic structures, but if these groups grow, a system of governance may be more difficult to set up later. BONEPWA guidelines for new support groups require a constitution and structure of officials before they can be registered. It is also worth noting that a majority of NGOs and support groups have been functioning without problems arising from governance, and while allegations of corruption are damaging to the whole network, they are a rarity and not the norm in Botswana. Yet the issue does illustrate the interdependence of organisations in a global network, with effects manifesting at all levels. The data collected here echoes comments from Edwards and Hulme (2002b), who argue that many of the problems with accountability and performance are related to the difficult position of NGOs. They frequently have a broad mandate, and are often made more to be accountable to international donors than the community they are supposed to serve. Yet many donors and larger NGOs noted that there was a lack of skills and training in governance and management, and were taking steps to address the problem. For example BONASO was providing training on governance targeted at committee members of NGOs and support groups {BONASO. 37}.

Informal networks of support, for example friends and family, no doubt suffer from their own problems in networking. Yet in the formal sphere of donors, government and civil society, there is evidence that a great potential flow of resources is being held back due to a serious lack of networking and trust. This also has a direct impact on the support at the level of the providers, since more burden is likely to be placed on carers, and the structured support services are stretched. Yet the will to co-operate and network is strong, and since it is the common opinion of both donors and recipients that networking needs to be improved, investing in facilitation and relationship building

through formal network structures might actually represent a more effective use of resources at this stage than direct service provision.

Chapter Eight

Conclusions

8.1 Introduction

This thesis set out with the aim of investigating social support at both formal and informal levels for people living with HIV/AIDS (PLWHA) in the Botswana field sites. It postulated that support could be conceptualised as a network operating at multiple levels, and suggested that people would get support from a number of different sources. Support was conceptualised in terms of three levels, individual, community and institutional. Four key questions were formulated to guide the investigation,

1. Identify the main sources and forms of support for people with HIV/AIDS in the study areas
2. Examine the current role and functions offered by support groups, how users experience them, and how support networks are evolving
3. Explore the needs of persons on ARV treatment, and how these needs are met by formal and informal methods of support
4. Explain the variance in objectives 1-3 along lines of social difference: e.g. gender and location, from which appropriate support strategies for people on ARV treatment can be formulated

This last chapter will demonstrate how the thesis has answered these key points in turn, then pull the threads together and demonstrate how the results represent a new contribution to the wider literature on social support for PLWHA in sub-Saharan Africa. Limitations with the fieldwork and data will be discussed, and the success of the methodology will be assessed. Some implications for national and international policy on HIV/AIDS will be introduced, especially on the importance of providing suitable support systems for PLWHA in the era of anti-retroviral treatment, and how networking between government and community based programmes can provide efficient service delivery. The research will suggest that many new questions have been opened up by the

research, and outline further avenues for study and investigation.

8.2 The structure of support

The framework of the thesis aimed to examine social support as flows in a networked system, an approach which it was hoped would show the complexity of links in the network, and also that support is multi-directional, comprising a more complicated dynamic than just being from provider to receiver. These issues revolve around the structure of support, especially, if it could be described as a two-way flow, where people use many overlapping spheres of support, suggested by theories developed by Fukuyama (2001) and Slineiderman (2004). At the individual level, the instances of support recorded in the data suggests that there is certainly a two way flow of support, with participants registering slightly more instances when they actually gave support than received it. This is demonstrated in chapter 6, through logging the instances of support listed in diary entries, and the opinions expressed by focus group participants. Officials in interviews also saw well trained PLWHA as a potential source of support, as well as being recipients. People relied on many different sources of support, and results clearly indicated that this wider approach to studying support is essential to develop an accurate picture, since individuals had such varying experiences with the same sources of support. Surprisingly, support from families was shown to be less common than the literature would suggest, and participants received support from individuals such as friends and neighbours, as well as institutions including support groups. The narratives collected from the focus groups and diaries, provide a richness to the data that shows the complexity of the network for individuals, where an individual family member or friend can be a negative influence, or a pillar of support. The unique approach of the study in examining multiple levels of support, reveals that a focus on the immediate family as caregivers, while an important effort to recognise the stress caused by epidemics on female family members (eg Kipp et al 2007) may be missing the large contributions made by the wider community and close friends, a finding echoed in some studies in Western contexts (Turner and Catania 1997), but rarely in the literature on sub-Saharan Africa. Other studies have not shown the divisions in the use of support for PLWHA shown here, but the variety of support expressed makes it clear that any approach which solely examines family, friends, or formal services, would exclude the wider picture of many people who have been stigmatised by that source of support.

At this stage, it is possible to address questions 1 and 3, what are the needs, sources and types of support for PLWHA in this study? Focus group discussions extensively covered types of support, and illustrated a very different mix of needs depending on each group and its location. As Chapter 5 suggests, groups have different approaches to support, especially as to the balance of practical and psychological assistance. Certain groups, where respondents were able to meet basic needs such as food and money, focused on providing love and counselling, while others provided regular meals and income generating projects. Clearly the support groups are flexible, and meet different needs of their members in different locations and circumstances, a finding which begins to engage with question 4. This has been a major contribution to the literature, since there is so little research currently focused on the role of support groups. At the very minimum this research has demonstrated that, at least for their members, they offer very important support, of a both physical and psychological nature. Yet they are also shown to be important community educators, going out into the public and raising awareness of the risks of HIV: an extremely noble and selfless cause. Considering their proliferation across sub-Saharan Africa, where they are arguably providing more

services for members than the well researched support groups in Western settings, this thesis acts as an urgent call to increase the empirical research into support groups as they have the potential to become indispensable partners in tackling HIV epidemics. The research has shown they provide long-term practical and psychosocial support for PLWHA, provide home-based care and regular check-ups more often than many stretched formal services can, ensure patients adhere to anti-retroviral medication and help prevention efforts in the community.

Question 2 also asks about how the networks of support are evolving, an area which was shown to be a much bigger issue than initially thought during the course of the fieldwork. Chapter 7 shows how the formal network between donors, government departments and community organisations had deteriorated during the fieldwork period. Local groups were sometimes competing rather than co-operating, and a few isolated examples of mismanagement, at both official and local group levels, led to a breakdown of trust between donors and recipients. This level of trust is critical, and challenges the general literature on donor and CBO partnerships which suggests that power is always from donor to recipient (eg Lister 2000). The relationship was usually more complex, with donors dependent on reports on successful use of their money to operate, hence respect had to be mutual, and was often lacking. Participant observation, witnessed groups collapsing, and directly illustrated the effects that the global network has on community groups, challenging the approach to examine networks of influence at three bounded scales of the individual, community and institutional. This possibly raises a weakness in the research approach, since there was little attempt made to study networks at the international level. However, these global networks had a very visible impact which was observed and examined during the study, and the institutional interviews revealed great insights into the influence of the global networks on Botswanan organisations. As Marston et al. (2005), Escobar (2007) and others have noted, it is limiting to examine scale in rigid hierarchies and it is not possible to clearly draw a line between them, since the local and the global have strong influences on each other. Power and resources in the network were examined as a two-way flow in a wide landscape, often impeded by frictional processes. This addressed some of the weaknesses in traditional network theory where flows are 'unfettered' and based around the analysis of hierarchical scales.

Many interviews with formal service providers noted that governance was a problem for some community based organisations, a finding which is in line with the critical literature on NGOs and CBOs (eg Kamat 2004), and was illustrated by the unsustainability of several organisations during the fieldwork, including some umbrella NGO bodies. However two positive points need to be made in this context, first that most organisations still have useful informal links, and that a majority of organisations are functioning well without the support network, although it is clearly hindering efficient service delivery. Even the problems with organisations demonstrate the importance of networks, since when they are weak, there are clear knock-on effects. Part of the strength in the network approach was to show similar issues occurring at separate scales, for example difficult relationships between some family members and participants, as well as between certain organisations, which in both cases restricted support. Funding also had impacts independent of scale, as poor governance in organisations at the national level and donors at the international level affected support in the whole network. When corruption in one community organisation can cause an international donor to cut or redirect funds internationally, it is clear that the local and global scales are multi-directional, interdependent and fluid.

To address question 4, support groups members were found to be mostly middle aged women with no reliable source of income. The gender imbalance was discussed in some detail in Chapter 5, and it was postulated that women sought support more than men for a variety of reasons: women were more affected because they are more likely to be caregivers, women were better at using health and support services in general, and they tended to have lower income than men, so were more likely to need the food and financial support the groups offer. The age range varied much more between groups, most had few people under 20, although the presence of the Centre for Youth of Hope (CEYOHO), an organisation that runs services targeted at young people, may suggest that most young people use these groups instead. The groups with younger memberships seemed to have a more outward focus, emphasising peer education through drama and other outreach activities, while older people seemed to have more psychological and day to day needs met by the group. Yet all these examples show that support groups are flexible and adapt to the needs of their clients in each area, exactly the role that NGOs would be expected to play, as partners with the less adaptable and more general state services (eg Risse 2002).

The difference between the urban and rural sites was much smaller than anticipated at the start of the fieldwork, and contradicts studies in other contexts where support for PLWHA shows a marked difference between urban and rural locations (eg Del Casino 2004). The activities and needs of the group and its members were broadly similar in both locations, although the rural group was much less networked with other groups due to a more isolated setting, but had a much closer relationship with the local government services. Needs of PLWHA in the urban and rural sites seemed fairly similar, support groups placed a similar emphasis on income generation, food provision, counselling and doing community outreach. The major difference was the more independent operation of the rural group, which without a network of other organisations and network bodies to assist them, started things themselves, and were more pro-active in seeking advice or support when required. This shows that groups can adapt and use the resources and partnerships available to them, and several examples suggested that it was mostly when sources of support were removed that dependent groups had difficulties. However, it is important to note that the research only studied a very small sample of groups in depth, so further research is needed to assess these differences, especially between urban or rural support systems.

The research has made a considerable contribution to the understanding of support networks for PLWHA in Botswana, where it has shown that many people rely on these networks at different levels, but as detailed in Chapter 7, there are serious consequences when partnerships fall apart. It has also shown the important functions that support groups in Botswana have in educating the public about prevention and reducing stigma, as well as providing adherence counselling, psychological support and material assistance for PLWHA. This is the first study to focus on support groups in Botswana, and also the first to address social support here at both the institutional and community level. It also suggests that the ARV programme in Botswana is working, since social and practical needs seem to be bigger issues than seeking medical treatment. Thus there needs to be a corresponding shift to provide long-term social support, or measures which can increase the independence of PLWHA. This should be an important lesson for other nations, encouraging them to adopt their own ARV programmes, and to consider how a shift to long-term support is needed. At an organisational level, the research suggested that the potential for more formal co-operation between groups was hindered by a lack of resources in the network bodies that were charged with facilitating group communication, and that at an even higher level there were some instances of a

lack of communication between donor bodies and community groups. Hopefully the findings can influence policy makers to better understand support groups as strong partners in service delivery, and emphasise the need to support co-operation and networking efforts to ensure efficient provision of services.

8.3 Contribution to the literature

One of the great strengths of health geography research has been how much it has drawn methods and approaches from a wide range of social science disciplines (Litva and Eyles 1995), a practice which this thesis has certainly taken up by including elements of social networking, ethnography, and an experience centred approach to studying health systems, which goes beyond the medical and includes the social and psychological side of epidemics. It especially tries to engage with the support system in terms of pluralities, showing that support systems, just like health systems, need to be considered not just as spheres of public/private space as Milligan (2000) has suggested, but also formal/informal and government/community assistance. The research has shown that these spheres are not clear cut, and that it can be productive to examine the whole system to show how people use many different sources of support. This is an extension to the concept of the landscape of care as used by Conradson (2003) and others, to recognise the complexities in the use of multiple spaces and sources of care and support.

It is hoped that the social network approach is a useful innovation in the health geography and geographies of care literature, and it should be applicable to many other settings, especially health service delivery in resource limited settings, but also for systems in developed countries. Especially when social research is increasingly focusing on social capital research, it is important to note that other frameworks can be more applicable to certain contexts. There is certainly evidence that social network research is regaining popularity (Carrington et al. 2005) and this thesis is proud to contribute to that field, especially as a new approach in both HIV/AIDS research in geography and development. Important developments were made to classical social network studies, integrating them with contemporary literatures on the geographies of scale, and globalised processes. Here, investigating support in terms of networks showed a range of functions and issues that would not otherwise have been revealed, and allowed them to be conceptualised in ways that were also clearly comprehensible to participants. Social network approaches have been successfully used to study the spread of HIV infections (eg Rothenberg et al 1998), perceptions of risk in prevention efforts (eg Helleringer and Kohler 2005) and this investigation adds to the literature the possibility to use networks to study support for those already infected.

In terms of a contribution to the general HIV/AIDS literature, there are several key areas covered, re-addressing the balance towards investigating the livelihoods of PLWHA rather than focusing on HIV prevention, and even working directly with PLWHA to research support, rather than focus on organisations or caregivers. The research also shows there is no clear distinction between caregivers and receivers in this context. Literature on care for caregivers is abundant, but there is little showing these reciprocal relationships of support, even though some have shown that giving back support is important to prevent people feeling dependant and a burden to others (Lewinter 2003)

Much has been contributed to the literature on institutional networks of NGOs and civil society, reinforcing and expanding the social network approach to organisations outlined by Kilduff and Tsai (2003) where relations between organisations are seen as fluid multiplicities, and that individual actors can have a strong role in creating and maintaining network ties. This thesis has not used quantitative attempts to measure networks, nor created traditional network diagrams, but the success of applying a qualitative approach to network analysis is significant, and it would be interesting to see it applied into other areas. In this respect it represents something of a hybrid between social capital, actor-network theory and social networks, where the focus is on the interconnected actors, not just a one dimensional view of a network. This is potentially a fertile and challenging approach that can be applied to research in other fields, especially in wider public health issues. However, it should also be noted that the ethnographic approach was important to understand the context of the study, and greatly strengthened the conclusions drawn from each method.

The multi-method research design worked well in meeting the needs of the research questions to examine both formal and informal support, and the combination of diaries, focus groups, participant observation and semi-structured interviews engaged with the individual, community and institutional levels respectively. This approach to cross-cutting data collection, linking the intentions of service providers, the experience of groups of affected individuals, and then a detailed self-written sample of individuals in the diaries, recording and validating instances of support over a period of time, could certainly be recommended for other public health investigations. It should be applicable in the investigation of other long-term illnesses where patients are still able to actively participate in support systems, such as multiple-sclerosis or cancer, in developed or developing contexts. Perhaps even wider than this, one could visualise using this comprehensive networked support approach for evaluating bereavement services, youth offender interventions, or assistance for people with mental or physical disabilities. These are all systems where participants are likely to get support from many different formal and informal sources, and there may also be an element of stigma which prevents individuals from using one particular source.

Diary methodologies are also bolstered from this research. Already a popular and growing research tool (eg Meth 2003), this research made a valuable contribution by pairing them with focus group methods, a partnership which showed participants as individuals and actors in a networked support system. It demonstrated their successful application in Botswana, and described a method where verbal diaries could be kept by participants using cheap digital voice recorders, an innovation which proved unnecessary. The diaries validated, and sometimes contradicted opinions expressed in group discussions, and added a time dimension, showing many instances of support, and potentially how the system changed.

While certainly not an innovation in research methods, the ethnographic approach of volunteering with community organisations for many months, proved a fertile source of information, and was probably essential in gaining trust and getting the honest, outspoken and detailed comments which made the data so rich. Participant observation in particular provided valuable context and insights, and researchers are increasingly engaging with and spending time understanding the people they research, (eg Bernard 2000). Just as with the participant diaries, the research journal added a temporal dimension to the research, showing changes to groups over time, and with examples such as the collapse of groups, created an ability to separate trends from one off occurrences

Lastly, conducting a workshop with all participants proved an extremely fertile source of information, especially since donors and recipient organisations seem to have so few opportunities to interact. This could be seen as being action-oriented research (Reason and Bradbury 2001), as it facilitated the very networking that the thesis was examining. Although this was certainly not the intention at the beginning of the project, it was only during this workshop that participants commented that they had few such opportunities to meet. Again it was not intended that the workshop on support groups for PLWHA Week 2006 would turn into a group protest against neglect of PLWHA on World AIDS Day. Both these examples merely illustrate the power of networking, and the effectiveness groups can have when they work together. Demonstrating this point like this may not have been planned, but was certainly a compelling example.

8.4 Further research and the wider picture

This research took a novel approach, putting an emphasis on group as well as individual responses. There was no quantified demographic profiling of individuals, and a study which took this approach would be valuable to provide more insights into the different experiences and needs of people from different groups, and even within different groups. It was hoped that the COCEPWA study (COCEPWA 2001), a questionnaire investigating the needs of dozens of PLWHA attending a support group drop-in centre, would provide this level of background to be integrated with the study, but since the organisation had effectively shut down before the fieldwork started, it was not possible to engage with this group and create a comparison with their members. However important questions about the group dynamics remain, for example, were the respondents who felt that love and caring were the most important type of support wealthy enough that they had basic food and shelter needs met? Or did these people just have a greater need for psychological support?

