An Investigation into the Levels of Support Mechanism Access by Disadvantaged HIV-Positive Individuals and their Households

Honours Dissertation

By
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The South African urban poor are increasingly feeling the affects of HIV. With little resources at their disposal they are often reliant on informal social networks and formal external support mechanisms to assist them to cope with the impacts of the disease. This paper is an investigation into the levels of support mechanism access by disadvantaged HIV infected individuals and their households. The three objectives guiding the study are firstly to investigate levels of support mechanism access, secondly to identify factors constraining access and thirdly to assess whether the first two objectives contribute to individual and household vulnerability. A vulnerability perspective was applied to uncover factors driving vulnerability. Five key areas were investigated: financial resources, access to health care, psychosocial support, access to information and environmental conditions. In depth interviews were undertaken with HIV positive individuals as well as participant observation in an outpatient setting at Delft Community Health Centre, Western Cape, South Africa. The results reveal under-usage of available support mechanisms, in both formal and informal spheres. The main factors constraining access were stigma, poor service integration, endemic unemployment and issues of acceptability. Key areas of vulnerability identified were financial and food insecurity as well as an absence of emotional support. Intricate connections between each of the five areas highlighted the need for a multi-sectoral and multi-disciplinary approach to effectively address the factors constraining use of support mechanisms.
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## Glossary of Terms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
</tr>
<tr>
<td>CBO</td>
<td>Community Based Organisation</td>
</tr>
<tr>
<td>DFID</td>
<td>Department for International Development</td>
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<tr>
<td>GEAR</td>
<td>Growth Employment and Redistribution</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People/Persons Living with HIV/AIDS</td>
</tr>
<tr>
<td>RDP</td>
<td>Reconstruction and Development Programme</td>
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<tr>
<td>STI</td>
<td>Sexually Transmitted Infection</td>
</tr>
<tr>
<td>TAC</td>
<td>Treatment Action Campaign</td>
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<tr>
<td>TAG</td>
<td>Treatment Action Group</td>
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<tr>
<td>VCT</td>
<td>Voluntary Counseling and Testing</td>
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HIV and AIDS have been defined as a disaster in terms of morbidity, mortality as well as in terms of secondary effects. The third world and more particularly sub-Saharan Africa, has been disproportionately affected, where 70 per cent of all new infections and 80 per cent of deaths occur (Global Policy Forum 2000). Furthermore, since AIDS deaths have been recorded – early 1980’s – 83 per cent of the world's deaths have occurred in this region. However these are not the sole disasters related to this disease.

Rate of progression – first infection to death – is five times faster in developing countries than in the developed world (Holden 2003). While a citizen in the developed world can live for as long as ten years, third world citizens have an average of two years to live after being infected.

South Africa has been particularly undermined by this epidemic, where AIDS is now the highest cause of death (Bachmann & Booysen 2003). The South African Government, in response to this, launched the Operational Plan for Comprehensive HIV and AIDS Care and Management for South Africa. Part of this plan addresses the problem of longevity and aims to slow progression from HIV to AIDS as well as maximise health. The plan proposes to do this by embracing clients into a continuum of care which includes: medical intervention (palliative care); counseling to promote healthy living and HIV awareness, nutritional assistance (information as well as food parcels; community-linked prevention strategies (home-based care) and anti-retroviral dispensation (dependent on stage of illness). The government also advocates a multi-sectoral approach which encourages – non-governmental organizations (hereafter NGO), community-based organizations (hereafter CBO), Media, Civil Society and Traditional healers to become active in the ‘fight against HIV/AIDS’ (South African Minister of Health, Dr Tshabalala-Msimang, Statement 2003, Government Communications 2003).

The populations most severely affected – in terms of infection levels – in South Africa are the urban poor (Ntuli et al. 2003, van Donk 2002) who are dependent on public clinics and hospitals for care (Benatar 2001). As mentioned by Holden (2003) the
rate of progression of the HI virus is determined by a range of factors including access to income, supportive social structures as well as access to assistance from the state.

In light of the effects of the aforementioned on disease progression the aim of this study is to assess the levels of support accessed by individuals infected with HIV and their households and whether this affects their vulnerability. Vulnerability in this study refers to “vulnerable to the likely impacts of HIV once transmission has taken place” (Holden 2003) and refers not only to the infected member but also affected household members. The three objectives are firstly to assess what support mechanisms are accessed, secondly to investigate barriers to accessing these and lastly to determine whether the mechanisms used and the current limitation affects vulnerability.

The remainder of this paper is organised as follows: Section 2 provides a literature review highlighting aspects of vulnerability common to urban PLWHA in South Africa. Section 3 describes the methodology employed and the study site. Section 4 presents the results for the support mechanisms accessed, factors constraining access to support mechanisms and affects of these on vulnerability. Lastly section 5 presents a discussion of the findings, the concluding remarks and recommendations for future research.
Chapter 2

2.1) Literature Review
Published literature on HIV and AIDS in developing countries is vast. This investigation applied a vulnerability perspective through which to view factors affecting people living with HIV and AIDS (hereafter PLWHA) and their households. The vulnerability perspective focuses on the internal aspects of risk, those prevailing or consequential conditions composed of physical, socioeconomic and/or political factors that adversely affect ability to respond to events\(^1\) (Jegillos 1999).

Two primary frameworks were used, firstly to uncover the unsafe conditions within which disadvantaged PLWHA live and secondly to investigate how these affect their vulnerability.

Firstly the British government’s Department for International Development’s (DFID) framework was used to develop an alternative framework. This alternative framework was used to illustrate how access to support mechanisms interact with individual and household vulnerability (as shown in Figure 1). Access is a function of both available support mechanisms and constraining factors, and this is termed possible transforming mechanisms. Livelihoods assets are the sources which people can draw on to cope with and recover from stress and shocks. This framework provided a more inclusive lens through which to view the constraints imposed and needs incurred due to HIV (versus a solely health related framework).

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\(^1\) For example in the case of HIV the adverse conditions may be poor living conditions, decreased income due to illness induced loss of employment and political exclusion (e.g. minority groups). These factors threaten the ability of PLWHA and their households to cope with the impacts of the illness.
Livelihood Assets:

**H - Human capital** refers to the skills, knowledge, ability to labour and the good health necessary to pursue different livelihood strategies

**E - Environmental capital** refers to the quality of the natural and built environment

**F - Financial capital** refers to the financial resources available to people whether this be savings, supplies of credit or regular remittances or pensions — and which provide them with different livelihood options.

**P - Physical capital** represents the basic infrastructure, including: transport, shelter, water and energy that enable people to pursue livelihoods

**S - Social capital** represents the social resources including: networks, memberships of groups, relationships of trust and access to wider institutions of society — upon which people draw in the pursuit of livelihoods

Figure 1: Interaction of individual and household vulnerability with livelihood assets and possible transforming mechanisms (as a function of constraints and Support Mechanisms).

This altered DFID framework was used in conjunction with Blaikie et al.'s (1994) Progression of Vulnerability to identify the unsafe conditions which undermine WHA as well as their households' capacities to deal with the impacts of HIV.

Applying these two frameworks to additional key literature sources highlighted the five areas, as important in this regard, that is as having the ability increase vulnerability. The five focus areas investigated were:

- Financial Support
- Access to Health Care
- Psychosocial Support
- Access to Information
- Environmental Factors

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2 In the original DFID framework environmental capital reads natural capital — the natural resource stocks from which resource flows useful for livelihoods are derived (DFID). For the urban context within which this study arises however, the quality of built and natural environment are of concern not as stocks from which resources flow but rather in terms of conditions allowing for safe/healthy living.
The investigation into support mechanisms accessed has been undertaken with respects to the first four areas. Environmental conditions were investigated specifically as the study is concerned with disadvantaged urban residents whom the literature often states lives on marginal areas\(^3\) (Pelling 2003). This allowed the results to be placed in a more specific context.

2.2) Focus on Progression of Vulnerability

“The late twentieth century plague known as AIDS is an out-of-control disaster, rooted primarily in human behaviour and volatile social and economic conditions”

\[(Hewitt 1997)\]

The Progression of Vulnerability traces through a series of levels of social factors that generate vulnerability. The root causes are the most distant of these factors, these are set of widespread processes within a society and the world economy (Blaikie et al 1994). Dynamic pressures are those processes that ‘translate’ the root conditions into the vulnerability of unsafe conditions. Unsafe conditions are the most proximal factors, ‘the specific forms in which the vulnerability of a population is expressed in time and place with a hazard’ (Blaikie et al. 1994). The hazard in this study is HIV infection (as well as tuberculosis and other opportunistic diseases). The unsafe conditions are those conditions that make PLWHA and their households vulnerable to the likely impacts of HIV.

This progression is shown in Figure 2. The results of this progression are presented below corresponding to the five focus presented above.

\(^{3}\) Pelling (2003) describes marginal areas as being exposed to environmental risks, having poor quality housing, and inadequate provision of basic services.
Chart 1: The progression of vulnerability resulting in unsafe conditions which may undermine PLWHA and their household’s ability to cope with the impacts of HIV (*Note this is also dependent on factors specific to the individual e.g. biology and resourcefulness).
2.2.1) Financial Resources

A descriptive study undertaken in South Africa, of 386 HIV - infected persons, found that the most compelling healthcare needs of participants were all financially related (Baegis-Smith et al. 1995). Lack of income or financial needs were found to affect the ability of the participants to cover living, healthcare and basic needs expenses. Dishearteningly it is the urban poor who constitute the majority of PLWHA in South Africa (van Donk 2002 and Shisana 2002). In times of low financial resources food-related expenditure comes under pressure, resulting in malnutrition (Booysen et al. 2002). This is because families either eat non-nutritious meals or skip meals (Pryer 1989, UNDP 2004). This is a serious problem as malnutrition in turn increases both the susceptibility to HIV infection\(^4\) and the vulnerability to its various impacts (Haddad & Gillespie 2001). Nutritional deficiencies may lead to immune suppression which in turn may lead to increased HIV replication and hastened disease progression (Haddad and Gillespie 2001). Poor immune systems in turn increase susceptibility to opportunistic infections as well as decrease the ability to fight off these infections (Stillwagon 2000). Non-HIV positive family or household members are also put at greater risk of malnutrition. This subsequently may, due to sickness\(^5\), affect their ability to contribute to household income or perform well at school (which in turn may compromise their future capacities). An ill household member also requires care possibly putting further strain on family resources (Pryer 1989).