As previously stated, support groups are worthy of much more empirical research, and while the multi-level investigation provides a good discussion of their importance in the overall landscape of care, this is of course only for a limited part of one small country. Here the impact of support groups was restricted by a perception that most people did not understand the benefits they could offer, but is this true in other countries? Do support groups have different roles in other areas? It would be interesting to see whether in regions where anti-retrovirals are not available, the role of support groups differs. Are they less important to PLWHA when they cannot even get medical treatment, or are they actually more important, because the situation is so stressful? While there is more research beginning to examine the role and successful attributes of support groups for PLWHA in sub-Saharan Africa (eg Fanelli et al. 2008, Visser and Mundell 2008), empirical research addressing these broader questions is still warranted. Being able to balance the social and medical needs of PLWHA is essential, especially as recent evidence demonstrates many other countries in sub-Saharan Africa are rolling-out ARV programmes, but are yet to achieve full coverage (eg Nattrass 2006). Thus in many countries, support mechanisms, including support groups, will have to be able to simultaneously cope with the needs of people with and without access to ARVs. The findings from this thesis should be able to guide other countries to ensure that they meet the social needs of PLWHA, especially highlighting some of the issues in building partnerships between the community and government sectors.

8.5 Limitations and further investigation

There are obvious opportunities to expand the research, especially considering the deep qualitative nature of this project which investigated a relatively small number of individuals and organisations in great depth. In particular, the use of only two field sites in one country, while necessary to fit the research design within the budget and time-scale of a PhD study, greatly limit the ability of the research to apply more widely to a wide group of PLWHA. This is even true within Botswana, since the study looked at areas which were dominantly Tswana, and did not fully represent other ethnic groups. While the support group workshop did contribute a sample of groups from across the country, it was not in the level of detail that the long-term relationships with the main groups provided. This research also does not reflect the experience of PLWHA in countries where there are different levels of formal support structures. Being able to draw a comparison across contexts with varying availability of official support and ARVs would show better the relative importance of different sources and types of support, and facilitate the creation of guidelines to develop and assist support structures for sub-Saharan African countries as they roll-out ARV treatment.

Again, it would be useful to have a comparison of network structures for support mechanisms in other countries. South Africa, Uganda and Zimbabwe for example also have network organisations for AIDS service organisations and support groups, and it would be interesting to compare the challenges they face, as well assess any different approaches to communication and cooperation they may have implemented. This research also paid very little attention to international networks. Some organisations had international links and assistance, especially church based groups, and this could be another interesting avenue for investigation using network analysis that would complement the research design by adding an international level.

As can only be expected in a project of this nature, some of the fieldwork did not go as intended, and there are clear limitations to the research, especially the smaller than anticipated number of support groups who participated, which limited the number of focus groups. This was largely due to the unexpectedly high failure rate of groups, which is out of the control of the researcher. In retrospect it would have been wise to increase the initial number of groups recruited so that should several collapse, there were still enough remaining for the research. However this was difficult to achieve considering the long period of time that it took to earn the trust of groups, indeed two groups collapsed after considerable time input, but before research with them was completed. It is hoped that the respectful and engaged participatory approach taken here will help the reputation of researchers in Botswana, and facilitate the success of further research projects.

Confidentiality issues also limited some of the scope of the investigation, and especially some of the final discussion, due to the importance of protecting the names of groups, and by inference, the major players within them. It prevented the thesis from identifying individuals who had contacts between support groups for example, as even if pseudonyms were used, within the tight circles of the groups, it would be possible to identify the individuals by their associations. This also prevented including details about individuals that might qualify their comments in diaries or focus groups, by saying that a particular comment came from for example a woman who used to belong to another group. The networks were small enough that details like this could allow other groups to identify individuals. It was difficult to write the thesis so that anyone involved in the project can read it and not identify officials or individuals by their comments or

association, as this could potentially cause conflict. The researcher was keen to keep in the more controversial discussion points, for example the collapse of groups and problems in relationships between some community organisations and government departments, which is an important part of the networking process. However it was important that the research not exacerbate the situation by providing fuel for comments that could be attributed to any particular group or individual, considering that the research permit stipulates that copies of the thesis must be sent to the Government and University of Botswana.

8.6 Final Summary

In conclusion, the landscape of care and support for PLWHA is complex and multifaceted. People obtain a wide variety of social support from many different places, often using individual, community and institutional sources in a wide network of care. Individual experiences and use of support varies considerably, but the multi-level nature of support allows for redundancy, so that, at least for PLWHA with strong network links, there are always other avenues for assistance. These ties are frequently bi-directional, with individuals both receiving support, as well as giving it to others when they are able. Organisations providing services to PLWHA also exist in a complex network of institutional support, in which information, funding and services flow back and forward

This research has taken a broad definition as to what constitutes support, and who acts as providers, an approach which has been justified by the results finding support links at all levels and from many different and unexpected sources. While the smaller, in-depth approach to data collection makes it difficult to justify applying generalisations to all PLWHA in similar situations, it is at the minimum strong evidence that support must be considered as a complex networked system, to which there is not one important source or service that can satisfy the disparate needs of PLWHA. It is also a warning to service providers and governments about the importance of networking, and the problems that arise when organisations with the same aims become competitors instead of co-operators. To properly address the needs of the increasing numbers of PLWHA in sub-Saharan Africa, new research must ensure it studies all levels of support, for both individuals and organisations, and visualising these functions as networks is a strong framework to tackle the social problems of this epidemic.

Appendix

Appendix (i)
List of cards used in participatory exercises

Sources of support

- λ church
- λ hospital / clinic
- λ home based carer
- λ social worker
- λ friends
- λ family
- λ husband/wife
- λ other PLWA
- λ government organisations
- λ NGO's
- λ library
- λ chief / local council
- λ support group
- λ newspaper / radio / tv
- λ telephone
- λ internet
- λ play / performance
- λ counsellor
- λ traditional healer
- λ buddy scheme

Types of support

Medical: wellness

- 5 Medical advice / information
- 6 ARV
- 7 pain control
- 8 nutrition
- 9 opportunistic infections
- 10 cleaning
- 11 dressing wounds
- 12 medical supplies
- 13 CD4 count tests
- 14 check ups
- 15 VCT
- 16 traditional healer
- 17 condoms
- 18 physiotherapy
- 19 herbs and special foods

Practical: self-sufficiency

- 5 financial help – advice or money
- 6 accommodation
- 7 income generation
- 8 legal help
- 9 food
- 10 child care
- 11 housework
- 12 transport
- 13 wills
- 14 childcare – bigger issues with children / pregnancy

Psychosocial: self worth

- 6 counselling
- 7 someone to talk to / listening
- 8 peer support
- 9 emotional help
- 10 advice / information
- 11 advocacy / lobbying
- 12 self worth
- 13 love / caring
- 14 respect
- 15 training
- 16 sticking up for me
- 17 fun / laughing
- 18 negatives as well. people being impatient / angry / ignoring me...
- 19 palative
- 20 hugs / touching
- 21 rest / relaxation
- 22 diaries / memory books
- 23 spiritual needs
- 24 education of those around / individuals
- 25 safe sex education
- 26 distraction - something so you forget about it
- 27 sport / cultural activities / singing / dancing / music

Appendix (ii) Key questions used in semi-structured interviews

Support

What key services do you run that offer support for PLWA?

What types of support do you offer?

- 28 Medical
- 29 Testing
- 30 Legal
- 31 Food
- 32 Training
- 33 Financial (for groups or individuals)
- 34 Information
- 35 Advice
- 36 Palliative
- 37 Peer support
- 38 Counselling
- 39 Home based care
- 40 Drop-in facilities
- 41 Other .

What other activities do you co-ordinate?

- 20 Funding projects
- 21 Group co-ordination
- 22 Advocacy / lobbying
- 23 Consultancy / research
- 24 Producing publications
- 25 Educational programmes
- 26 Fund raising / Income generating
- 27 Poverty reduction

What are the key aims of the support that you offer?

Who is the support available to? How is it promoted?

Services

- >What do you consider to be the most important service that your organisation provides?
- >How long have your services been running? How long will they run?
- >What services do you plan / would like to offer in the future?

Needs

- >What do you consider to be the most important needs of PLWA?
- >How do you assess the needs of your clients?

Impact of ARV

- >How has the availability of ARVs changed the support you offer / perceive as needed?
- >Has your organisation made specific changes to service delivery in response to ARV availability?
- >What has been the biggest change ARV's have made to the services your organisation provides?
- >How do you feel other organisations have adapted to the ARV era?

Sources

What are your key sources for.

- 15 Funding
- 16 Information
- 17 Recruitment
- 18 Awareness of the organisation / its programmes

How much do you rely on **other** organisations for the above?

How much do other organisations rely on **you** for the above?

Which of these do you have the most/least trouble sourcing?

Networking

How closely does your organisation work with others?

- >Which organisations do you work closest with?
- >Do you work with other organisations to deliver services / key events?

How much does your organisation rely on other organisations to carry out its objectives?

- >Does your organisation rely on other organisations for day to day operation?
- >Has it received information/training from another organisation it could not do without?

Do you feel that HIV/AIDS service organisations in Botswana work well together?

- >How could these organisations work together more effectively?
- >Does your work duplicate that of another working in the same area?
- >Are there organisations or institutions which hinder your work, or diminish your sources?

Do you feel that you are aware of most of the relevant organisations in this field?

- >How do you mostly hear about other organisations, and their successes/failures?
- >Would you say that your organisation is able to learn from projects run by other organisations?

Appendix (iii) Service provider consent form

**Formal and Informal Care and Support for
People Living with HIV/AIDS in two sites in Botswana**

A PhD research project co-ordinated by Daniel Turner in collaboration with
the University of Sheffield, UK and the University of Botswana

Organisation Consent Form

**I state that I have freely given consent to be interviewed for the study, that my
comments will be anonymous if I request it, and that I can withdraw my comments
at any time before the report is published.**

Signed:

Print Name:

Position:

Organisation:

Date:

Electronic

Paper

I wish to receive an copy of the provisional and final report

I wish to receive an electronic copy of the full thesis (due 2008)

**Please provide delivery details
including an e-mail address:**

Please keep this copy:

**Formal and Informal Care and Support for
People Living with HIV/AIDS in two sites in Botswana**

A PhD research project co-ordinated by Daniel Turner in collaboration with
the University of Sheffield, UK and the University of Botswana

**I state that I have freely given consent to be interviewed for the study, that my
comments will remain anonymous if I request it, and that I can withdraw my
comments at any time before the report is published.**

Any queries, please contact Daniel Turner:

Signed:

E-mail: **D.Turner@sheffield.ac.uk**

Mobile: **(+267) 72 51 87 91**

Department of Geography, University of Sheffield,
Winter Street, Sheffield, S10 2TN, UK

#	Time	Speaker	Comment	Summary	Key themes	Codes
127	00:37:08	Respondent 2	The other thing is that if I am HIV positive and I am being taken care of by my family, they understand me much better than anyone else, they know what I need and what I don't need. They also know what they are supposed to do for me, and what they are not supposed to do for me unlike if they were to hire someone else to come and take care of me without understanding me as a patient so family are the ones who are supposed to be there for me at all times.	The family understands the person better than someone that was hired to provide care, and should be the ones to look after them	Care, family, needs, support, hired, help, time, understanding, duty, role	NetVID, Sppt, Nds, Srv, Kee
128	00:37:37	Respondent 5	Even with adherence, you know, a family member is someone who is the immediate supporter because whenever I forget to take my treatment, that person would be there to remind me of the times that I have to take my medication other than having to hire any member of the community who would be staying on the other side of the village, take for instance Tlokweg. So it's important to have someone immediate.	It is important to have immediate care from a family member. for example to remind about adherence	Medication, adherence, family, assistance, support, drugs, medication, ARVs	ARVr, Sppt, Nds, NetIND
129	00:38:06	Moderator	Okay.			
130	00:38:07	Respondent 4	But it's different with other families. Others would stigmatise you after you have disclosed your status. Sometimes it's difficult for them to understand.	Some families can stigmatise people living with HIV	Family, stigma, stigmatise, status, understanding, problem	Frct, NetIND, Sppt, Kee
131	00:38:18	Respondent 5	They need to be empowered.	Families need to be empowered	Family, empowerment, awareness, education	Frct, NetIND, Comm, Info
132	00:38:20	Respondent 4	For instance, my grandmother is always telling us that we have contracted a youth's disease. Even if we try to explain to her that not only the youth contract this disease, she always defends herself by saying that she won't contract it. She totally does not understand.	One grandmother believes only young people can get infected with HIV	Infection, transmission, knowledge, awareness, family, elderly, grandmother	Frct, Inf, Comm, NetIND

Appendix (iv): Example of coded focus group transcription

Appendix (v) Participant consent form (Setswana)

Tlhokomelo ya semmuso le e e seng ya semmuso ya batho ba ba tshelang le mogare wa HIV/AIDS mo mafelong mangwe a a mebedi mo Botswana

*Patlisiso ya PhD ya ga Daniel Turner
go tswa University ya Sheffield, ko U.K*

Matseno (Introduction)

Palo ya batho ba ba tshelang ka mogare wa HIV lefatshe ka bophara e akanyediwa mo di dikadikeng di le masome a mararo le boferabongwe. Le fa bolwetsi jo bo tlhoafetse e bile bo ka baka pihelo mo go ba ba tshelang ka bone, go botlhokwa thata gore ba neelwe kemonokeng e lebaneng. Le fa diritibatsi di letla batho gore ba tshole botshelo jo bo siameng, ga di kake tsa alafa go kgaphelwa ko thoko le kgethollo ya ba ba bolawang ke mogare mme mananeo a kalafi a ka fetola mefuta ya kemonokeng e tlhokwang ke batho ba ba tshelang ka mogare wa HIV.

Lefatshe la Botswana le nale mananeo a a siameng a a itebagantseng le kalafi le kemonokeng ya ba ba tshelang ka mogare wa HIV/AIDS. Le ntswa go kwadile go le gontsi ka kalafi le go emisa kanamo ya mogare, ke dipatlisiso dile palo potlana tse di dirilweng di itebagantse le tlhokomelo le kemonokeng. Patlisiso e, e tlabo e itebagantse le go botsa batho ba ba nayang kemonokeng le ba ba neelwang kemonokeng gore e botlhokwa go le kahe, e ba thusa go le kahe le gore e tswa kae. Se se tla aga setshwantsho sa kemonokeng e le tomagano ya ditsa tikologo, e nne sekao go supa mefuta yotlhe ya thuso e ka tswang mo masakeng, maphata, makgotla a tumelo kana kae fela.

Maikaelelo (Aims)

Maikaelelo a tshokatsheko e, ke go tswa ka patlisiso e tla tswelang mosola makgotla a a itebagantseng le go neela batshela le mogare wa HIV/AIDS kemonokeng mo lefatsheng la Botswana le go thusa mafatshe a mangwe a a lekanang go tswa ka methale e e itebagantseng le kemonokeng. Go solofetswe gore patlisiso e, e tla sedimosa fa tlhokomelo le kemonokeng e le bontlha jo bo botlhokwa mo kalafing ya batho ba bolwetsi jwa HIV/AIDS le go rurifaletsa baabi ba mafatshefatshe ka fa go leng botlhokwa ka teng.

Tshokatsheko e, e tla leka go batlisisa gore ke kemonokeng efe e e tlhokwang le e e neelwang le gore e fetoga jang fa kalafi e nna teng go fetisa. Kakanyo ke go leka go sekegela kemonokeng e newang ke maphata, makgotla a tumelo, le ba masika le ditsala gore sekao sa motho a tshela ka dikakanyo tse dintle se sedimosege. Go tla nna le ditekeletso tsa go leka go bona gore a ditlhopa tsotlhe tsa batho di bona kemonokeng ka go lekalekana, sekai: a bomme ba tlwaelesogile go dirisa ditlhopa tsa kemonokeng go fetisa bo mo.

Patlisiso e, e diretswe go kanoka boleng jwa dikakgelo le ditshwanelo tsa batsaakarolo mo patlisisong e. Batsaakarolo batla kgona go bua go le gonnye kana go le gontsi ka fa ba ka kgonang ka teng e bile dikakgelo tsa bone e tla nna sephiri. Go rurifatsa gore tirisano mmogo e nna teng, go tla nna go neelanwa phetolo e mo go yone batho batla bo ba neelwa tshoboko ya patlisiso pele ga e ka gatisiwa gore ba kgone go akgela mo go yone le go fetola fa ba akanyang e se nnete.