Financial insecurity has also been linked to unsafe sexual behaviour\(^6\) and with respects to women, this may in turn entrench gender inequality. This further erodes their negotiating power in sexual relations, as they may engage in sexual practices which allow them to benefit from food or other needs (Arntz 2003). The “inequality underpinning poverty is a core factor in the transmission of AIDS” (van Donk 2002). Gender and

\(^4\) People with poor nutritional status are more likely to become infected with the HI virus than those with good nutritional status (ACC/SCN 1998).

\(^5\) It has been found that poor households tend to be especially vulnerable to ill-health due to a combination of poor living conditions and under-nutrition (Corbett 1989)

\(^6\) It has been suggested that endemic unemployment is likely to enhance feelings of social disillusionment, frustration and boredom, which could discourage safe sex, especially when immediate survival needs are urgent (van Donk 2002).
economic inequality are for the same reasons aspects of poverty that promotes progression⁷.

Income is not only important for nutrition. Urban residents must pay for education, housing transport as well as levies to access certain social networks (e.g. savings clubs (UNDP 2004). As a livelihoods strategy the poor therefore immerse themselves (or at least attempt to) in the cash economy (UNDP 2004).

The urban economy however is particularly vulnerable to changes in the global and macro-economic environment and therefore so to are the urban poor. Macro-economic policy in South Africa since 1996 has taken a turn, that is to say a turn away from the previous ‘radical’ redistributive strategy of the Reconstruction and Development Programme (RDP) to a market oriented policy termed the Growth Employment and Redistribution (GEAR) policy (Benatar 2001)⁸.

The RDP sought to address the inequalities left by Apartheid by developing the infrastructure of the country through public works and community development programmes. Its aims were to create employment build houses and inject new resources and development into thus far neglected areas of the country (ANC 1994). It emphasised popular access to education, human rights and housing, as enshrined in the Freedom Charter (Ntuli et al. 2003). GEAR sought to rectify previous disadvantage through economic growth and job creation. Instead of creating jobs however massive job losses ensued, thereby entrenching poverty and making little in roads in the reduction of apartheid era inequality (Development Update 2003).

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⁷ It is possible for a PLWHA to be re-infected with the virus. This may speed up progression where infected with different strains (pers com HIV and AIDS Clinic doctor 16/08/05)
⁸ The policy originally arose as the emerging government had to contend with the global corporatist and consumerist society in which the power of the market oriented economy predominates (Habib & Padayachee 2000).
2.2.2) Access to Health Care

With respects to health care South Africa’s macroeconomic policy GEAR has also had far-reaching effects. Numerous studies have shown that access to health care has the ability to undermine or enable PLWHA ability to cope (e.g. Bachmann and Booysen 2003, Booysen et al. 2002). Access to health care is made up of five dimensions, these include: availability, accessibility, accommodation, affordability, and acceptability. Availability refers to the extent to which the provider has the required resources to meet the needs of the client (including personnel and medication); accessibility refers to the geographic accessibility, which is determined by how easily a client can reach the service (including transport resources, costs, travel time and distance); accommodation refers to the extent to which the providers operation is organized in ways that meet the constraints and preferences of the client, and the clients ability to receive care without prior appointments; affordability is determined by how the providers charges relate to the clients ability and willingness to pay; acceptability captures the extent to which the providers immutable characteristics are accepted by the client (Penchansky & Thomas 1981).

To return to South Africa’s macro-economic position, Health spending has mirrored this change in national policy, with a preference for funding the private sector over the public. Although the private sector treats only 20 per cent of the country’s population, 60 per cent of healthcare spending is allocated toward it, compared with 40 per cent expenditure on the public sector which services almost 80 per cent of the population (Benatar 2001). This has resulted in under-resourced public health facilities both in terms of infrastructure as well as personnel (Ntuli et al. 2003) – the public sector employs only 40 per cent of the nation’s doctors, with the majority working in the private sector (Benatar 2001).

The burden on public health facilities due to HIV/AIDS morbidity is only expected to increase and this is exacerbated due to the possible loss of health care workers who are also infected with HIV/AIDS (PlusNews 2005).

Therefore although in principal health care is free for all South African citizens this does not guarantee utilisation, as was found by a study which investigated utilisation of various primary health care facilities. Certain facilities were found to be utilised well
below nationally established norms (Lehmann et al. 2002.). Therefore as highlighted by Penchansky and Thomas (1981) not only must affordability be taken into account but also other factors that make the service acceptable, for the recipient. The under-resourced and overburdened public health system is projected to increasingly come under strain as the full effects of HIV/AIDS takes its toll, leaving the work of caring for the nation’s sick on too few health care workers. At the present levels of pressure poor health care experiences have already been reported, with health care workers being brusque or not even speaking to clients, and in other cases prescribing treatment without consultation (Ntuli et al. 2003). PLWHA have also been subject to prejudice and on occasion’s abuse.

Funds available to the government are not only limited by this neo-liberal oriented fiscal policy; debt repayments tie up potential funds available for social services. South Africa’s debt repayment currently stands at 13.7 per cent of National Expenditure while health expenditure is 13.3 per cent (Fair Share & ESSET 2004). Debt repayments have impacted a range of socioeconomic variables, as well as undermined the development of health systems (Nandy & Scott 2000 and Logie & Benatar 2000).

2.2.3) Psychosocial Support

In this study psychosocial support is comprised of two spheres. The first sphere is the formal support available, including services provided by non-governmental organisations, employers as well as religious groups. In this study these are termed external support mechanisms. The second sphere is the informal sphere and is comprised of informal safety networks (used interchangeably in this study with social networks). These consist of family (immediate and extended), neighbours and the broader community with whom respondents are involved in transfers or from whom they access help.