Metlhale ya Patlisiso (Methods)

Tshekatsheko e, e tlabo e dirwa mo Gaborone le Bobonong magareng ga kgwedi ya Phukwi (July) 2006 le Ferikgong (January) 2007 e bile go tla dirisiwa metlhale e botlhokwa ya patlisiso e le meraro:

Dipuisano le Maphata a lemosegang (Interviews with Formal Organisations)

Go tla nna le dipuisano le batho go tswa mo maphatheng a a neelang kemonokeng gore ba neela kemonokeng e ntseng jang le gore baka tswa ba akanya gore mathata a botlhokwa a lebaneng maloko a bone ke a ntseng jang. Mangwe a maphata a, atla kopiwa go itsise maloko a bone ka tshekatsheko e le go batla batho ba ba eletsang go tsaya karolo mo ditlhopheng tsa dipuisano.

Ditlhopha tsa Dipuisano (Focus Groups)

Batho ba ba tshelang le mogare wa HIV/AIDS le ba ba thusang ba ba tshelang le mogare wa HIV/AIDS ba tla lalediwa go tsenelela ditlhopha tsa dipuisano. Di tla bo di akaretsa ditlhopha tse tharo le batho ba ba inakantseng le go neela kemonokeng e bile batho batla nna le sebaka sa go tsaya karolo mo puisanong e e itebagantseng le kemonokeng le thuso e ba a neelwang ke ditsala, masika le ditlhopha. Dipuisano tse, di tla bo di gololesegile e bile di tla bo di rotloetsa puisano gareng ga batho ka ga tse di kileng tsa ba diragalala mabapi le tsa kemonokeng. Dikakgelo go tswa mo ditlhopheng e tla bo e le bontlha jwa pego ya bofelo e bile batsaakarolo mo setlhopheng sa puisano ya bofelo batla kopiwa go akgela mo pegong e o le go tlaelelsa kana go fetola mo ba sa go itumeleleleng.

Go tla dirisiwa sekapamantswe mo dipuisanong e bile go tla bo go nale moranodi gore batho ba kgone go bua ka sekgoa kana setswana. Dintlha le mo mantswa a kapetsweng mo teng e tla nna tsa mmatlisisi fela e bile di tla phimolwa morago ga tshekatsheko e. Maina otlhe a batsaakarolo, batho le ditlhopha tse batla buang ka tsone a tla fetolwa go rurifatsa gore ope ga a amanngwe le tshokatshoko e.

Dibuka tsa mananeo (Diaries)

Go tla kopiwa batho ba le mmalwa ba ba neelang kana ba ba neelwang kemonokeng go nna le dibuka tsa mananeo beke tse pedi, gore ba kwale ka mofuta mongwe wa kemonokeng e ba e neelwang ka nako eo, e ka tswa e le go etela ditlhopha tsa dipuisano kana go bua le ba masika. Go solofetswe gore dibukana tse, di tla letlelela dithuso tse di potlana gore di iragadiwe le go tshwantshwanya kemonokeng go tswa mo bathong le kemonokeng go tswa mo maphatheng. Batho ba ka kwala go le gontsi kana le go nnye ka fa ba ratang ka teng e bile ba ka itlhophela gore ba batla go kwala ka ga eng. Go ka kwalwa ka sekgoa kana ka setswana e bile maina le mafelo a beng ba dibuka tsa mananeo a tla fetolwa. Go tla dirisiwa bontlha bongwe ba dibuka tsa mananeo mo go kwaleng pego e bile dibuka tsa mananeo di tla busediwa beng ba tsone fa ba elotsa go di busediwa. Motho o gololesegile go dirisa sekapamantswe fa a sa batle go ikwalela buka ya lenaneo.

Phetholo/Pego (Feedback / Reporting)

Morago ga kgwedi tsa ntlha dile mmalwa go sena go nna le dipuisano gareng ga ditlhopha, mmatlisisi o tla kwala pego e tla ranolelwang ko setswaneng gore batsaakarolo ba e buise. Ditlhopha tsa dipuisano di tla soboka dikakgelo tsothe mo pegong e, pele ga pego ya bofelo e ka kwalwa. Meriti ya pego ya bofelo e tla romelwa maphatha otlhe a tsereng karolo le batsaakarolo ba ba eletsang go nna nayo, e bile e tla nna teng e le mahala mo letloeng (internet) e be e romelwe mo maphatheng otlhe a a tlotlegang. Pego e, e tla romelwa gape ko lephateng la botsogo le mmadikolo mo Botswana.

Tshekatsheko e, e tlabo ele bontlha bongwe jwa patlisiso ya PhD e tla bewang mo metlobong ya dibuka kwa U.K. Go ka nna ga gatsiwa bontlha bongwe jwa pego ya patlisiso mo pampiring ya dikgang tsa sekolo.

Ka ga mmatlisisi (About Me)

Leina la me ke Daniel Turner, ke moithuti wa PhD kwa mmadikolo wa Sheffield kwa U.K, ke ithutha ka ditsa tlhologo (Geography). Ke setse ke kile ka inakanya le ditlhopha di le dintsi ke itebagantse le go kokoanya madi le go lemotsha ka ga HIV/AIDS lefatshe ka bophara ke kopa gore go iragadiwe go le gontsi go thusa batho ba ba tshelang ka mogare wa HIV/AIDS le go bapalela ka tsa thibelo mogare le mananeo a kemonokeng. Tshekatsheko e, ga e na go nthusa fela gore ke atlege mo dithutong tsame, mme e tsile go ntletla go tswela ke inakantse letsa HIV/AIDS le go lemotsha botlhokwa jwa go akaretsa dikakanyo le di tlhokwang ke batho ba ba setseng ba tshela ka mogare wa HIV/AIDS mo dingangisanong le bopo lotlhe.

Tshekatsheko e, e tlabo e eteletswe pele ke Dr. Deborah Sporton, Jan Rigby botlhe e le ba mmadikolo wa Sheffield ko U.K. le babereki go tswa mmadikolo wa Botswana. Tshekatsheko e, e tla sala morago melao ya setho ya mmadikolo ka nako tsotlhe. Maiteko otlhe a tla iragadiwa go rurifatsa gore ba ba nnileng le seabe mo patlisisong e, e ba tswela mosola le gore batla neelwa meriti ya pego e ba thusitseng gore e diragadiwe.

kgolaganyo (Contacts)

Fa go nale sengwe se le eletsang go se itse go feta fa,
le ka ikgolaganya le Daniel Turner mo mogaleng wa:
72 51 87 93 kgotsa e-mail ya:
D.Turner@sheffield.ac.uk



Mokwalo o o supang tumalano ya go tsaya karolo

Ke supa ja ke ithaopile go tsaya karolo mo dipatlisisong tse nme e bile ke tlhaloganya gore go diragala eng e bile go raya eng. Ka jalo ke tlhaloganya gore ke ka ikogela morago nako e nngwe le e nngwe gape ga ke kila ke ntshetswa mo pontsheng.

Tshano

Tletsatsi

Appendix (vi) Participant consent briefing (English)

Formal and Informal Care and Support for People Living with HIV/AIDS in two sites in Botswana

*A PhD Research Project by Daniel Turner
from the University of Sheffield, UK*

Introduction

It is estimated that there are 39 million people in the world living with HIV, and it is vital that they get enough support to help them live with this serious and stigmatising illness. Anti-retroviral treatment may now allow people to live healthy lives with HIV, but it does not cure isolation and stigma, and treatment programmes will change the kind of support that people with HIV need.

Botswana has an excellent programme offering treatment and support for HIV/AIDS sufferers, and while lots has been written about treatment and prevention, few studies have looked at the importance of care and support groups. This project will ask people who give and receive support how important support is to them, how it helps and where help comes from. This will build a picture of support as a social network, a map showing all kinds of help from family, organisations, religious groups or anywhere else.

Aims

The aim of the project is to create a piece of research that will be useful to organisations providing support for people with HIV/AIDS in Botswana, and also for other countries designing support strategies. It is hoped that the research will demonstrate that care and support is a vital part of treatment for people with HIV/AIDS, and make sure that international donors are aware of its importance.

The project will try to find out what support is needed and offered and how it changes as treatment becomes more available. The idea is that both formal support offered by organisations and religious groups, and informal support given by friends and family will be considered so that a complete map of positive living can be obtained. Attempts will also be made to see if all groups of people have access to the same kinds and amounts of support, or for example if women are more likely to use support groups than men.

The research is designed to value the views and rights of the people taking part in the research. At all times participants will be able to say as little or as much as they want to, and their contributions will be completely anonymous. To ensure the work is a partnership, there will be a feedback process where people are given a summary of the research before it is published, so that they can comment on it, and change aspects they think are inaccurate.

Methods

The study will be in Gaborone and Bobonong between July 2006 and January 2007, and there will be three main methods used in the research:

Interviews with formal organisations. People from organisations providing support will be interviewed to find out what support they offer, and what they think are the most important problems for their members. Some of these organisations will then be asked to tell some of their members about the project, to find people willing to take part in focus group sessions.

Focus groups. People living with HIV/AIDS and people who give help to those living with HIV/AIDS will be invited to a series of focus groups. These will consist

of three group sessions with other people involved with support, where people will be able to take part in discussion about support and help from friends, family and groups. These sessions will be relaxed and will encourage people to talk with each other about their experiences of support. Comments from these groups will form a large part of the final report, and in the last focus group the participants will be asked to comment on the report, and add to it or change parts they are unhappy with.

These sessions will be recorded on a tape recorder, and there will be a translator present, so that people can talk in Setswana or English. The tapes and notes of the session will only be available to the researcher, and will be erased after the project. All names of participants, people and groups that they discuss will be changed to ensure that no-one can be identified from the project.

Diaries. A few people who give or receive support will be asked to keep diaries for two weeks so they can write about any kinds of support they get during that time, anything from going to focus groups or talking to their family members. Hopefully the diaries will allow for even small offers of help to be documented, so that community support can be compared with support from organisations. People can write as little or as much as they like, and can choose what they want to write about. They can write in English or Setswana, and the diaries will have names of people and places changed. Only short sections from the diaries will be used in the report, and the diaries will be returned to their authors if they wish. If someone is uncomfortable with writing a diary, they may use a tape recorder instead.

Feedback / Reporting

After the first few months of focus groups and interviews, the researcher will write a report to be translated into Setswana for participants to discuss. Focus groups will collect comments on this report before the final document is written. Copies of the final report will be sent to all organisations that took part and to participants who request it, and it will be freely available on the Internet and sent to major organisations. The report will also be sent to the Ministry of Health and the University of Botswana.

The research will be part of a PhD thesis, which will be stored in libraries in the UK. Parts of the report may be published in an academic journal.

About Me

My name is Daniel Turner, and I am a PhD student based at the University of Sheffield, studying Geography. I have been involved in many groups raising money and awareness about HIV/AIDS across the world. In this work I was able to bring people from across the world together to call for more to be done for people living with HIV/AIDS, and to campaign for holistic prevention and support projects. This research will not only help me get a qualification, but will allow me to keep working on HIV/AIDS and show the importance of including the views and needs of people already living with HIV/AIDS in the global debate.

The project will be supervised at all times by Dr. Deborah Sporton and Jan Rigby at the University of Sheffield in the UK, and by staff at the University of Botswana. The research will follow the University ethics codes at all times. Every effort will be made to ensure that the people who are involved in the project benefit from it, and get copies of the report that they helped to make.

Contact Details

For any more information, please contact Daniel Turner:
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REPUBLIC OF BOTSWANA

REFERENCE No: HRU-13/18/1 Vol I (94) April 10, 2006

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Formal and Informal Care and Support for People Living with HIV/AIDS in two sites in Botswana.

Reference is made to the above titled study re-submitted to the Health Research and Development Committee (HRDC) for ethical and scientific review and appraisal. We note that the revisions have satisfactorily addressed the concerns raised in our letter.

Permission is therefore granted to conduct the above-mentioned study. This approval is valid for a period of 1 year, effective March 3 2006. **Approval will expire on March 3, 2007.**

This permit does not however give you authority to collect data from selected institutions without prior approval from the management of the institutions. Furthermore, consent should also be sought from all those that will be interviewed.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal will need to be resubmitted to the Health Research Unit in the Ministry of Health.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research Unit, Ministry of Health within 3 months of completion of the study. Copies should also be sent to relevant authorities.

Thank you,

S. El-Halabi
For Permanent Secretary Ministry of Health

References

ACHAP, 2004, *Annual Report 2004*, ACHAP, Gaborone

Ackerman, L., de Klerk, G., 2002, Social factors that make South African women vulnerable to HIV infection, *Health care for Women International*, **23**(2), pp163-172

Acton, E., 1887, *Letter to Bishop Mandell Creighton*

Aggleton, P., Davies, P., Hart, G., 1990, *AIDS: Individual, cultural and policy dimensions*, Falmer Press, London

AIDS.org, 2000, AIDS denialists: how to respond, *AIDS Treatment News*, **342**(10), [accessed online Nov 2005] <http://www.aids.org/atn/a-342-10.html>

AllAfrica.com, 23/01/2008, *Botswana: Mogae Leaves Office Haunted by Passion Killings*, [accessed online 24/01/2008: <http://allafrica.com/stories/200801230921.html>]

Allen, T., Heald, S., HIV/AIDS policy in Africa: what has working in Uganda and what has failed in Botswana?, *Journal of International Development*, **16**, pp1141-1154

Alloway, P., Bebbington, P., 1987, The buffer theory of social support – a review of the literature, *Psychological Medicine*, **17**(1), pp91-108

Alter, C., 1990, An exploratory study of conflict and coordination in interorganisational service delivery systems, *Academy of Management Journal*, **33**:3, pp478-502

Altman, D., 1994, *Power and community: organizational and cultural responses to AIDS*, Routledge, London

Anderson, H., 1997, *Conversation language and possibilities: A post-modern approach to theory*, Basic Books,

Ansell, N., 1997, Producing knowledge about 'Third World Women': the politics of fieldwork in a Zimbabwean secondary school, *Ethics, Place and Environment*, **4**(2), pp101-116

Ansell, N., van Blerk, L., 2004, Children's migration as a household/family strategy: coping with AIDS in Lesotho and Malawi, *Journal of Southern African Studies*, **30**(3), pp673-690

Ansell, N., van Blerk, L., 2005, Joining the conspiracy? Negotiating ethics and emotions in researching (around) AIDS in southern Africa, *Ethics, Place and Environment*, **8**(1), pp61-81

Ansell, N., 2008, Childhood and the politics of scale: descaling children's geographies, *Progress in Human Geography*, **OnlineFirst**, pp1-20

Armstrong, J., 1995, *Uganda's AIDS crisis*, World Bank Publications, Washington DC

Ars, B., 2004, The global-local nexus: NGOs and the articulation of scale, *Tijdschrift voor Economisch en Sociale Geografie*, **95**(5), pp498-510

Asjo, B., Morfeldt-Manson, L., Albert, J., Biberfeld, G., Karlsson, A., Lidman, K., Fenyo, E., 1986, Replicative capacity of human immunodeficiency virus from patients with varying severity of HIV infection, *Lancet*, **2**(8508), pp660-662

Atack, I., 1999, Four criteria of development NGO legitimacy, *World Development*, **27**(5), pp855-864

Atkinson, P., Hammersley, M., 1994, Ethnography and Participant Observation, in Denzin and Lincoln [eds] 2000

Attwood, H., Gaventa, J., 1997, *Participatory Research. Ideas on the use of participatory approaches by post graduate students and others in formal learning and research institutes*, IDS Topic Pack, IDS, Brighton

Avert, B., Taljaard, D., Lagarde, E., Sobngwi-Tambekou, J., Sitta, R., Puren, A., 2002, Randomized, controlled intervention trial of male circumcision for reduction of HIV infection risk. the ANRS 1265 trial, *PLoS Medicine*, **2**(11), e298

Avert, 2005, *Introduction to HIV and AIDS treatment*, [accessed online Oct 2005 <http://www.avert.org/introtrn.htm>]

Badri, M., Cleary, S., Maartens, G., Pitt, J., Bekker, L., Orrell, C., Wood, R., 2006, When to initiate highly active antiretroviral therapy in sub-Saharan Africa? A South African cost-effectiveness study, *Antiviral Therapy*, **11**, pp63-72

Baghramian, M., 2004, *Relativism*, Routledge, Abington

Baier, A., 1986, Trust and Antitrust, *Ethics*, **96**(2), pp231-260

Baleia, A., 2006, "Dr Beetroof" sidelined in South Africa, *The Lancet Infectious Diseases*, **6**(10), pp620

Barnes, B., Henry, J., Bloor, D., 1996, *Scientific knowledge. a sociological analysis*, University of Chicago Press, Chicago

Barnett, T., 2005, HIV/AIDS: sex, abstinence, and behaviour change, *The Lancet*, **5**(9), pp590-593

Baron, S., Field, J., Schuller, T., 2000, *Social Capital. Critical Perspectives*, Oxford University Press, Oxford

Bateson, G., 1979, *Mind and nature: a necessary unity*, Ballantine, NY

Batsell, J., 2005, AIDS, Politics and NGOs in Zimbabwe, in Patterson [ed]

Baum, F., 1999, Social capital. is it good for your health? Issues for a public health agenda, *Journal of Epidemiological and Community Health*, **53** pp195-196

BBC News, 06/02/2006, *Botswana floored by passion killings*, [accessed online 24/01/06: <http://news.bbc.co.uk/1/hi/world/africa/4685216.stm>]

BBC News, 2008, *S Africa bans Aids vitamin trials*, [accessed online July 2008: <http://news.bbc.co.uk/1/hi/world/africa/7453449.stm>]

Beach, R., Mantero-Aienza, E., Shor-Posner, G., Javier, J., Szapocznick, J., Morgan, R., Sauberlich, H., Cornwell, P., Eisdorfer, C., Baum, M., Specific nutrient abnormalities in asymptomatic HIV-1 infection, *AIDS*, **6**(7), pp701-708

Belman, G., 2004, *The invisible people*, Free Press, New York

Bell, L., 1998, Public and private meetings in diaries: researching family and childcare.