Informal safety nets are defined as “...a subset of coping strategies that draw on support from other households or individuals during periods of particular livelihood hardship” (Deverux 1999). Their most significant function revolves around issues of poverty and vulnerability reduction. The UNDP reported that besides income and labour, the urban poor are strongly reliant on social networks as assets which can be drawn on in

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9 Support includes both non-market commodities (where recipients gain items of use, such as cas or clothing), or services (such as child care or home help) (Arnall et al. 2004).
pursuit of their livelihoods (UNDP 2005, and Cox et al. 1997)). Dersham & Gzirishvili (1998) found that the utilisation of informal safety nets decreased the likelihood of respondents defining themselves as vulnerable with regard to their household food, economic and housing conditions.

It has been found that this social capital can be undermined by moral hazards resulting from the cost of obtaining information of recipient behaviour (Arnal et al. 2004). As with other sexually transmitted infections (STIs), the sexual mode of transmission means that HIV is highly stigmatised by taboos, moral judgements, misinformation and blame (Holden 2003). This moral judgement has roots in tradition, religion as well as misinformation regarding HIV.

The stigma associated with HIV and AIDS therefore has the ability to seriously undermined access to informal safety nets. The inability to access these networks, undermines the ability of PLWHA to cope with the illness both emotionally and physically/materially. Baigis-Smith et al. (1995) note that lack of supportive relationships may have deleterious affects on the individuals' health due to stress and the fear of “being found out”. In terms of material and physical assistance help may not be forthcoming once the HIV status of an individual is known (van Niekerk 2001) and where networks are accessed these may be exhausted due to the greater need for help as disease progresses.

2.2.4) Access to Information
Informed decision making requires accessible, relative and timely information.

Many health workers claim that HIV/AIDS campaigns were seriously set back by the initial confusion of government regarding the progression of HIV to AIDS and ultimately death. This together with the denial of death due to HIV/AIDS by government officials fed into the denial and refusal to take seriously the behavioural connection between sex and HIV infection by many South Africans (van Niekerk 2001).

Since this controversy the South African government has come to support the understanding that HIV causes AIDS (AIDSInfo 2005).

10 This is especially true for women in underdeveloped communities who may be banished and even physically harassed (van Niekerk 2001).
As part of the South African governments' attempt to maximize health and slow progression of HIV, an emphasis has been placed on HIV awareness and education. This is both to reduce stigma, therefore providing a more positive and enabling environment for PLWHA\textsuperscript{11}, as well as provide accurate information to PLWHA with respects to the disease and healthy living. To this end the government has called on all of civil society and in particular the media to rise to this challenge\textsuperscript{12}.

According to van Niekerk (2001) 'Effective communication with people is to a significant extent, a function of their ability to read, and on the basis of that reading, to grasp concepts that are not self evident to them'. As the majority of people vulnerable to HIV infection are relatively uneducated and illiterate\textsuperscript{13}, effective communication poses a considerable challenge (van der Vliet 1996). This is also relevant to HIV progression, whereby the majority of infected individuals are the poor who are largely uneducated or have low levels of education (van Niekerk 2001). Effective communication regarding issues of healthy living to slow progression therefore also poses a problem. Lack of knowledge of the disease has the ability to undermine a PLWHA capacity to care for themselves (van Niekerk 2001).

In this study information refers to general information regarding HIV and AIDS (e.g. healthy living and proper nutrition, human rights, tuberculosis etc). Respondents’ knowledge of available support mechanisms is another dimension of information that will be investigated.

\textsuperscript{11} This is also part of the South African governments plan to decrease new infections, i.e. a prevention strategy.

\textsuperscript{12} The Partnerships against AIDS adopted a broad based multi-sectoral approach towards fighting the disease. As HIV and AIDS affects all sectors of society, all initiatives – awareness campaigns, care for the effected and research – are strengthened by a partnership approach (AidsInfo 2005).

\textsuperscript{13} This refers to the adult population who due to Apartheid era inequalities were denied quality education (Ntuli \textit{et al.} 2003, and vanNiekerk 2001).
2.2.5) Environmental Factors

Certain environmental\textsuperscript{14} conditions have been shown to increase people's vulnerability to the effects of HIV as well as affect progression. Living conditions as they interact with access to basic services, personal safety issues as well economic inequalities effect progression. The urban poor are more likely to be subjected to environmental hazards (Pelling 2003) which affects quality of life due to lack of basic services. This is often compounded by overcrowding which aids the spread of contagious diseases (Hewitt 1997). Of specific relevance in the case of HIV is tuberculosis (TB) pneumonia and meningitis – all communicable diseases that affect PLWHA disproportionately (Whiteside 2002). Tuberculosis is the most frequent opportunistic disease to affects PLWHA\textsuperscript{15} (Haddad & Gillespie 2001) and is the leading cause of death. In this study this dimension is used to contextualise the conditions within which people pursue their livelihoods.

\textsuperscript{14} Environmental conditions here refer to the built environment, which includes social dimensions.

\textsuperscript{15} There is a 50 per cent lifetime risk of PLWHA developing TB (Global AIDS Care Watch Campaign 2005).
Chapter 3

3.1) Methodology

The research methodology encompassed two parts, firstly a desk review and secondly field research.

3.1.1) Desk Review

Initially a keyword search including the words: HIV, AIDS, coping, household vulnerability, South Africa, Southern Africa, response, were used in various combinations, to familiarise myself with the study topic. Metacrawler, Google Scholar as well as a range of Academic Search Engines including (but not exclusively): Medline and AIDSearch. The resultant finds from these searches were used to identify a range of written texts from sources such as journals, Government publications, Non-Governmental Organisations publications, International Donor Publications as well as theses. Bibliographies of these texts were also sourced where needed.

Case study literature related to HIV/AIDS effected households and their coping strategies as well as a range of more theoretical documents were used to guide my study and highlight areas of importance that were previously (at the preparatory stages) not identified. This included literature related to health seeking behaviour as well as various development related reports. In this way a multitude of conceptual frameworks have been gleaned, to provide an interdisciplinary lens within which to view the areas vulnerability pertinent to PLWHA.

Government and NGO publications have been reviewed to provide information on current institutional support mechanisms. The Government literature review included relevant literature concerned with country wide and provincial plans for treatment and care of HIV positive people.

To ascertain information on the study context (study site as well as the broader context within which the study arises) a key word search was undertaken including the words: Delft, Western Cape, South Africa, HIV, AIDS, debt, globalisation, health care, household, livelihoods and urban. This yielded a range of literature which was reviewed and as with the above findings presented in the literature review as well as in the
discussion of the findings. Data from Statistics South Africa’s Census 2004 were also used to obtain information of the study area.

3.1.2) Field Research
The field research has been divided into seven components.

3.1.2.1) Description of Study Site
A community profile of the study site, Delft in the Western Cape was undertaken. This consisted mostly of a literature review but also involved interviews with various members of the Delft “community” to obtain socio-economic information of the area in question. The study site has been chosen because of its low economic status and the dialogue that has been opened up surrounding HIV/AIDS which may make people less inhibited to come forward and share their experiences.

3.1.2.2) Gaining Entry
The first step in gaining entry involved presenting the study proposal to the Metro District Health Officer together with a letter of introduction from the University of Cape Town. Permission was given by this authority and the proposal was then presented to the Delft Community Health Centre’s Facility Manager for approval. Permission was granted to undertake the study at the facility with the help of the HIV and AIDS counsellors who are affiliated with the HIV and AIDS Health Centre. These counsellors initially acted as the medium through which contact was made with respondents. As changes were made within their organisation certain counsellors were removed and others for other reasons become inaccessible. As a result the nurses at the HIV and AIDS Health Centre assisted me making contact with possible interviewees.

3.1.2.3) Ethical Considerations
Two dimensions of ethical concern have been identified (for a full discussion on ethics in HIV research see Thomas 2001). The first relates to confidentiality and the second to reciprocity. The first consideration has been addressed in three ways: firstly all prospective respondents were invited to participate on a voluntary bases; secondly a
written agreement was signed by both the researcher (myself) and each participant to ensure transparency and confidentiality (Appendix 1); and thirdly the utmost confidentiality with respects to their interviews (as well as the final report) was attempted at all times but was not always possible. Privacy was difficult to adhere to as the space available in the Health Centre was limited. Interviews were therefore often performed in the HIV and AIDS Health Centre in the adjacent room to the doctors and closed off from the nurse performing consultations in the same room. In all cases however respondents participation was voluntary as mentioned above. All questions that were asked in the study were first fielded to the councillors so that issues they deemed sensitive could be excluded (as respondents were sourced from them, their knowledge of respondents situations was quite good\(^{16}\)).

The issue of reciprocation has been more challenging. The main area that I have attempted to be of assistance is in information provision. Part of the study was to compile a list (which is yet to be completed) with sources of support emotional (e.g. support groups and counselling) and physical (e.g. skills teaching) or material (mostly with respects to food parcels) available in Delft. This list will be made available to the Delft Community Health Centre as well as the various service providers, to encourage service integration.

During interviews this knowledge was imparted to respondents. Respondents were provided with my telephone number should they have other queries. Where respondents had questions in interviews which could not be answered\(^{17}\) they were contacted after the interview (by telephone) and were provided with the requested information.

### 3.1.2.4) Data Collecting Instruments

The study is qualitative in nature, with in depth interviews, each lasting between 1½ - 2 hours being undertaken. Each respondent acted as the key informant for their households. In this investigation a household is defined a person or group of persons who eat together

\(^{16}\) This was more pertinent to the first few respondents as later respondents were contacted through the nurses.

\(^{17}\) In some cases they did not want to ask the health care workers
and share resources (Arnall et al. 2004). The questionnaires were developed from the literature review as well as informal interviews with Sothemba councillors and counsellor trainers.

3.1.2.5) Qualification characteristics for Study Participants

The respondent pool for interviews consisted of 17 HIV positive individuals (hereafter HIV positive). The majority of respondents had a CD4 count above 200 (14), three had CD4 counts less than 200\(^{18}\) (refer to Appendix 2). Only two respondents lived in an area outside the study area – Kalkfontein. This area however exhibited similar socio-economic characteristics as the study area allowing for the information to be placed within a larger socio-economic context.

Before healthcare workers (counsellors and nurses) requested client participation they assessed whether respondents were emotionally fit enough to take part, as some respondents had not come to terms with their HIV status to the extent where they could speak freely of their experiences.