Benner, T., Reinicke, W., Witte, J., 2004, Multisectoral networks in global governance: towards a pluralistic system of accountability, *Government and Opposition*, **39**(2), pp191-210

Berger, P., Luckmann, T., 1966, *The social construction of reality. a treatise in the sociology of knowledge*, Anchor Books, New York

Berkman, L., 1995, The role of social relations in health promotion, *Psychosomatic Medicine*, **57**(3), pp245-254

Bernard, H., 2006, *Research methods in anthropology: qualitative and quantitative approaches*, Altamira, Lanham

Bhatnagar, B., Williams, A., 1992, *Participatory Development and the World Bank: Potential Directions for Change*, World Bank, Washington DC

Biberfeld, G., Lyanuya, E., 2003, Monitoring immune function, in Essex et al. [eds]

Biernacki, P., Waldorf, D., 1981, Snowball sampling: problems and techniques in chain-referral sampling, *Social Methods and Research*, **10**, pp141-163

Bisset, K., Grey, J., 1992, Feelings and needs of women who are HIV positive, in Bury et al

Bird, J., 1993, *Mapping the Futures*, Routledge, London

Blackburn, J., Holland, J., 1998, *Whose Voice? Participatory research and policy change*, Intermediate Technology Publications

Bloor, M., 1995, *The Sociology of HIV Transmission*, Sage, London

Bloor, M., 2001, *Focus groups in social research*, Sage, London

Bollinger, L., Stover, J., 1999, *The economic impact of HIV/AIDS in Botswana*, Futures Group International, Glastonbury

BONEPWA, 2006, About us: objectives, [accessed online 29/04/08 <http://www.bonepwa.botsnet.co.bw/html/objectives.htm>]

Boone, C., Batsell, J., 2001, Politics and AIDS in Africa: Research agendas in political science and international relations, *Africa Today*, **48**(2): pp2-33

- Borgatti, S., Everett, M., 1992, Notions of Position in Social Network Analysis. *Sociological Methodology*, **22**, pp1-35
- Bourdieu, P., 1985, The Forms of Capital, in *Handbook of Theory and Research for the Sociology of Education*, p241-58, ed JG Richardson, New York, Greenwood
- Bourdieu, P., 2003, Participant Objectivation. *Journal of the Royal Anthropological Institution*, **9**, pp281-294
- Bowser, B., Sieber, J., 1993, AIDS prevention research, in Renzetti and Lee [eds]
- Bowser, B., Sieber, J., 1993, AIDS prevention research: old problems and new solutions, in Bowser et al [eds]
- Boyer, J., Bebenek, K., Kunkel, T., 1992, Unequal human immunodeficiency virus type 1 reverse transcriptase error rates with RNA and DNA templates. *PNASU*, **89**, pp6919-6923
- Bratton, M., 1990, Non-governmental organizations in Africa: can they influence public policy. *Development and Change*, **21(1)**, pp87-118
- Brennan, T., Sarill, W., Norwood, C., 1999, Effects of an oral vitamin B12 formulation on AIDS-related neuropathy and other symptoms: a pilot study. *Journal of Advancement in Medicine*, **12(2)**, pp97-117
- Brenner, N., 2001, The limits to scale? Methodological reflections on scalar structuration. *Progress in Human Geography*, **25**, pp591-614
- Brewer, J., Hunter, A., 1989, *Multimethod research. a synthesis of styles*, Sage, NY
- Broadhead, R., Rist, R., 1976, Gatekeepers and the social control of social research. *Social Problems*, **23(3)**, pp325-336
- Brown, L., Ashman, D., 1996, Participation, social capital and intersectoral problem solving: African and Asian cases. *World Development*, **24(9)**, pp1467-1479
- Brown, L., Macintyre, K., Trujillo, L., 2003, Interventions to reduce HIV/AIDS stigma. what have we learned?. *AIDS Education and Prevention*, **15(1)**, pp49-69
- Brown, T., 2000, AIDS, risk and social governance. *Social Science and Medicine*, **50(9)**, pp1273-1284
- Buchbinder, S., Katz, M., Hessel, N., O'Malley, P., Holmberg, S., 1994, Long-term HIV-1 infection without immunologic progression. *JAIDS*, **8(8)**, pp1123-1128
- Burgess, R., 1984, *In the Field: An Introduction to Field Research*, Routledge, London
- Burgoynne, R., 2005, Exploring direction of causation between social support and clinical outcome for HIV-positive adults in the context of highly active antiretroviral therapy. *AIDS Care*, **17(1)**, pp111-124
- Burleson, B., 1994, Comforting messages: significance, approaches, and effects in Burleson et al. [eds]

- Burleson, B., 2003. Emotional Support Skill in Greene and Burleson [eds]
- Burleson, B., Albrecht, T., Sarason, I., 1994, *Communication of social support: messages, interactions, relationships and community*, Sage, London
- Burnett, A., Baggaley, R., Ndovi-Macmillan, M., Sulwe, J., Hang'Omba, B., Bennett, J., 1999, Caring for people with HIV in Zambia: are traditional healers and formal health workers willing to work together?, *AIDS Care*, **11**(4), pp 481-491
- Burt, R., 2000, The network structure of social capital, in Staw and Sutton [eds]
- Bury, J., Morrison, V., McLachlan, S., *Working with women and AIDS: medical, social and counselling issues*, Routledge, London
- Campbell, C., 2000, Social capital and health: contextualising health promotion within local community networks, in Baron et al [eds]
- Campbell, C., Williams, B., Beyond the biomedical and behavioural: towards an integrated approach to HIV prevention in the Southern African mining industry. *Social Science and Medicine*, **48**(11), pp1625-1639
- Cantwell, M., Binkin, N., 1997, Impact of HIV on tuberculosis in sub-Saharan Africa: a regional perspective, *International Journal of Tuberculosis and Lung Disease*, **1**(3), pp205-214
- Carapico, S., NGOs, INGOs, GO-NGOs and DO-NGOs: Making sense of non-governmental organisations, *Middle East Report*, **214**, pp12-15
- Carlsmaes, W., Risse, T., Simmons, B., 2002, *Handbook of International Relations*, Sage, London
- Carroll, T., 1992, *Intermediary NGOs: the supporting link in grassroots development*, Kumarian Press, Bloomfield
- Carroll, M., Walton, M., 1997, *Handbook of counselling in organisations*, Sage, London
- Cassel, J., 1976. The contribution of the social environment to host resistance, *American Journal of Epidemiology*, **104**, pp107-123
- Catterall, M., Maclaran, P., Focus group data and qualitative analysis programs. Coding the moving picture as well as the snapshots, *Social Research Online*, **1**(6)
- CDC, 1992, Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults, *MMWR*, **41**, pp1-19
- Chabal, P., 1996. The African crisis: context and interpretation, in Webner and Ranger [eds]
- Chambers, R., 1980, *Rapid rural appraisal: rationale and repertoire*, IDS, Brighton
- Chambers, R., 1985, *Rural Development: Putting the first last*, Longman, London

- Chambers, R., 1994, The origins and practice of participatory rural appraisal. *World Development*, **22**(7), pp953-967
- Chambers, R., 1997, *Who's reality counts?: putting the last first*, ITP, London
- Chambers, R., Blackburn, J., 1996, The power of participation. PRA and policy, *HDS Policy Briefing*, 7
- Chesney, M., 2003, Adherence to HARRT regimens, *AIDS Patient Care and STD's*, **17**(4), pp169-177
- Chiodi, F., Åsjö, E., Feyö, E., Norkrans, L., Hagberg, L., Albert, J., 1986, Isolation of human immunodeficiency virus from cerebrospinal fluid of antibody-positive virus carrier without neurological symptoms. *Lancet*, **328**(8518), pp1276-1277
- Chipfakacha, V., 1997, STD/HIV/AIDS/ knowledge, beliefs and practices of traditional healers in Botswana, *AIDS Care*, **9**(4), pp417-425
- Chirimuuta, R., Chirimuuta, R., 1987, *AIDS, Africa and Racism*, Free Association Books, London
- Choe, H., Farzan, M, Sun, Y, Sullivan, N., Rollins, B., Ponath, P., Wu, L., Mackay, C., LaRosa, G., Newman, W., Gerard, N., Gerard, C., Sodroski, J., 1996, The beta-chemokine receptors CCR3 and CCR5 facilitate infection by primary HIV-1 isolates. *Cell*, **85**, pp1135-1148
- Chun, T., Fauci, A., 1999, Latent reservoirs of HIV: obstacles to the eradication of virus, *PNAS*, **96**(20), pp10959-10961
- Cobb, S., 1976, Social support as a moderator of life stress, *Psychosomatic Medicine*, **38**, pp300-314
- Cohen S., Syme, L., 1984, *Social support and health*, Academic Press, Orlando
- Cohen, D., Underwood, L., Gottlieb, B., 2000, *Social Support Measurement and Intervention*, Oxford University Press, Oxford
- Cohen, D., 2002, *Human capital and the HIV epidemic in sub-Saharan Africa*, ILO Working Paper, Geneva
- Coleman, J., 1988, Social Capital in the Creation of Human Capital, *American Journal of Sociology*, **94**, Supplement, ppS95-S120
- Collinge, C., 1999, Self-organisation of society by scale: a spatial reworking of regulation theory, *Environment and Planning D*, **17**, pp557-574
- Conradson, D., 2003, Spaces of care in the city: the place of a community drop-in centre, *Social and Cultural Geography*, **4**, pp507-525
- Conradson, D., 2005, Landscape, care and the relational self: Therapeutic encounters in rural England, *Health and Place*, **11**(4), pp337-348

Cooper, C., Payne, R., 1991, *Personality and stress: individual differences in the stress process*, Wiley and Sons, London

Corbett, E., Watt, C., Walker, N., Maher, D., Williams, B., Raviglione, M., Dye, C., 2003, *Archives of Internal Medicine*, **163**(9), pp1009-1021

Cornwell, A., Jewkes, R., 1995, What is participatory research?, *Social Science and Medicine*, **41**(12), pp1667-1676

Cosgrove, D., Jackson, P., 1987, New directions in cultural geography, *Area*, **19**, pp95-101

Courtenay, W., 2000, Constructions of masculinity and their influence on men's well-being: a theory of gender and health, *Social Science and Medicine*, **50**(1), pp1385-1401

Coyne, I., 1997, Sampling in qualitative research. Purposeful and theoretical sampling, merging or clear boundaries?, *Journal of Advanced Nursing*, **26**, pp623-630

Crang, M., 2005, Qualitative methods: there is nothing outside the text?, *Progress in Human Geography*, **29**(2), pp225-233

Crush, J., Williams, V., Peberdy, S., 2005, *Migration in Southern Africa*, Global Commission on International Migration

Creese, A., Floyd, K., Alban, A., Guinness, T., 2002, Cost-effectiveness of HIV/AIDS interventions in Africa: a systematic review of the evidence, *The Lancet*, **359**, pp1635-1642

Crosswaite, C., Curtice, L., 1994, Disseminating research results – the challenge of bridging the gap between health research and health action, *Health Promotion International*, **9**(4), pp289-296

D'Allesandro, C., 2006, *Missing mothers: meeting the needs of children affected by AIDS*, Save the Children, London

Daily News, 2004, *Pre-employment HIV testing is stoking*, [accessed online 20/01/08 <http://www.gov.bw/cgi-bin/news.cgi?d=20040217>]

Daily News, 2006a, *NACA funds groups through BONEPWA*, [accessed online 29/04/08. http://www.gov.bw/cgi-bin/news.cgi?d=20060117&i=NACA_funds_groups_through_BONEPWA]

Daily News, 2006b, *Ministry: BONEPWA resolves differences*, [accessed online 29/04/08, http://www.gov.bw/cgi-bin/news.cgi?d=20061221&i=Ministry_BONEPWA_resolves_differences]

Daily News, 2007, *Foreign Exchange Reserves Increase*, [accessed online 19/01/08; <http://www.gov.bw/cgi-bin/news.cgi?d=20070207>]

Dalglish, A., Weiss, R., 1999, *HIV and the New Viruses*, Academic Press, London

Dale, H., Dondero, T., Rayfield, M., George, R., Schochelman, G., Harold, J., Luo, C., Kalish, M., 1996, The emerging genetic diversity of HIV: the importance of global surveillance for diagnostics, research, and prevention, *JAMA*, **275**, pp210-216

Daly, K., Sellars, T., Pimenta de Oliveira, M., Liluka, R., 2004, Meeting the challenges of providing financial and technical support to NGOs and CBOs in the context of increased funding, *International Conference on AIDS*, **15**, # MoOrE1040

Datta, K., 2004, A coming of age? Re-conceptualising gender development in urban Botswana, *Journal of Southern African Studies*, **30**:2, pp251-268

de Waal, A., Whiteside, A., 2003, New variant famine: AIDS and food crisis in southern Africa, *Lancet*, **362**(9391), pp1234-1237

DeLong, J., 2003, *Making and impact in HIV and AIDS : NGO experiences of scaling up*, ITDG, London

Del Casino, V., 2001, Healthier geographies – medicating the gaps between the needs of people living with HIV and AIDS and health care in Chiang Mai, Thailand, *Professional Geographer*, **53**(3), pp407-421

Delaney, M., 2000, Why are AIDS dissidents still making 15-year-old, long-refuted claims?, *Nature*, **408**, pp287

Della Porta, D., Diani, M., 2006, *Social Movements: An Introduction*, Blackwell

Denzin, N., 1997, *Interpretive Ethnography: Ethnographic Practices for the 21st Century*, Sage, London

Denzin, N., Lincoln, Y., 2000, *Handbook of Qualitative Research*, Sage, London

Desai, V., and Potter, R., 2006, *Doing Development Research*, Sage, London

Devereux, S., Hoddinott, J., 1993, *Fieldwork in developing countries*, Lynne Rienner Publications, Boulder

Dey, I., 1993, *Qualitative data analysis*, Routledge, London

Di Matteo, R., Hays, R., 1981, Social support and serious illness, in Gottlieb [ed]

Diani, M., McAdam, D., 2003, *Social Movements and Networks: Relational Approaches to Collective Action*, Oxford University Press, Oxford

Dingake, M., 2008, *Democracy without political parties?*, Mmegi Online, [accessed online 22/08/09; <http://www.mmegi.bw/index.php?sid=2&aid=15&dir=2008/July/Thursday3>]

Drimie, S., 2002, The impact of HIV/AIDS on rural households and land issues in southern and eastern Africa, FAO, Geneva

Durkheim, E., 1952, *Suicide*, Routledge and Kegan Paul, London

Dwyer, C., Modood, T., Sanghera, G., Shah, B., Thapar-Bjorkert, S., *Ethnicity as social capital? Explaining the differential educational achievements of young British Pakistani men and women*, [accessed online, 11/05/08,

www.bristol.ac.uk/sociology/leverhulme/conference/conferencepapers/dwyer.pdf]

Dyck, I., 1999, Using qualitative methods in medical geography: deconstructive moments in a subdiscipline?, *Professional Geographer*, **51**(2), pp243–53

Eade, D., 2000, *Development, NGOs and civil society*, Oxfam Publishing, Oxford

Eastwood, J., Couray, R., Naicker, S., West, P., Tutt, R., Plange-Rhule, J., 2005, Loss of health professionals from sub-Saharan Africa: the pivotal role of the UK, *Lancet*, **365**, pp1893-1900

Edelman, L., Bresnen, M., Newell, S., Swan, J., 2004, The benefits and pitfalls of social capital: empirical evidence from two organizations in the United Kingdom, *British Journal of Management*, **15**(S1), ppS59-S69

Edwards, M., Hulme, D., 1992, Scaling up NGO impact on development: learning from experience, *Development in Practice*, **2**(2), pp777-91

Edwards, M., Hulme, D., 1995, *Non-governmental Organisations: Performance and Accountability Beyond the Magic Bullet*, Earthscan, London

Edwards, M., Fowler, A., 2002, *The Earthscan Reader in NGO Management*, Earthscan, London

Ell, K., 1996, Social networks, social support and coping with serious illness: the family connection, *Social Science and Medicine*, **42**(2), pp173-183

Ellison, G., Parker, M., Campbell, C., 2003, *Learning from HIV and AIDS*, Cambridge University Press, Cambridge

Elster, J., 1982, The Case for Methodological Individualism, *Theory and Society*, **11**:4, pp453-482

Elster, J., 1989, *Nuts and Bolts for social sciences*, Cambridge University Press, Cambridge

England, K., 1994, Getting personal: reflexivity, positionality, and feminist research, *Professional Geographer*, **46**(1), p80-89

Epstein, A., 1996, HIV prevention for intravenous drug users, *Lancet*, **347**(8988), pp401-402

Eriksen, T., 2001, *What is Anthropology? Anthropology, Culture and Society*, University of Michigan Press, Michigan

Escobar, A., 1994, *Encountering Development*, Princeton University Press, Princeton

Escobar, A., 2007, The 'ontological turn' in social theory, *Transactions of the Institute of British Geographers*, **32**, pp106-111

- Essex, M., Mboup, S., 2002, Introduction: the etiology of AIDS, in Essex et al. [eds]
- Essex, M., Mboup, S., 2002b, Regional variations in the African Epidemics, in Essex et al [eds]
- Essex, M., Mboup, S., Kanki, P., Marlink, R., Flou, S., Holme, M., 2002, *AIDS in Africa*, Springer
- European Study Group on Heterosexual Transmission of HIV, 1992, Comparison of female to male and male to female transmission of HIV in 563 stable couples, *British Medical Journal*, **304**(6830), pp809-814
- Faby, P., 2003, Indicators of support in online interaction, *The International Review of Research in Open and Distance Learning*, **4**(1), pp1-16
- Fanelli, C., Moyo, A., Lovick, L., 2008, *Supporting support groups for PLHIV in Zimbabwe*, Poster of the XVII International AIDS Conference
- FAO, 2005, *FAO Statistical Yearbook*, FAO, Geneva
- Faugier, J., Sargeant, M., 1997, Sampling hard to reach populations, *Journal of Advanced Nursing*, **26**, 790-797
- Fife, B., Wright, E., 2000, The dimensionality of stigma: a comparison of its impact on the self of persons with HIV/AIDS and cancer, *Journal of Health and Social Behaviour*, **41**, pp50-67
- Fischl, M., Richman, D., Grieco, M., Gottlieb, M., Volberding, P., Laskin, O., Leedom, J., Groopman, J., Mildvan, D., Schooley, R., 1987, The efficacy of zidovudine (AZT) in the treatment of patients with AIDS and AIDS-related complex. A double-blind, placebo-controlled trial, *New England Journal of Medicine*, **317**(4), pp195-191
- Flaskerud, J., Anderson, N., 1999, Disseminating the results of participant-focused research, *Journal of Transcultural Nursing*, **10**(4), pp340-349
- Flowerdew, R., Martin, D., 2005, *Methods in Human Geography*, Prentice Hall, London
- Foddy, W., 1993, *Constructing Questions for Interviews and Questionnaires*, Cambridge University Press, Cambridge
- Foley, M., Edwards, B., 1996, The paradox of civil society, *Journal of Democracy*, **7**(3), pp38-52
- Fontana, A., Frey, J., 1994, *Handbook of qualitative research*, Sage, London
- Forsyth, A., Carey, M., 1998, Measuring self-efficacy in the context of HIV risk reduction: research challenges and recommendations, *Health Psychology*, **17**(6), pp559-568
- Foster, G., 2000, The capacity of the extended family safety net for orphans in Africa, *Psychology, Health and Medicine*, **5**(1), pp55-62

- Fornie, P., Schönleich, M., 2001, Africa's new security threat: HIV/AIDS and human security in Southern Africa, *African Security Review*, **10**(4)
- Fowler, A., 1992, Decentralisation for international NGOs, *Development in Practice*, **2**(2), pp121-124
- Fox, M., Brooks, D., Kuhn, T., Aldrovandi, G., Sinkala, M., Jankasa, C., Mwiva, M., Horsburg, R., Thea, D., 2008, Reduced mortality associated with breast-feeding-acquired HIV infection and breast-feeding among HIV-infected children in Zambia, *JAHDS*, **48**(1)
- Freeman, L., White, D., Romney, A., 1992, *Research Methods in Social Network Analysis*, Transaction, New Brunswick
- Friedland, J., Renwick, R., McColl, M., 1996, Coping and social support as determinants of quality of life in HIV/AIDS, *AIDS Care*, **8**(1), p15-32
- Fukuyama, F., 2001, Social capital, civil society and development, *Third World Quarterly*, **22**(1), pp7-20
- Gadd, C., [ed], 2005, *HIV & AIDS treatment directory*, NAM, London
- Gaffeo, E., 2003, The economics of HIV/AIDS: a survey, *Development Policy Review*, **21**(1), pp27-50
- Garbarino, J., 1983, Social support networks: Rx for the helping professions, in Whittaker and Garbarino [eds]
- Gariyo, Z., 1995, NGOs and development in East Africa. a view from below, in Edwards and Hulme [eds]
- Garrett, L., 2004, *HIV and national security: where are the links?*, Council on Foreign Relations, New York
- Garry, M., Sharman, S., Feldman, J., Marlatt, A., Loftus, E., 2002, Examining Memory for Heterosexual College Student's Sexual Experiences Using an Electronic Mail Diary, *Health Psychology*, **21**(6), pp629-634
- Gaventa, J., 1993, The powerful, the powerless, and the experts. knowledge struggles in an information age, in *Voices of change: participatory research in the United States and Canada*, Park et al. [eds]
- Gazette, 2006, 11/10/06, *AIDS money should 'trickle down' to deserving people*, Botswana Gazette, Gaborone
- Gazette, 2006, 6/12/06, *AIDS Patients protest in Tsoabong*, Botswana Gazette, Gaborone
- Gazette, 2007, 24/01/07, *NACA only used half of money donated by Global Fund*, Botswana Gazette, Gaborone
- Gerson, K., Horowitz, R., 2002, Observation and interviewing: options and choices in qualitative research, in May [eds]

Gesler, W., 1992, Therapeutic landscapes: medical issues in light of the new cultural geography, *Social Science and Medicine*, **34**(7), pp735-746

Glaser, B., 1978, *Theoretical sensitivity*, Sociology Press, Mill Valley

Glass, T., Mended de Leon, C., Seeman, T., Berkman, L., 1997, Beyond single indicators of social networks. A LISREL analysis of social ties among the elderly, *Social Science and Medicine*, **44**(10), pp1503-1517

Glen, J., Caracl, M., Auvert, B., Kahindo, M., Chege, J., Musonda, R., Kaona, F., Buve, A., 2001, Why do young women have a much higher prevalence of HIV than young men? A study in Kisumu, Kenya and Ndola, Zambia, *AIDS*, **15**(Sup. 4), ppS51-S60

Goffman, E., 1963, *Stigma: notes on the management of spoiled identity*, Penguin, London

Goss, J., 1996, Introduction to Focus Groups, *Area*, **38**(2), pp113-114

Goss, J., Leinbach, T., 1996, Focus groups as alternative research practice: experience with transmigrants in Indonesia, *Area*, **38**(2), pp115-123

Gottlieb, B., 1981, *Social Networks and Social Support*, Sage, London

Gould, P., 1993, *The slow plague*, Blackwell, Oxford

Government of Botswana, 2005, *Botswana second generation HIV/AIDS surveillance, technical report*, Government of Botswana, Gaborone

Government of Botswana, 2005b, *Census Data*, Government of Botswana, Gaborone

Grassly, N., Morgan, M., Walker, N., Garnett, G., Stanecki, K., Stover, J., Brown, T., Ghys, P., 2004, Uncertainty in estimates of HIV/AIDS: the estimation and application of plausibility bounds, *Sexually Transmitted Infections*, **80**, pp31-38

Green, E., Halperin, D., Natulya, V., Hogle, J., 2006, Uganda's HIV prevention success: the role of sexual behaviour change and the national response, *AIDS and Behaviour*, **10**(4), pp1573-3254

Greene, J., Caracelli, V., Graham, W., 1989, Toward a conceptual framework for mixed-method evaluation designs, *Educational evaluation and policy analysis*, **11**(3), pp255-274

Groves, L., Hinton, R., 2004, *Inclusive Aid: Changing power and relationships in International Development*, Earthscan, London

Gruskin, S., Maluwa, M., 2002, Human rights and HIV/AIDS, In *AIDS in Africa*

Guardian, 2002, *Botswana battles against 'extinction'*, [accessed online 22/01/08; <http://www.guardian.co.uk/international/story/0,3604,751071,00.html>]

Guardian, 2006, 7/12/06, *Degeneration of World AIDS Day must stop*, Guardian, Gaborone

Guha, R., Spivak, G., 1989, *Selected Subaltern Studies*, Oxford University Press, Oxford

Gustavsen, B., 2001, Theory and practice: mediating discourse, in Reason and Bradbury (eds) 2001

Haacker, M., 2004, HIV/AIDS: The impact on the social fabric and the economy, in *The Macroeconomics of HIV/AIDS*, IMF, Washington, DC

Hagey, R., 1997, The use and abuse of participatory action research, *Chronic Diseases in Canada*, **18**(1), pp1-4

Hall, E., 2004, The 'geneticisation' of heart disease: a network analysis of the production of new genetic knowledge, *Social Science and Medicine*, **60**(12), pp2673-2683

Hammer, S., Squiers, K., Hughes, M., Grimes, J., Demeter, L., Currier, J., Eron, J., Feinber, J., Balfour, H., Deyton, L., Chodakewitz, J., Fischl, M., Phair, J., Spreen, W., Pedneault, L., Nguyen, D., Cook, J., 1997, A controlled trial of two nucleoside analogues plus indinavir in persons with human immunodeficiency virus infection and CD4 cell counts of 200 per cubic millimeter or less, *NEJM*, **337**(11), pp 725-733

Hampton, J., *Living positively with AIDS. the AIDS support organization (TASO), Uganda*, WHO, Geneva

Hansell, P., Hughes, C., Caliandro, G., Russo, P., Budin, W., Hartman, B., Hernandez, O., 1998, The effect of a social support boosting intervention on stress, coping, and social support in caregivers of children with HIV/AIDS, *Nursing Research*, **47**(2), 79-86

Hansen, M., 1999, The search-transfer problem. the role of weak ties in sharing knowledge across organization subunits, *Administrative Science Quarterly*, **44**(1), pp82-111

Haran, L., Tswana medicine in interaction with biomedicine, *Social Science and Medicine*, **33**(2), pp167-175

Harcourt, W., 1994, *Feminist perspectives on sustainable development*, Zed Books, London

Hardon, A., Davey, S., Gerrits, T., Hodgkin, C., Irunde, H., Kgallwane, J., Kinsman, J., Nakiyemba, A., Laing, R., 2006, *From access to adherence: the challenges of antiretroviral treatment*, WHO, Geneva

Hartwig, K., Humphries, D., Matebeni, Z., 2008, Building capacity for AIDS NGOs in southern Africa: evaluation of a pilot initiative, *Health Promotion International*, **23**(3), pp251-259

Hay, I., 2000, *Qualitative Research Methods in Human Geography*, Oxford University Press, Oxford

Hays, R., Turner, H., Coates, T., 1992, Social support, AIDS-related symptoms, and depression among gay men, *Journal of Consultant Clinical Psychology*, **60**(3), pp463-469

Heald, S., 1995, The power of sex: reflections on the Caldwell's 'African sexuality' thesis, *Africa*, **65**, pp489-505

Heald, S., 2003, An absence of anthropology. critical reflections on anthropology and AIDS policy and practice in Africa, in Ellison et al. [eds]

Heald, S., 2004, It's never as easy as ABC: Understandings of AIDS in Botswana, *African Journal of AIDS Research*, **1**(1), pp1-10

Heald, S., 2005, Abstain or die: the development of HIV/AIDS policy in Botswana, *Journal of Biosocial Science*, **38**, pp29-41

Held, D., McGrew, A., 2002, *Governing globalization: power, authority and global governance*, Polity Press, Cambridge

Helgeson, V., Gottlieb, B., 2000, Support Groups, in Cohen and Gottlieb [eds]

Helleringer, S., Kohler, H., 2005, Social networks, perceptions of risk, and changing attitudes towards HIV/AIDS – new evidence from a longitudinal study using fixed-effects analysis, *Population Studies*, **59**(3), pp265-282

Helleringer, S., Kohler, H., 2007, Sexual network structure and the spread of HIV in Africa: evidence from Likoma Island, Malawi, *AIDS*, **21**(17), pp2323-2332

Herod, A., 1993, Gender issues in the use of interviewing as a research method, *Professional Geographer*, **45**(3), pp305-317

Hess, M., 2004, 'Spatial' relationships? Towards a reconceptualization of embedded ness, *Progress in Human Geography*, **28**(2), pp165-186

Herzog, H., 2005, On home turf: interview location and its social meaning, *Qualitative Sociology*, **28**(1), p25-47

Hill, J., Farrar, W., Pert, C., Autoradiographic localization of T4 antigen, the HIV receptor, in human brain, *International Journal of Neuroscience*, **32**(3-4), pp687-693

Hillcrest, 2007, *Craft Income-Generation*, Hillcraft AIDS Centre Trust. [accessed online 31/03/08. http://hillcraftaids.org.za/craft_income_generation]

Hillcrest, 2007, *Home-based care*, Hillcraft AIDS Centre Trust. [accessed online 31/03/08 http://hillcraftaids.org.za/home_based_care]

Hinton, R., 2004, Enabling inclusive aid. Changing power and relationships in international development, in Groves et al [eds]

Hirsch, J., Menses, S., Thompson, B., Negroni, M., Pelcastre, B., 2007, The inevitability of infidelity: sexual reputation, social geographies, and marital HIV risk in rural Mexico, *American Journal of Public Health*, **97**(6), pp986-996

Hirsch, V., Olmsted, R., Murphey-Corb, M., Purcell, R., Johnson, P., 1989, An African primate lentivirus (SIVsm) closely related to HIV-2, *Nature*, **339**, pp389-392

- Ho, D., Neumann, A., Perelson, A., Chen, W., Leonard, J., Markowitz, M., 1995 Rapid turnover of plasma virions and CD4 lymphocytes in HIV-1 infection, *Nature*, **373**, pp123-126
- Holloway, I., 1997, *Basic concepts for qualitative research*, Blackwell, Oxford
- Homsy, J., Kind, R., Balaba, D., Kabatesi, D., 2004, Traditional health practitioners are key to scaling up comprehensive care for HIV/AIDS in sub-Saharan Africa, *AIDS*, **18**(12), pp1723-1725
- House, J., 1981, *Work stress and social support*, Addison-Wesley, Mass.
- Houtum, H., Naerseen, T., 2002, Bordering, ordering and othering, *Tijdschrift voor Economische en Sociale Geografie*, **93**(2), pp125-136
- Howe, K., 2004, A critique on experimentalism, *Qualitative Inquiry*, **10**(1), pp42-61
- Howitt, R., 2002, Scale and the other: Levinas and geography, *Geoforum*, **33**, pp299-313
- Hughes, J., Sharrock, W., 1997, *The philosophy of social research*, Longman, Harlow
- Hulme, D., Edwards, M., 2002, Beyond the magic bullet: conclusions and consequences, in Edwards and Fowler [eds]
- Hulme, D., Edwards, M., 2002, NGO Performance and Accountability: Introduction and Overview, in Edwards and Fowler [eds]
- IMF, 2004, *The Macroeconomics of HIV/AIDS*, IMF, Washington, DC
- ING Barings, 1999, *The demographic impact of AIDS on the South African economy*, ING Barings, Johannesburg
- Tssiaka, S., Cartoux, M., Ky-Zerbo, O., Tiendrebéogo, S., Meda, N., Van de Perre, P., 2001, Living with HIV: women's experience in Burkina Faso, West Africa, *AIDS Care*, **13**(1), pp123-128
- Jaros, L., 1992, Constructing the dark continent. metaphor as geographic representation of Africa, *Geografiska Annaler B*, **74**(2), pp105-115
- Jewkes, R., Nduna, M., Levin, J., Dunkle, K., Khuzwayo, N., Koss, M., Puren, A., Wood, K., Duvvury, N., 2006, A cluster randomized-controlled trial to determine the effectiveness of Stepping Stones in preventing HIV infections and promoting safer sexual behaviour amongst youth in the rural Eastern Cape, South Africa. trial design, methods and baseline findings, *Tropical Medicine and International Health*, **11**(3), pp3-16
- Jochelson, K., Mofhibeli, M., Leger, J., 1991, Human Immunodeficiency Virus and migrant labour in South Africa, *International Journal of Health Services*, **21**(1), pp157-173