Respondents were interviewed with respects to five areas: access to healthcare; financial strategies; psychosocial support; information acquisition; and environmental related questions

3.1.2.6) Support Providers

Informal discussions were undertaken with individuals and organisations active in the specific area (Delft, Western Cape) as well as the Delft Community Health Centre. Enquiries as to which organisations are active in the areas as well as what services they provide were the main focus of discussion.

Services available were also identified by respondents through interviews, especially with respects to the informal support mechanisms available.

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\(^{18}\) Only one of these respondents was about to begin ART
3.1.2.7) Information Analysis
Data analysis included firstly the cleaning of data and the categorising of information into the predefined categories. Emergent categories were then identified and categorised. It should be noted that analysis of financial support mechanisms (those requiring a financial contribution) incorporated grants into available household funds as they were all either used by respondents directly or their dependents and so indirectly benefited them.

3.1.2.8) Study Limitations
Several unforeseen limitations occurred during the interviewing period. Firstly a private space in which interviews could be undertaken was not always available. This resulted in interviews being carried out in the HIV/AIDS Health Centre (consisting of two rooms see 3.3.2) where consultations were simultaneously taking place.

A second limitation was that of language. Originally counsellors offered to translate interviews (both Xhosa and Afrikaans) but as they had other responsibilities this was not possible. Interviews were therefore only possible with English or English/Afrikaans speaking individuals. One interview was undertaken with a Xhosa speaking man who spoke no English. This was made possible as one of the previous respondents acted as the translator, with the permission of both respondents.

A third limitation effected access to potential respondents. Firstly this was as a result of counsellors being moved to other health facilities. This was a problem as it was these individuals who acted as my liaison with prospective respondents. Secondly while involved in field research the HIV and AIDS Health Centre underwent many changes resulting in even less space available for interviews. The above to two adjustments resulted in a small respondent pool as access to respondents and space available for interviewing became limited.
3.2) Description of the Study Site

3.2.1) Suburb Profile

Delft is located in the Eastern District of the City of Tygerberg municipality in the Western Cape, South Africa (Figure 3). It is made up of five areas namely: Delft South, Eidenhoven, The Hague, Rosendal and Voorbrug. The population totals 60 674 (Census 2001), of which 73.4 per cent are coloured, 25.5 per cent black, 1 per cent Asian/Indian and 0.1 per cent white. The most commonly spoken languages are Afrikaans (67 per cent) and Xhosa (22 per cent) with only 10 per cent of residents speaking English. Over half of the population receives no monthly income (Appendix 3 Chart 1), whilst 21.5 per cent house holds receive income from employment. Chart 2 (Appendix 3) shows household income levels. While 36 per cent of the population has received secondary schooling only 9 per cent has completed grade 12 and only 1 per cent of the residents have received higher education (See Appendix 3 Chart 3).

The area has poor access to the Cape Town Metropolitan Area’s (CMA) transport network. The predominant mode of travel for residents of Delft is firstly by foot (47 per cent where applicable19) and secondly informal transport – taxi/minibus (24 per cent). There is no fixed timetable as their operations are controlled by passenger demand, resulting in a less than reliable service (pers com delft resident 11/08/05 and GLTY Plan 99 Sout 1999). The area is also geographically isolated from the CMA’s physical structure, as such many work opportunities require costly journeys to reach20.

The whole area is serviced by one health facility, namely the Delft Community Health Centre.

Delft is devoid of any scenic and environmental features and its residents are plagued by windblown sand. With respects to the quality of the natural environment, dumping of waste on vacant land and poor management with associated health risks, due to vector breeding, causes poor environmental health (GLTY Plan 99 Sout 1999).

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19 Refer to Census 2001 guidelines.
20 No significant local employment, commercial or retail facilities, tertiary education and health institutions resulting in long and costly travel distances (GLTY Plan 99 Sout 1999)
Figure 3: Map showing the location of Delft (dark orange). Clients of the Delft Health Care Centre come from all the shaded areas (map compiled by A. Rand and edited by U. Periera)
The number of people per unit stands at 7.7 per housing unit (GLTY Plan 99 Sout 1999) and has been described as overcrowded (Adonis et al. 2000).21

3.2.2) Delft Community Health Centre

The Delft Community Health Centre is owned and funded by Western Cape Provincial Department of Health and operates under the Tygerberg Eastern Health District of the Metro Region. Over and above the services it provides in its capacity as a Primary Health Care Facility it provides the following services pertinent to HIV/AIDS care:

- Voluntary Counselling and Testing
- Support Groups
- Follow up Counselling
- Family Counselling
- Rape Intervention
- HIV/AIDS Health Centre
- Antiretroviral therapy
- Tuberculosis Health Centre
- Health Promotion
- Home - based are (sourced from community Non-Governmental Organisations)
- Nutritional Schemes (food parcels as well as education)

(Source: AIDS resource Centre: AIDS Survival Kit, pers com. Delft Health Care Facility Manager and the facility Health Promoter)

The hospital, according to the Facility Manager, was originally meant to service residents of Delft, for a range of reasons however – including issues such the 24hour service offered, personal choice of clients22, and the fact that it is only one of the three hospitals in the Tygerberg Health District to have an HIV/AIDS Health Centre – people from

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21 The area is to be further developed as part of the N2 Gateway project. This will see an influx of people which is anticipated to increase the levels of communicable diseases in the area, especially tuberculosis (pers com Catholic Welfare Developer, Delft 11/08/05)

22 When clients were asked why they do not attend the Health Centre in their area they reported that they were not happy with the services they provided.
Kleinvlei, Mfuleni, Eerste River, Khayalitsha, Belhar and even Witsands also make use of the Health Centre (pers com. 21/09/05, Figure 3). On average for the year August 2004-August 2005 the Health Centre was visited by 13,301 clients. During this time (and currently) the client to doctor ratio stands at approximately 1,663 clients per doctor\(^{23}\), which is below the provincial average of one doctor to 2,979. The Health Centre is presently under resourced both in terms of staff and structure (i.e. not enough space), the Facility Manager commented: "...the Health Centre has long time outgrown...its bursting at the seems". This, she said, is as a result of the Health Centre receiving a higher number of clients than it was projected to receive.

The HIV/AIDS Health Centre has been running since November 2004. Since then it has received approximately 170 clients a month in Stages 1 or 2 and approximately 68 in stages 3 and 4\(^{24}\). The Health Centre runs every Tuesday and Thursday from 8:00am to 17:00. At the time of this study the team consisted of one doctor, one Health Centre Clinical Nurse Practitioner, one Adherence Counsellor, one Nursing sister and three Voluntary Counselling and Testing (hereafter VCT) counsellors. Five of these staff were outsourced\(^{25}\) from two NGOs – Sothemba and ARK.

The three VCT counsellors were\(^{26}\) also available from Monday to Thursday for VCT sessions, although their schedules were subject to change sometimes without prior notice. Visitations to the HIV/AIDS Health Centre would entail either a visit with the Health Centre clinical nurse practitioner or the doctor (depending on Cd 4 count and health status) and required an appointment.

Due to insufficient space in the hospital, consultations take place in two rooms in close proximity to each other, with two or three consultation occurring simultaneously. The only privacy afforded to the two clients in the second room is by means of a curtain, through which one can hear the happenings both on the other side of the curtain as well as in the room where the doctor is carrying out examinations and consultations.

\(^{23}\) Doctors will see on average 45 to 50 clients a day, while nurses will see approximately 35 clients a day (pers com Facility Manager 21/09/05).

\(^{24}\) Up until September 2005 clients who required ART were sent to Tygerberg Health Centre as the HIV/AIDS Health Centre in Delft has not begun dispensing ART.

\(^{25}\) These NGOs provided staff for the Centre until the HIV and AIDS Clinic is operational and permanent health care workers are employed by the Centre.

\(^{26}\) During the study two counselors left and new counselors arrived.
As there is limited secretarial coverage for the HIV/AIDS Health Centre to which questions can be directed there are often clients interrupting sisters/nurses in the middle of consultations, affording the clients even less privacy.

NGO’s active at the Health Centre (beside ARK and Sothemba) include the Treatment Action Group (TAG) and Lovelife. Volunteers from these organisations undertake Health Centre visits where they impart HIV and AIDS information to clients. These volunteers are also to answer questions and encouraging discussion with Health Centre clients.

Other NGO’s active in the Health Centre include: Grace House which provides meals for clients who wait long hours for appointments and CARE – an NGO offering home-based care (accessed through doctor referrals).

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27 There is one receptionist that services the entire hospital.
Chapter 4

4) Results
The results are presented in five sections drawing on the five categories identified in the literature review. These are financial resources, access to health care, psychosocial support, access to information and environmental resources. Environmental resources are presented together with socio-economic profile of sample population.

4.1) Socio-economic profile of sample population
Socio-economic information of the respondents is described under the following headings: demographic characteristics, employment, education, dwelling characteristics (human and physical) basic services, living conditions and transport.

4.1.1) Demographic characteristics
Respondents were all between the ages of 20 – 51. The majority of respondents were female and African, as can be seen in Table 1.

<table>
<thead>
<tr>
<th>Racial Group</th>
<th>Female</th>
<th>Male</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>African</td>
<td>10</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Coloured</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>12</td>
<td>5</td>
<td>17</td>
</tr>
</tbody>
</table>

Table 1: Racial and gender composition of respondents

Eight respondents were married or in lifetime partnerships with their current partner and 14 respondents had dependents for 12 of these the dependents were children, for one respondents a parent and another her siblings.

4.1.2) Education
Sixteen respondents had attended school, the levels of which are shown in Table 2, one respondents received no schooling.

<table>
<thead>
<tr>
<th>No. of Respondents</th>
<th>Some Primary Education</th>
<th>Some Secondary Education</th>
<th>Grade 12</th>
<th>Higher Education</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2</td>
<td>11</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 2: Levels of schooling and higher education completed by respondents.
The four respondents who attained higher education completed courses and were in possession of certificates: one for bricklaying, two for security and a fourth respondent held three certificates these being basic health, first aid level 1 and home nursing.

4.1.3) Employment and Income

In households of ten respondents there is only one member working, in three households there are two members working. Between these households five household members receive welfare grants. Dependency ratios in these households are generally high (equal to or greater than one wage earner to three dependents). Four households have no income from employment, three of which have income from welfare grants. Respondent work status is shown in Table 3, four respondents are the sole breadwinner.

<table>
<thead>
<tr>
<th>Employment Type</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Formal</td>
</tr>
<tr>
<td>No. of Respondents</td>
<td>5</td>
</tr>
</tbody>
</table>

Table 3: Respondent work stability

All work done by respondents and their households is unskilled. Work included: domestic workers, contract, cleaning, factory line work and waitressing.