- Jones, P., 2000, Why is it alright to do development 'over there' but not 'here'? Changing vocabularies and common strategies of inclusion across the 'First' and 'Third' Worlds, *Area*, **32**(2), pp2137-241
- Jones, P., 2004, When 'development' devastates: donor discourses, access to HIV/AIDS treatment in Africa and rethinking the landscape of development, *Third World Quarterly*, **25**(2), pp385-404
- Jones, J., Woodward, K., Marston, S., 2007, Situating flatness, *Transactions of the Institute of British Geographers*, **32**, pp264-276
- Jónsson, C., Söderholm, P., 1995, IGO-NGO relations and HIV/AIDS: innovation or stalemate?, *Third World Quarterly*, **16**(3), pp459-476
- Kaleeba, N., Kalibala, S., Kaseje, M., Ssebhanja, P., Anderson, S., Van Praag, E., Tembo, G., Katabira, E., 1997, Participatory evaluation of counselling, medical and social services of The Aids Support Organization (TASO) in Uganda, *AIDS Care*, **9**(1), pp13-26
- Kalec, A., 2003, AIDS-talk in everyday life: the presence of HIV/AIDS in men's informal conversation in Southern Malawi, *Social Science and Medicine*, **59**, pp 285-297
- Kalibala, S., Kaleeba, N., 1989, AIDS and community-based care in Uganda: The AIDS support organization TASO, *AIDS Care*, **1**(2), pp173-175
- Kalichman, S., Nachimson, D., 1999, Self-efficacy and disclosure of HIV-positive serostatus to sex partners, *Health Psychology*, **18**(3), pp281-287
- Kalichman, S., DiMarco, M., Austin, J., Luke, W., DiFonzo, K., 2003, Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women, *Journal of Behavioral Medicine*, **26**(4), pp1573-3521
- Kamat, S., 2003, Kamat, S., NGOs and the new democracy: the false saviours of international development, *Harvard International Review*, **25**(1), pp65-69
- Kamat, S., 2004, The privatization of public interest: theorizing NGO discourse in a neoliberal era, *Review of International Political Economy*, **11**(1), pp155-176
- Kanki, P., Hamel, D., Sankalé, J., Hsieh, C., Thior, I., Barin, F., Woodcock, S., Guéye-Ndiaye, A., Zhang, F., Montano, M., Siby, T., Marlink, R., NDoye, I., Essex, M., MBoup, S., 1999, Human immunodeficiency virus type 1 subtypes differ in disease progression, *Journal of Infectious Diseases*, **181**, pp76-81
- Kanki, P., Mani, I., 2003, Monitoring viral load, in *AIDS in Africa*
- Kapoor, I., 2004, Hyper-self-reflexive development? Spivak on representing the Third World 'other', *Third World Quarterly*, **25**(4), pp627-647
- Karim, A., 2005, *HIV/AIDS in South Africa*, Cambridge University Press, Cambridge
- Katz, C., 1994, Playing the field: questions of fieldwork in Geography, *Professional Geographer*, **46**(1), pp67-72

- Kearns, R., 2000, Being there: research through observing and participating, In Hay, [ed]
- Kebaabetswe, P., 2007, Barriers to participation in the prevention of mother-to-child HIV transmission program in Gaborone, Botswana. a qualitative approach. *AIDS Care*, **19**(3), pp355-360
- Kebba, A., 2003, Antiretroviral therapy in sub-Saharan Africa: myth or reality?, *Journal of Antimicrobial Chemotherapy*, **52**, pp747-749
- Keenan, J., Fuller, J., Cahill, I., Kelly, K., 2000, *Catholic ethicists on HIV/AIDS prevention*, Continuum, NY
- Kelly, P., Baboo, K., Wolff, M., Ngwenya, B., Luo, N., Farthing, M., 1996, The prevalence and aetiology of persistent diarrhoea in adults in urban Zambia, *Acta Tropica*, **61**(3), pp183-190
- Kesby, M., 2000a, Participatory diagramming: deploying qualitative methods through an action research epistemology, *Area*, **32**(4), 423-435
- Kesby, M., 2000b, Participatory diagramming as a means to improve communication about sex in rural Zimbabwe: a pilot study, *Social Science and Medicine*, **50** pp1732-1741
- Kesby, M., Kinson, S., Pain, R., 2005, 'Participatory' approaches and diagramming techniques, in Flowerdew and Martin, *Methods in Human Geography*
- Kiesler, C., 1985, Policy implications of research on social support and health, in Cohen and Syme [eds]
- Kilduff, M., Tsai, W., 2003, *Social Networks and Organisations*, Sage, London
- Kipp, W., Tindyebwa, D., Rubaale, T., Karamagi, E., Bajenja, E., 2007, Family caregivers in rural Uganda. The hidden reality, *Health Care for Women International*, **28**(10), pp856-871
- Kitchin, R., Tate, N., 2000, *Conducting Research into Human Geography: Theory, Methodology and Practice*, Pearson, Harlow
- Kitzinger, J., 1995, Qualitative research: introducing focus groups, *British Medical Journal*, **311**, pp299-302
- Koenig, R., 2007, Firing of AIDS policy champion seen as setback, *Science*, **317**(5840), pp881
- Konde-Lule, J., Musagara, M., Musgrave, S., 1993, Focus group interviews about AIDS in Rakai district of Uganda, *Social Science and Medicine*, **37**(5), pp679-684
- Korten, D., 1990, *Getting to the 21st Century: voluntary action and the global agenda*, Kumarian Press, Hartford
- Kumarasamy, N., 2004, Generic antiretroviral drugs – will they be the answer to HIV in the developing world?, *Lancet*, **364**(9428), pp3-4

Kumarasamy, N., Vallabhaneni, S., Flanigan, T., Balakrishnan, P., Cecelia, A., Carpenter, C., Solomon, S., Mayer, K., 2005, Rapid viral load suppression following generic highly active antiretroviral therapy in Southern Indian HIV-infected patients, *AIDS*, **19**(6), pp625-627

Kvale, S., 1996, *InterViews*, Sage, London

Laine, 2000, *Fieldwork, participation and practice. ethics and dilemmas in qualitative research*, Sage, London

Laireiler A., Baumann, U., 1992, Network structures and support functions, in Veiel and Baumann [eds]

Langen, T., 2005, Gender power imbalance on women's capacity to negotiate self-protection against HIV/AIDS in Botswana and South Africa, *African Health Sciences*, **5**(3), pp188-197

Lather, P., 1991, *Getting smart: feminist research and pedagogy within/in the postmodern*, Routledge, London

Laumann, E., Marsden, P., Prensky, D., 1992, The boundary specification problem in network analysis, in Freeman et al. [eds]

Law, J., Hassard, J., 1999, *Actor Network Theory and after*, Blackwells, Oxford

Lawson, V., 2007, Geographies of care and responsibility, *Annals of the association of American Geographers*, **97**(1), pp 1-11

Leigh, B., Gillmore, M., Morrison, D., 1998, Comparison of Diary and Retrospective Measures for Recording Alcohol consumption and Sexual Activity, *Journal of Clinical Epidemiology*, **31**(2), pp 119-127

Leith, C., 2005, *Why Botswana Prospered*, McGill, Ontario

Leserman, J., Jackson, E., Petitto, J., Golden, R., Silva, S., Perkins, D., Cai, J., Folds, J., Evans, D., 1999, Progression to AIDS: the effects of stress, depressive symptoms, and social support, *Psychosomatic Medicine*, **61**, pp397-406

Lett, H., Blumenthal, J., Babvak, M., Strauman, T., Robins, C., Sherwood, A., 2005, Social support and coronary heart disease. epidemiologic evidence and implications for treatment, *Psychosomatic Medicine*, **67**(6), pp869-878

Levy, L., Derby, J., 1992, Bereavement support groups: Who joins; who does not; and why, *American Journal of Community Psychology*, **20**(5), pp 649-662

Lewinter, M., 2003, Reciprocities in caregiving relationships in Danish elder care, *Journal of Aging Studies*, **17**(3), pp357-377

Liddell, C., Barrett, L., Bydowell, M., 2004, Indigenous representations of illness and AIDS in Sub-Saharan Africa, *Social Science and Medicine*, **60**(4), pp691-700

- Lin, N., Ensel, W., Simeone, R., Kuo, W., 1979, Social support, stressful life events and illness: a model and an empirical test, *Journal of Health and Social Behaviour*, **20**, pp108-119
- Lindsey, E., Hirschfeld, M., Tlou, S., 2003, Home-based care in Botswana: experiences of older women and young girls, *Health Care for Women International*, **24**(6), pp486-501
- Lipschutz, R., 2005, *Globalisation, Governmentality and Global Politics: Regulation for the rest of us?*, Routledge, NY
- Lister, S., 2000, Power in partnership? An analysis of NGO's relationships with its partners, *Journal of International Development*, **12**(2), pp227-239
- Litva, A., Eyles, J., 1995, Coming out: exposing social theory in medical geography, *Social Science and Medicine*, **37**, pp711-717
- Livingston, J., 2004, AIDS as chronic illness: epidemiological transition and health care in south-eastern Botswana, *African Journal of AIDS Research*, **3**(1), pp15-22
- Lockman, S., Sheppard, J., Braden, C., Mwasckaga, M., Woodley, C., Kenyon, T., Binkin, N., Steinman, M., Montsho, F., Kesupile-Reed, M., Hirschfeldt, C., Notha, M., Moeti, T., Tappero, J., 2001, Molecular and Conventional Epidemiology of Mycobacterium tuberculosis in Botswana: a Population-Based Prospective Study of 301 Pulmonary Tuberculosis Patients, *JCM*, **39**(3), pp1042-1047
- Lucas, G., Chaisson, E., Moore, R., 1999, Highly active antiretroviral therapy in a large urban clinic: risk factors for virologic failure and adverse drug reactions, *Annals of Internal Medicine*, **131**, pp81-87
- Lucchini, S., Cisse, B., Duran, S., Cenival, M., Comiti, C., Gaudry, M., Moatti, J., 2003, Decrease in prices of antiretroviral drugs for developing countries: from political "philanthropy" to regulated markets?, in *HIV/AIDS Care in Developing Countries: Issues and Challenges*, IAEN
- Lytleton, C., 2004, Fleeing the fire: transformation and gendered belonging in Thai HIV/AIDS support groups, *Medical Anthropology*, **23**(1), pp1-40
- Macallan, D., 1999, Nutrition and immune function in human immunodeficiency virus infection, *Proceedings of the Nutrition Society*, **58**, pp743-748
- MacDonald, D., 1996, Notes on the socio-economic and cultural factors influencing the transmission of HIV in Botswana, *Social Science and Medicine*, **42**(9), pp1325-1333
- MacQueen, K., 1994, The epidemiology of HIV transmission: trends, structure and dynamics, *Annual Review of Anthropology*, **23**, pp509-526
- Malcolm, A., Aggleton, P., Bronfman, M., Galvao, J., Mane, P., Verrall, J., 1993, HIV-related stigmatization: its forms and contexts, *Critical Public Health*, **8**, pp347-370
- Mamadouli, V., Kransch, O., Van Der Velde, M., 2004, Articulating local and global scales, *Tijdschrift voor Economische en Sociale Geografie*, **95**(5), pp455-466

- Mandel, J., 2003, Negotiating expectations in the field: gatekeepers, research fatigue and cultural biases, *Singapore Journal of Tropical Geography*, **24**, pp198-210
- Mann, J., Tarantola, D., 1992, *AIDS in the World*, Harvard University Press, Cambridge
- Mann, J., Tarantola, D., Netter, T., 1992, National AIDS plans, in Mann and Tarantola, [eds]
- Marcell, A., Klein, J., Fischer, I., Allan, M., Kokotailo, P., 2002, Male adolescent use of health care services: where are the boys?, *Journal of Adolescent Health*, **30**(1), pp35-43
- Marlink, R., Kanki, P., Thior, I., Travers, K., Eisen, G., Siby, T., Traore, I., Hsieh, C., Dia, M., Gueye, E., 1994, Reduced rate of disease development after HIV-2 infection as compared to HIV-1, *Science*, **256**, pp1587-1590
- Marmot, M., Wilkinson, R., 2005, *Social Determinants of Health*, Oxford University Press, Oxford
- Marselle, F., Hofmann, P., Kahn, J., 2002, HIV prevention before HAART, *Lancet*, **359**, pp1851-1856
- Marston, S., 2000, The social construction of scale, *Progress in Human Geography*, **24**(2), pp219-242
- Marston, S., Jones, J., Woodward, K., 2005, Human geography without scale, *Progress in Human Geography*, **30**, pp416-432
- Martin, G., 2005, *A comparative analysis of the financing of HIV/AIDS programmes*, IISRC Press, Cape Town
- Martinson, J., Chapman, N., Rees, D., Liu, Y., Clegg, J., 1997, Global distribution of the CCR5 gene 32-basepair deletion, *Nature Genetics*, **16**, pp100-103
- Marwell, P., Oliver, P., Prahl, R., 1988, Social Networks and Collective Action: A Theory of the Critical Mass. III, *The American Journal of Sociology*, **94**:3, pp502-534
- Massey, D., 1993, Power-geometry and a progressive sense of place, in Bird [ed] 1993
- Mathison, S., 1998, Why triangulate?, *Educational Researcher*, **17**(2), pp13-17
- Maunsell, E., Brisson, J., Deschenes, L., 1995, Social support and survival among women with breast cancer, *Cancer*, **76**(4), pp631-637
- May, T., 1997, *Social research: issues, methods and process*, Open University Press, Buckingham
- May, T., 2002, *Qualitative Research: Theory, Method and Practice*, London, Sage
- Mayall, B., Suzanne, H., Oliver, S., 1999, *Critical issues in social research. power and prejudice*, Open University Press, Buckingham
- McCarthy, M., 2007, The Global Fund: 5 years on, *Lancet*, **370**(9584), pp307-308

- McGuirk, P., 1997, Multiscaled interpretations of urban change: the federal, the state, and the local in the western area strategy of Adelaide, *Environment and Planning D*, **15**, pp481-491
- McKendrick, J., 1999, Multi-method research: an introduction to its application in population geography, *Professional Geographer*, **51(5)**, p40-50
- McNeill, J., Lomax, P., Whitehead, J., 2003, *You and your action research project*, Routledge, London
- Mercer, C., 2002, NGOs, civil society and democratization: a critical review of the literature, *Progress in Development Studies*, **2(1)**, pp5-22
- Mercer, C., 2006, Working with partners: NGOs and CBOs, in Desai and Potter [eds]
- Meth, P., 2003, Entries and omissions: using solicited diaries in geographical research, *Area*, **35(5)**, pp 195-205.
- Meth, P., 2004, Using diaries to understand women's responses to crime and violence, *Environment and Urbanisation*, **16(2)** pp 153-164
- Meth, P., Malaza, K., 2003b, Violent research: the ethics and emotions of doing research with women in South Africa, *Ethics, Place and Environment*, 2003, **6(2)**, pp143-159
- Michels, R., 1915, *Political parties; a sociological study of the oligarchical tendencies of modern democracy*, [accessed online 23/04/08, <http://etext.lib.virginia.edu/loc/modeng/public/MicPoli.html>]
- Miles, M., Huberman, A., 1994, *Qualitative data analysis: and expanded sourcebook*, Sage, London
- Milligan, C., 2000, Bearing the burden: towards a restructured geography of caring, *Area*, **32(1)**, pp49-58
- Ministry of Health, 2005, *Botswana second generation HIV/AIDS surveillance: technical report*, MoH, Gaborone
- Mmegi, 2006, 06/12/06, *We are dying -BONEPWA*, Mmegi, Gaborone
- Mmegi, 2007, 01/02/06, *HIV/AIDS organisations speak out on Global Fund grant*, Mmegi, Gaborone
- Mmegi, 2008, *BONEPWA to stage Mr 2008 HIV Positive Living pageant*, [accessed online 29/04/09, <http://www.mmegi.bw/index.php?sid=7&aid=12&dir=2008/April/Wednesday9>]
- Moalosi, G., Floyd, K., Phatshwane, J., Moeti, T., Binkin, N., Kenyon, T., 2003, Cost-effectiveness of home-based care versus hospital care for chronically ill tuberculosis patients, Francistown, Botswana, *The International Journal of Tuberculosis and Lung Disease*, **7(S1)**, ppS80-S85

- Mohan, G., Stokke, K., 2000, Participatory development and empowerment: the dangers of localism, *Third World Quarterly*, **21**(2), pp247-268
- Monasch, R., Boerma, J., 2004, Orphanhood and childcare patterns in sub-Saharan Africa: an analysis of national surveys from 40 countries, *AIDS*, **S2**, pp S55-S65
- Monforte, A., Lepri, A., Rezza, G., Pezzotti, P., Antinori, A., Phillips, A., Angarano, G., Colanelli, V., Luca, A., Ippolito, G., Caggese, L., Soscia, F., Filice, G., Gritti, F., Narciso, P., Tirelli, U., Moroni, M., 2000, Insights into the reasons for discontinuation of the first highly active antiretroviral therapy (HAART) regimen in a cohort of antiretroviral naïve patients, *AIDS*, **14**(5), pp499-507
- Moore, J., Doms, R., 2003, The entry of entry inhibitors: a fusion of science and medicine, *Proceedings of the National Academy of Sciences of the United States of America*, **100**(19), pp10592-10602
- Morgan D., 1993, *Successful focus groups: Advancing the state of the art*, Sage, California
- Morgan, D., Krueger, R., 1998, *The focus group kit*, Sage, California
- Morgan, D., Mahe, C., Mavanja, B., Okongo, J., Lubega, R., Whitworth, J., 2002, HIV-1 infection in rural Africa: is there a difference in median time to AIDS and survival compared with that in industrialized countries?, *AIDS*, **16**(4), pp597-603
- Morgan, D., Maude, G., Malamba, S., Okongo, M., Wagner, H., Mulder, D., Whitworth, J., 1997, HIV-1 disease progression and AIDS-defining disorders in rural Uganda, *Lancet*, **350**, pp245-250
- Morris, L., Cilliers, T., 2005, Viral structure, replication, tropism, pathogenesis and natural history, in Karim [ed]
- Morton, N., Browne, K., 1998, Theory and observation of attachment and its relation to child maltreatment: a review, *Child Abuse and Neglect*, **22**(11), pp1093-1104
- Moser, P., Mulder, D., Trout, J., 1998, *The theory of knowledge: a thematic introduction*, Oxford University Press, Oxford
- Moser, S., 2008, Personality: a new positionality?, *Area*, **40**(3), pp383-392
- Moss, G., 1973, *Illness, immunity and social interaction*, John Wiley, New York
- Moss, H., 1994, Consumption and Fertility, in Harcourt [ed]
- Moss, P., Dyck, I., 1999, Body, corporeal space, and legitimating chronic illness: women diagnosed with M.E., *Antipode*, **31**(4), pp372-397
- Mukherjee, N., 2002, *Participatory learning and action. with 100 field methods*, Concept Publishing, New Delhi
- Mullings, B., 1999, Insider or outsider, both or neither: some dilemmas of interviewing in a cross-cultural setting, *Geoforum*, **30**, pp337-350

- Mustard, C., Kaufert, P., Kozyrskyj, A., Mayer, T., 1998, Sex differences in the use of health care services, *New England Journal of Medicine*, **338**, pp1678-1683
- NACA, 2003, *Botswana national strategic framework for HIV/AIDS 2003-2009*, Government of Botswana, Gaborone
- Nachega, J., Lehman, D., Hlatshwayo, D., Mothopent, R., Chaisson, R., Karstaedt, A., 2005, HIV/AIDS and antiretroviral treatment knowledge, attitudes, beliefs and practices in HIV-infected adults in Soweto, South Africa, *JAIDS*, **38**(2), pp196-201
- NAM, 2005, *HIV & AIDS treatment directory*, NAM, London
- Nast, H., 1994, Women in the field: critical feminist methodologies and theoretical perspectives, *Professional Geographer*, **46**(1)
- Nattrass, N., 2006, South Africa's 'Rollout' of highly active antiretroviral therapy: a critical assessment, *JAIDS*, **43**(5), pp618-623
- Ndaba-Mbata, R., Seloiwe, F., 2001, Home-based care of the terminally ill in Botswana: knowledge and perceptions, *International Nursing Review*, **47**(4), pp218-223
- Nelson, N., Wright, S., 1995, *Power and Participatory Development*, ITDG, Bourton-on-Dunsmore
- New Scientist, 2007, *Legal wrangle puts India's generic drugs at risk*, [accessed online 28/05/08: <http://www.newscientist.com/article.ns?id=dn11053>]
- Nixon, J., 1997, *Line management and counselling*, in Carroll and Walton 1997 [eds]
- Nsutebu, E., Walley, J., Malaka, E., Simon, C., 2001, Scaling-up HIV/AIDS and TB home-based care: lessons from Zambia, *Health Policy and Planning*, **16**(3), pp240-247
- Ntere, N., 2001, *The role of rural co-operatives in rural development: a comparative study of Bobonong and Tonota co-operative societies*, Masters Thesis, University of Botswana, Gaborone
- Ntozi, J., 2002, *Impact of HIV/AIDS on fertility in sub-Saharan Africa*, ECA/OAU/ADB/UNECA Joint Report, Cameroon
- Nustad, K., 2001, Development - the devil we know?, *Third World Quarterly*, **22**(4), pp479-489
- Nwokoji, U., Ajuwon, A., 2004, Knowledge about AIDS and HIV risk-related sexual behaviour among Nigerian naval personnel, *BMC Public Health*, **4**(21), [accessed online Jan 2006] <http://www.biomedcentral.com/1471-2458/4/24>
- O'Leary, A., 1984, Self-efficacy and health, *Behaviour Research and Therapy*, **23**:4, pp437-451
- Oakley, A., 1999, People's way of knowing: gender and methodology, in Mayall et al. [eds]

ODI, 1995, *NGOs and official donors*, Briefing Paper 4. ODI, London

Oluwagbemiga, A., 2007, HIV/AIDS and family support systems: A situation analysis of people living with HIV/AIDS in Lagos State. *Journal of Social Aspects of HIV/AIDS*, 4(3), pp668-677

Osmond, D., Buchbinder, S., Cheng, A., Graves, A., Vittinghoff, E., Cynthia, K., Cossen, B., Forghani, B., Martin, J., 2002, Prevalence of Kaposi Sarcoma – associated herpesvirus infection in homosexual men at beginning of and during the HIV epidemic. *JAMA*, 287(2), pp221-225

Pain, R., Francis, P., 2002, Reflections of participatory research, *Area*, 35(1), pp46-54

Papadopoulos-Eleopoulos, E., Turner, V., Papadimitriou, J., Page, B., Alfonso, H., Causer, D., 2006, Would Montagnier please clarify whether HIV or oxidation by the risk factors is the primary cause of AIDS?, *Medical Hypothesis*, 67(3), pp666-668

Park, P., Bryndon-Miller, M., Hall, B., Jackson, T., 1993, *Voices of Change: Participatory Research in the United States and Canada*, Bergin and Garvey, Westport

Parker, R., 2001, Sexuality, culture and power in HIV/AIDS research, *Annual Review of Anthropology*, 30, pp163-179

Parkhurst, J., 2001, The crisis of AIDS and the politics of response, *International Relations*, 15(6), pp69-78

Parks, T., 2008, The rise and fall of donor funding for advocacy NGOs: understanding the impact, *Development in Practice*, 18(2), pp213-222

Parpart, J., 2002, Rethinking Participatory Empowerment, gender and development, in Parpart et al [eds]

Parpart, J., Rai, S., Staudt, K., 2002, *Rethinking Empowerment: Gender and Development in a Global/Local World*, Routledge, London

Parr, H., 2002, Medical geography: diagnosing the body in medical and health geography 1999–2000, *Progress in Human Geography*, 26(2), pp240-251

Parr, H., 2003, Medical geography: care and caring, *Progress in Human Geography*, 27(2), pp212-221

Pasquini, M.W., Olaniran, O. (2004) The researcher and the field assistant: a cross-disciplinary, cross-cultural viewing of positionality *Interdisciplinary Science Reviews*, 29 (1) 24-36

Patterson, A., 2005. *The African state and the AIDS crisis*, Ashgate, Aldershot

Patton, C., 1990, What Science Knows: Formulations of AIDS Knowledges, in Aggleton et al [eds] 1990

Patton, M., 1980, *Qualitative evaluation methods*, Sage, London

- Paxton, S., 2002, The paradox of public HIV disclosure, *AIDS Care*, **14**(4), pp559-567
- Pennisi, E., 2008, Revising HIV's history, ScienceNOW, [accessed online 16/08/08: <http://sciencenow.sciencemag.org/cgi/content/full/2008/625/1>]
- Pescosolido, B., 1992, Beyond rational choice: The social dynamics of how people seek help, *American Journal of Sociology*, **97**(4), pp 1096-1098
- Philips, A., 1999, HIV dynamics: lessons from the use of antiretrovirals, in Dalgleish and Weiss [eds]
- Pilcher, C., Miller, W., Beatty, Z., Eron, J., 1999, Detectable HIV-1 RNA at levels below quantifiable limits by Amplicor HIV-1 monitor is associated with virologic relapse on antiretroviral therapy, *AIDS*, **13**(11), pp1337-1342
- Pilisuk, M., Parks, S., 1986, *The Healing Web. Social Networks and Human Survival*, University Press of New England, NY
- Pinfold, V., 2000, 'Building up safe havens .. all around the world' users' experiences of living in the community with mental health problems, *Health and Place*, **6**(3), pp201-212
- Poku, N., Whiteside, A., 2004, *The Political Economy of AIDS in Africa*, Ashgate, London
- Pope, C., Ziebland, S., Mays, N., 2000, Qualitative research in health care: analysing qualitative data, *BMJ*, **320**, pp1140-116
- Portes, A., 1998, Social capital: it's origins and applications in modern sociology, *Annual Review of Sociology*, **24**(1), pp1-24
- Powell, T., 1990, *Working with self-help*, NASW Press, Maryland
- Proval, K., Sebastian, J., 1998, Networks within networks: service link overlap, organisational cliques, and network effectiveness, *Academy of Management Journal*, **41** 4, pp453-363
- Provan, K., Milward, H., Do networks really work? A framework for evaluating public sector organizational networks, *Public Administration Review*, **61**(4), pp414-423
- Putnam, H., 1983, *Realism and reason*, Cambridge University Press, Cambridge
- Putnam, R., 1995, *Bowling Alone: The Collapse and Revival of American Community*, Simon and Schuster, New York
- Putnam, R., 2007, E Pluribus Unum: Diversity and community in the twenty-first century, *Scandinavian Political Studies*, **30**:2, pp137-174
- Putzel, J., 2004, The politics of action on AIDS: a case study of Uganda, *Public Administration and Development*, **24**, pp19-30

- Quinn, T., 1994, Population migration and the spread of types 1 and 2 human immunodeficiency viruses. *Proceedings of the National Academy of Science of the United States of America*, **91**, pp2407-2414
- Rallanti, S., Fusco, J., Sherrill, B., Hansen, N., Justice, A., D'Aquila, R., Mangialardi, W., Fusco, G., 2004, Effect of persistent moderate viremia and HIV disease progression during HIV therapy. *J AIDS*, **37**(1), pp1147-1154
- Ramjee, G., Gouws, E., 2002, Prevalence of HIV among truck drivers visiting sexworkers in KwaZulu-Natal, South Africa. *Sexually Transmitted Diseases*, **29**(1), pp44-49
- RBM, 2005, *World Malaria Report 2005*, WHO/UNICEF, Geneva
- Reason, P., Bradbury, H., 2001, *Handbook of action research. participative inquiry and practice*, Sage, London
- Reeves, P., Merriam, S., Courtenay, B., 1999, Adaptation to HIV infection: the development of coping strategies over time. *Qualitative Health Research*, **9**(3), pp344-361
- Reinhardt, J., Boerner, K., Horowitz, A., 2006, Good to have but not to use: Differential impact of perceived and received support on well-being. *Journal of Social and Personal Relationships*, **23**(1), pp117-129
- Reunilo, B., Fawzi, W., Mwakagile, D., Hunter, D., Msamanga, G., Spiegelman, D., Garland, M., Kagoma, C., Kim, A., Chaplin, B., Hertzmark, E., Essex, E., 2001, Differences in perinatal transmission among human immunodeficiency virus type 1 genotypes. *Journal of Human Virology*, **4**(1), pp16-25
- Renwick, N., 2007, Global Society's Response to HIV/AIDS: Botswana's Experience. *Global Society*, **21**(2), pp133-153
- Reuzelli, C., Lee, R., 1993, *Researching Sensitive Topics*, Sage, London
- Richman, D., Meng, T., Spector, S., Fischl, M., Resnick, L., Lai, S., 1994, Resistance to AZT and ddC during long-term combination therapy in patients with advanced infection with human immunodeficiency virus. *Journal of Acquired Immune Deficiency Syndrome*, **7**(2), pp 135-138
- Risse, T., 2002, Transnational actors and world politics, in Carlsnaes et al [eds]
- Robson, E., 2000, Invisible carers. young people in Zimbabwe's home-based healthcare. *Area*, **32**, pp59-70
- Roca, B., Gomez, C., Amedo, A., 2000, Adherence, side effects and efficacy of stavudine plus lamivudine plus nevirapin in treatment-experienced HIV-infected patients. *Journal of Infection*, **41**(1), pp50-54
- Rose, G., 1997, Situating knowledges: positionality, relexivities and other tactics. *Progress in Human Geography*, **21**(3), pp 305-320

- Rosenau, J., 2002. Governance in a New Global Order. in Held and McGrew [eds] (2002)
- Rothenberg, R., Narramore, J., 1996, Commentary. The relevance of social network concepts to sexually transmitted diseases control, *Sexually Transmitted Diseases*, **23**(1), pp24-29
- Rothenberg, R., Potterat, J., Woodhouse, D., Muth, S., Darrow, W., Klovdahl, A., 1998, Social network dynamics and HIV transmission, *AIDS*, **12**(12), pp1529-1536
- Rugalema, G., 2004, Understanding the African HIV epidemic, In *HIV and AIDS in Africa*, Kalipeni et al. Blackwell, Oxford
- Russel, M., Schneider, H., 2000, *A rapid appraisal of community-based HIV/AIDS care and support programs in South Africa*, University of Witwatersrand, Johannesburg
- Russell, B., 2006, *Research Methods in Anthropology*, Sage, London
- Sarason, B., Sarasib, I., Pierce, G., 1990, *Social support: an interactional view*, John Wiley, New York
- Schatz, E., Ogunme, C., 2005, *Caring and contributing, the role of older women in multigenerational households in the HIV/AIDS era*, Population Ageing Center, Colorado
- Schatzman, L., Strauss, A., 1973, *Field Research*, Prentice Hall, NY
- Schmit, J., Cogiaux, J., Hermans, P., Van Vaecq, C., Sprecher, S., Van Remoortel, B., Witvrouw, M., Balzarini, J., Desnyter, J., De Clercq, E., Vandamme, A., 1996, Multiple drug resistance to nucleoside analogues and nonnucleoside reverse transcriptase inhibitors in an efficiently replicating human immunodeficiency virus type 1 patient strain, *Journal of Infectious Diseases*, **175**(5), pp962-968
- Schuerman, L., Seynhaeve, V., Bachschmidt, I., Tchotch, V., Quattara, S., de The, G., 1988, Severe malnutrition and paediatric AIDS diagnostic problem in rural Africa, *AIDS*, **2**, pp232-233
- SCN, 2004, *5th report in the world nutrition situation: nutrition for improved development outcomes*, United Nations System Standing Council on Nutrition, NY
- Seeley, J., Wagner, U., Mulemwa, J., Kengeya-kayondo, J., Mulder, D., The development of a community-based HIV/AIDS counselling service in a rural area in Uganda, *AIDS Care*, **3**(2), pp207-217
- Seibel, W., Anheier, H., 1990, *The third sector. comparative studies of non-profit organisations*, Walter de Gruyter, Berlin
- Semba, R., Tang, A., Micronutrients and the pathogenesis of human immunodeficiency virus infection, *British Journal of Nutrition*, **81**, pp181-189

- Sethi, A., Celentato, D., Gange, S., Moore, R., Gallant, J., 2003, Association between Adherence to antiretroviral therapy and human immunodeficiency virus drug resistance, *Clinical Infectious Diseases*, **37**, pp1112-1118
- Shaibu, S., 2007, Ethical and cultural considerations in informed consent in Botswana, *Nursing Ethics*, **14**(4), pp503-509
- Shaibu, S., Wallhagen, M., 2002, Family caregiving of the elderly in Botswana. Boundaries of culturally acceptable options and resources, *Journal of Cross-Cultural Gerontology*, **17**:2, pp139-154
- Shannugam, V., Switzer, W., Nkengasong, J., Garcia-Lema, G., Green, T., Ekpini, E., Sassan-Morokro, M., Antunes, F., Manshino, K., Soriano, V., Wiktor, S., Heneine, W., 2000, Lower HIV-2 plasma viral loads may explain differences between the natural histories of HIV-1 and HIV-2 infections, *JAHDS*, **23**(3), pp257-263
- Shenton, A., Hayter, S., 2004, Strategies for gaining access to organisation and informants in qualitative studies, *Education for Information*, **22**(3-4), pp223-231
- Shepard, R., Schock, J., Robertson, K., Slugars, D., Dyer, J., Verazza, P., Hall, C., Cohen, M., Fiscus, S., 2000, Quantitation of Human Immunodeficiency Virus type 1 RNA in different biological compartments, *Journal of Clinical Microbiology*, **38**(4), pp1414-1418
- Shilts, R., 1988, *And the band played on*, Penguin, NY
- Shneiderman, B., 2004, *Leonardo's Laptop: Human Needs and the New Computing Technologies*, MIT Press, Cambridge, Mass.
- Shumaker, S., Brownell, A., 1984, Toward a theory of social support: closing the gaps, *Journal of Social Issues*, **40**, pp11-36
- Shumate, M., Falk, J., Monge, P., 2005, Predictors of the international HIV-AIDS INGO network over time, *Human Communication Research*, **31**(4), pp482-510
- Siegel, K., Schrimshaw, E., 2002, The perceived benefits of religious and spiritual coping among older adults living with HIV/AIDS, *Journal for the Scientific Study of Religion*, **41**(1), pp91-102
- Silverman, D., 2000, Analyzing talk and text, in Denzin and Lincoln [eds]
- Simon, S., 1996, *Gender in translation: cultural identity and the politics of transmission*, Routledge, London
- Singh, S., Darroch, J., Bankole, A., 2004, A, B and C in Uganda: the roles of abstinence, monogamy and condom use in HIV decline, *Reproductive Health Matters*, **12**(23), pp129-135
- Singleton, A., 2008, 'It's because of the invincibility thing': Young men, masculinity and testicular cancer, *International Journal of Men's Health*, **7**(1), pp40-58

Sivaram, S., Johnson, S., Bentley, M., Srikrishnan, A., Lalkin, C., Go, V., Solomon, S., Celentano, D., 2007. Exploring 'wine shops' as a venue for HIV prevention interventions in Urban India, *Journal of Urban Health*, **84**(4), pp563-576

Skogmar, S., Shakely, D., Lnas, M., Danell, J., Andersson, R., Tshandu, N., Odén, A., Roberts, S., Venter, W., 2006. Effect of antiretroviral treatment and counselling on disclosure of HIV-serostatus in Johannesburg, South Africa. *AIDS Care*, **18**(7), pp725-730

Skumick, J., Abrams, J., Kennedy, C., Valentine, S., Cordell, J., 1998. Maintenance of safe sex behaviour by HIV-serodiscordant heterosexual couples. *AIDS Education and Prevention*, **10**(6), pp493-505

Smith, F., 1996. Problematising language. limitations and possibilities in 'foreign language' research. *Area*, **28**(2)

Smith, J., 1983. Quantitative versus qualitative. an attempt to clarify the issue. *Educational Researcher*. **15**(1), pp4-12

Smith, J., Jarman, M., Osborn, M., 1999, *Qualitative Health Psychology*, Sage, London

Smith, M., Martinez-Jones, Anyama, N., 2002, *Generic competition, price and access to medicines: the case of antiretrovirals in Uganda*, Briefing paper 26, Oxfam, Oxford

Smith, N., 1993, Homeless/global: Scaling places, in Bird [ed] 1993

Smith, N., Shaw, T., Berry, N., Vella, C., Okorafor, L., Taylor, D., Ainsworth, J., Choudhury, A., Daniels, R., El-Gadei, S., Fakoya, A., Moyle, G., Oxford, J., Tedder, R., O'Shea, S., de Ruiter, A., 2001, Anti-retroviral therapy for HIV-2 infected patients. *Journal of Infection*. **42**(2), pp126-133

Smith, S., Easterlow, D., 2005, The strange geography of health inequalities. *Transactions of the Institute of British Geographers*, **30**(2), pp173-190

Smyth, F., 2005, Medical geography: therapeutic places, spaces and networks. *Progress in Human Geography*, **29**(4), pp488-495

Snow, R., Craig, M., Deichmann, U., Marsh, K., 1999. Estimating mortality, morbidity and disability due to malaria among Africa's non-pregnant population. *Bull World Health Organ*, **77**(8), pp 624-640

Sontag, S., 1989, *AIDS and its metaphors*, Farrar, NY

Sobhayan, V., 2003, Ethics, truth and politics in constructivist qualitative research. *Westminster Studies in Education*, **26**(2), pp107-123

Sowell, R., Seals, B., Moneyham, L., Demi, A., Cohen, L., Brakes, S., 1997, Quality of life in HIV-infected women in the south-eastern United States. *AIDS Care*, **9**(5), pp501-512

- Spire, B., Duran, S., Souville, M., Lepout, C., Raffi, F., Moatti, J., 2002, Adherence to highly active antiretroviral therapies (HAART) in HIV-infected patients: from a predictive to a dynamic approach, *Social Science and Medicine*, **54**, pp1481-1496
- Spirig, R., 1997, Support groups for people living with HIV/AIDS: a review of literature, *Journal of the Association of Nurses in AIDS care*, **9(4)**, pp43-55
- Spivak, G., 1989, Subaltern studies: deconstructing historiography, in Guha and Spivak [eds]
- Stanic, A., Schneider, T., 2005, Overview of antiretroviral agents in 2005, *Journal of Pharmacy Practice*, **18(4)**, pp228-246
- Stansfield, S., 1999, Social support and social cohesion, in Marmot and Wilkinson [eds]
- Staw, B., Sutton, R., 2000, *Research in Organizational Behavior*, JAI Press, Greenwich
- Steinberg, M., Johnson, S., Schierhout, G., Ndegwa, D., 2002, *Hitting Home: How Households cope with the impact of the HIV/AIDS epidemic*, Kaiser, California
- Stevens, P., Hall, J., 1998, Participatory action research for sustaining individual and community change: a model of HIV prevention education, *AIDS Education and Prevention*, **10(5)**, pp387-402
- Stine, G., 2000, AIDS update 2000, Prentice-Hall, New Jersey
- Stirrat, R., Henkel, H., 1997, The development gift: the problem of reciprocity in the NGO world, *ANNALS*, **554(1)**, pp66-80
- Stoecker, R., 1999, Are Academics Irrelevant in Participatory Research?, *American Behavioural Scientist*, **42(5)**, pp840-854
- Stopka, T., Springer, K., Khoshnood, K., Shaw, S., Singer, M., 2004, Writing about Risk: Use of Daily Diaries in Understanding Drug-User Risk Behaviors, *AIDS and Behaviour*, **8(1)**
- Stringer, E., 1996, *Action Research*, Sage, London
- Stulberg, J., Buckingham, S., 1988, Parallel issues for AIDS patients, families, and others, *Social Casework: The Journal of Contemporary Social Work*, **69(6)**, pp355-359
- Surr, F., Kaba, M., 2000, The role of religious leaders in HIV/AIDS prevention, control, and patient care and support, *Northeast African Studies*, **7(2)**, pp59-79
- Swyngedouw, E., 2000, Authoritarian governance, power, and the politics of rescaling, *Environment and Planning D*, **18**, pp63-76
- Tandon, R., 2002, 'Board Games': Governance and accountability in NGOs, in Edwards and Fowler [eds]
- Tashima, K., Carpenter, C., 2003, Fusion inhibition – a major but costly step forward in the treatment of HIV-1, *New England Journal of Medicine*, **348(22)**, pp2249-2250

- Taylor, I., Williams, P., 2004, *Africa in International Politics*, Routledge London
- Temple, B., Edwards, R., 2001, Interpreters/translators and cross-language research: reflexivity and border crossings, *International Journal of Qualitative Methods*, **1**(2)
- Thapar-Björkert, S., Henry, M., 2004, Reassessing the research relationship: location, position and power in fieldwork accounts, *International Journal of Social Research Methodology*, **7**(5), pp363-381
- Thomas, F., 2006, Stigma, fatigue and social breakdown: Exploring the impacts of HIV/AIDS on patient and carer well-being in the Caprivi Region, Namibia, *Social Science and Medicine*, **63**(12), pp3174-3187
- Thompson, P., Dutton, R., Hayashi, K., Toga, A., Lopez, O., Aizenstein, H., Becker, J., Thinning of the cerebral cortex visualized in HIV/AIDS reflects CD4+ T lymphocyte decline, *Proceedings of the National Academy of Sciences of the United States of America*, **102**(43), pp15647-15652
- Transparency International, 2007, Global Corruption Report 2007, [accessed online http://www.transparency.org/publications/gcr/download_gcr]
- Turner, H., Catania, J., 1997, Informal caregiving to persons with AIDS in the United States: Caregiver burden among central cities residents eighteen to forty-nine years old, *American Journal of Community Psychology*, **25**(1), pp35-59
- Twyman, C., Morrison, J., Sporton, D., 1999, The Final Fifth: Autobiography. Reflexivity and Interpretation in Cross-cultural Research, *Area*, **31**(4), 313-325
- Uchino, B., Cacioppo, J., Kiecolt-Glaser, J., 1996, The relationship between social support and physiological processes: a review with emphasis on underlying mechanisms and implications for health, *Psychological Bulletin*, **119**(3), pp488-531
- UNAIDS, 2003, *AIDS epidemic update*, UNAIDS, Geneva
- UNAIDS, 2007, *AIDS epidemic update December 2007*, UNAIDS, Geneva
- UNAIDS, 2008, *AIDS epidemic update December 2008*, UNAIDS, Geneva
- Uphoff, N., 1995, Why NGOs are not a third sector: a sectoral analysis with some thoughts on accountability, sustainability and evaluation, in Edwards and Hulme 1995
- US Department of State, 2006, *Botswana: Country reports on human rights practices*, [accessed online 23/01/07: <http://www.state.gov/g/drl/rls/hrrpt/2006/78720.htm>]
- USAID, UNICEF, UNAIDS, 2004, *Children on the brink 2004: A joint report of new orphan estimates and a framework for action*, USAID, Washington DC
- Vakil, A., 1997, Confronting the classification problem: Toward a taxonomy of NGOs, *World Development*, **25**(12), pp2057-2070
- Valentine, G., 2005, Tell me about .. using interviews as a research methodology, in Flowerdew and Martin [eds]

- Van Damme, W., Kober, K., Laga, M., 2006, The real challenges for scaling up ART in sub-Saharan Africa, *AIDS*, **20**(5), pp653-656
- Veenstra, N., 2004, *The actual burden of HIV/AIDS on the KwaZulu-Natal Provincial Health Service (Work in progress)*, HEARD, Durban
- Veiel, H., Baumann, U., 1992, *The meaning and measurement of social support*, Hemisphere, NY
- Verhoeff, F., Brabin, B., Hart, A., Chimsuku, L., Kazembe, P., Broadhead, R., 1999, Increased prevalence of malaria in HIV-infected pregnant women and its implications for malaria control, *Tropical Medicine and International Health*, **4**(1), pp5-12
- Visser, A., Mhone, H., 2001, Needs Assessment Report: People Living with HIV/AIDS in Botswana, COCEPWA, Gaborone
- Visser, M., Mundell, J., 2008, Establishing support groups for HIV-infected women. Using experiences to deliver guiding principles for project implementation, *Journal of Social Aspects of HIV/AIDS*, **5**(2), pp 65-73
- Wagner, G., 2002, Predictors of antiretroviral adherence as measured by self-report, electronic monitoring, and medication diaries, *AIDS Patient Care and STDs*, **16**(12), pp599-608
- Wasserman, S., Faust, K., 1994, *Social Network Analysis: Methods and Applications*, Cambridge University Press, Cambridge
- Watters, J., Biernacki, P., 1989, Targeted sampling: options for the study of hidden populations, *Social Problems*, **36**(4), pp416-430
- Webb, D., 1997, *HIV and AIDS in Africa*, Pluto Press, London
- Webb, D., 2004, Legitimate actors? The future roles for NGOs against HIV/AIDS in Sub-Saharan Africa. in Poku and Whiteside [Eds]
- Webner R., Rainer, T., 1996, *Postcolonial Identities in Africa*, Zed Books, London
- Weiser, S., Heisler, M., Leiter, K., Percy-de Korte, F., Tlou, S., DeMonner, S., Phaladze, N., Bangsberg, D., Iacopino, V., 2006a, Routine HIV Testing in Botswana: A Population-Based Study on Attitudes, Practices, and Human Rights Concerns, *PLoS Med*, **3**(7), e261
- Weiser, S., Leiter, K., Bangsberg, D., Butler, L., Percy-de Korte, F., Hlanze, Z., Phaladze, N., Iacopino, V., Heisler, M., 2007, Food insufficiency is associated with high-risk sexual behaviour among women in Botswana and Swaziland, *PLoS Med*, **4**(10), e260
- Weiser, S., Leiter, K., Heisler, M., McFarland, W., Percy-de Korte, F., DeMonner, S., Tlou, S., Phaladze, N., Iacopino, V., Bangsberg, D., 2006b, A population-based study on alcohol and high-risk sexual behaviours in Botswana, *PLoS Med*, **3**(10), e392

Weiser, S., Wolfe, W., Bangsberg, D., Thior, I., Gilbert, P., Makhema, J., Kebaabetswe, P., Dickenson, D., Mompoti, K., Essex, M., Marlink, R., 2003, Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *JATDS*, **34**(3), pp281-288

Welbourn, A., 1995, *Stepping Stones: A Training Package on HIV/AIDS, Communication and Relationship Skills*, ActionAid, London

Wellman, B., 1983, Network Analysis: Some Basic Principles, *Sociological Theory*, **1**, pp155-200

Wengraf, T., 2001, *Qualitative Research Interviewing: Biographic Narrative and Semi-Structured Methods*, Sage, London

Wester, C., Kim, S., Bussmann, H., Ayalos, A., Ndwapi, N., Peter, T., Gaolathe, T., Mujugira, A., Busang, L., Vanderwerker, C., Cardillo, P., Johnson, O., Thior, I., Mazonde, P., Mollat, H., Essex, M., Marlink, R., 2005, Initial response to highly active antiretroviral therapy in HIV-1C infected adults in a public sector treatment program in Botswana, *JATDS*, **40**(3), pp336-343

WGSG, 1997, *Feminist Geographies: Explorations in Diversity and Difference*, Longman, London

Whaites, A., 2000, Let's get civil society straight: NGOs, the state, and political theory, in *Eade 2000*

White, H., 1992, *Identity and Control: A Structural Theory of Social Action*, Princeton University Press

Whiteside, A., 2002, Poverty and HIV/AIDS in Africa, *Third World Quarterly*, **23**(2), pp313-332

Whiteside, A., Andrade, C., Arrehag, T., Dlamini, S., Ginindza, T., Parikh, A., 2006, *The socio-economic impact of HIV/AIDS in Swaziland*, HEARD, Durban

Whittaker, J., Garabino, J., 1983, *Social support networks*, Hawthorne, New York

WHO 2003a, *Nutrient requirements for people living with HIV/AIDS: report of a technical consultation*, [accessed online November 2005]
http://who.int/nut/documents/hivaids_nut_require.pdf

WHO and FAO, 2002, *Living well with HIV/AIDS. a manual on nutritional care and support for people living with HIV/AIDS*, WHO, Geneva

WHO, 1946, *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference*, WHO, New York

WHO, 2003, *Antiretroviral therapy in primary health care: experience of the Khayelitsha programme in South Africa*, WHO, Geneva

Wiggins, S., 2005, *Southern Africa's food and humanitarian crisis of 2001-04. causes and lessons*, Overseas Development Institute, London

Williams, A., 2002, Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space, *Social Science and Medicine*, **55**(1), pp141-154

Williamson, O., 1985, *The Economic Institutions of Capitalism*, Free Press, New York

Wilton, R., 1996, Diminished worlds? The geography of everyday life with HIV/AIDS, *Health and Place*, **2**(2), pp69-83

Winkler, C., O'Brian, S., 2003, Effect of genetic variation on HIV transmission and progression to AIDS, in Essex et al [eds]

Wise, J., 2006, Access to AIDS medicines stumbles on trade rules, *Bulletin of the World Health Organisation*, **84**(5), pp340-344

Wituk, S., Shepherd, M., Warren, M., Meissen, G., 2002, Factors contributing to the survival of self-help groups, *American Journal of Community Psychology*, **30**(3), pp349-366

Woods, N., 2002, Global governance and the role of institutions, in Held and McGrew (2002)

Woods, T., Ironson, G., 1999, Religion and spirituality in the face of illness: how cancer, cardiac and HIV patients describe their spirituality/religiosity, *Journal of Health Psychology*, **4**(3), pp393-412

World Bank, 2002, *Education and HIV/AIDS: a window of hope*, World Bank, Washington DC

World Bank, 2005, *World Development Report: 2006*, World Bank, Washington DC

World Bank, 2007, *Gross national income per capita 2007, Atlas method and PPP*, [accessed online 16/08/08]
<http://siteresources.worldbank.org/DATASTATISTICS/Resources/GNTPC.pdf>

World Bank, 2007, World Development Indicators Online, [accessed online 7/02/08]:
<http://devdata.worldbank.org/dataonline>

Wulfert, E., Wan, C., 1993, Condom use: a self-efficacy model, *Health Psychology*, **12**(5), pp346-353

Yanos, P., Rosenfield, S., Horvitz, A., 2001, Negative and supportive social interactions and quality of life among persons diagnosed with severe mental illness, *Behavioural Science*, **37**(5), pp1573-2789

Zaidi, S., 1999, NGO failure and the need to bring back the state, *Journal of International Development*, **11**, pp259-271

Zyderduin, J., 2004, *The buddy system of care and support for and by women living with HIV/AIDS in Botswana*, PhD Thesis, University of South Africa