4.1.4) Household Composition and Dwelling Characteristics

The majority of respondents were household heads (12 – nine female, three male), while four are related to (three mother and one husband) and one respondent is friends with the head of household. Tenure status is shown in Table 4. The majority of respondents lived with immediate family (15); one with extended family (cousin) and one with a friend

<table>
<thead>
<tr>
<th>Tenure Status</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Owner</td>
</tr>
<tr>
<td>No. Respondents</td>
<td>8</td>
</tr>
</tbody>
</table>

Table 4: Respondent tenure status

The majority of dwellings (12) consisted of one room with an average of four people in each of these dwellings. Four respondents lived in 2 bedroom homes, with an average of

²⁸ One respondent was a victim of the January 15th 2005 fire in Langa, and was put up in the Government temporal housing scheme.
five people in each dwelling and one respondent lived in a three bedroom home with five people. Six respondents lived in informal dwellings ("shack\textsuperscript{29}"), five in RDP dwellings one in a government asbestos dwelling (temporary home), four in ordinary dwellings (non-government brick dwellings) and one in a Wendy House\textsuperscript{30}.

4.1.5) Basic services

16 Dwellings had access to piped water in their homes, 15 of which had only 1 tap. One dwelling has access to piped water outside the dwelling, this tap servicing approximately 20 people (temporary housing scheme\textsuperscript{31}). In most households the main source of energy for cooking, lighting and appliances (where applicable) was electricity (16) and one household used paraffin as the main energy supply. Out of the dwellings with electricity seven used paraffin for heating.

All dwellings had access to sanitation with 11 having access to a toilet in the dwelling, four to a toilet in the main house (these shacks or Wendy houses are in a backyard), and two on site: one in the back yard and the other a communal toilet which serviced about ten people (temporal housing scheme).

Refuse removal levels were quite high; 16 of the households had their litter removed once a week. One respondent however did not have a refuse removal service and commented that her and her neighbours litter lie in street (respondent in Temporal Housing Scheme).

4.1.6) Living Conditions

A large number of respondents (14) expressed discomfort with their living conditions, reasons included: lack of privacy (1); poor building design resulting in leaky roofs, water coming through windows, very cold conditions in winter months (14) and in one case windblown sand entered a respondent’s dwelling in windy months (1).

\textsuperscript{29} House made of corrugated iron and various other materials.
\textsuperscript{30} Prefabricated wooden house.
\textsuperscript{31} Respondent noted that there are other taps in the area but everyone used the closest one.
One respondent commented:

"...in winter all the top is wet (no ceiling) and water comes through, the walls are rotten and smelling...the blankets and everything gets wet...” (Respondent 15 6/08/05). This respondent said that she could not use a paraffin stove for heating as it causes her partner, who is also HIV positive to cough. Although this was the case, seven respondents made use of paraffin heaters for warmth.

Three respondents spoke of crime in the area. During a discussion with non-HIV positive Delft residents, one commented:

"...I felt safe, but face reality there’s lotsa shebeens and gangsterism...”

Alcohol abuse by people in the Delft community was mentioned by a number of respondents.

Many other respondents however commented that they were comfortable in Delft but that if their neighbours new their status they may swear at them, ignore them or even physically mistreat them.

4.1.7) Transport

The predominant modes of travel used by all respondents were busses, taxi/minibus as well as travel by foot.

4.2) Financial Coping and Support Mechanisms Accessed

Results of financial strategies are divided into the household level coping (including access of informal social networks) and external support mechanisms accessed. In this section, financial support mechanisms differ from welfare support mechanisms in that financial support mechanisms require some sort of contribution on behalf of the beneficiary.
4.2.1) The Household Level

4.2.1.1) HIV, employment and unemployment

Four respondents reported that they were unemployed due to HIV related illness. Although two met the requirements for receiving a grant (i.e. Cd4 < 200) only one received financial assistance. All of the unemployed (excluding the four above who could not work) respondents (five) reported that they would like to work, although they were often tired and found working a full day very difficult. These respondents all said that the only reason they are not working is that they cannot find a job. Only one of the ten unemployed respondents mentioned that she felt completely fit to work. One of the two informally employed respondents mentioned that she can only work three days a week now (compared to the whole week before) and that having HIV has greatly decreased her earnings, as her eyesight is deteriorating (as well as experiencing fatigue).

One respondent stated that she was finding it increasingly difficult to walk to and from her taxi pick up point - at the end of her working day. This, she reported, had begun since developing shingles.

Out of the unemployed respondents four reported that their previous jobs did not provide them with sufficient income for day to day expenses.

Five out of the seven employed respondents (including informal, formal and casual) mentioned that their present jobs could not cover all their expenses (refer to 4.2.1.2 below) especially the extra expenses related to being HIV positive (refer to 4.2.1.3 below).

4.2.1.2) Established Expenses

Most respondents either stated that they were financially insecure or did not have enough money for everyday expenses. Established expenses that had already been under strain included school fees, transport costs as well as electricity costs. One respondent.

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32 Decreased endurance, physical mobility and sensory perception are the most frequently reported problems reported by clients with HIV (e.g. Bennett 1988 and Whiteside 2002).
33 The employment of all these respondents required them to be on their feet for the duration of the working day.
34 Refer to 32 above
35 Refer to 32 above
36 Shingles, or Herpes Zoster, occur as a result of infected nerve roots, causing a rash or boils. Although these dry up the pain may last for many months (Lynfield, Y.L. 1987 World Book Dictionary).
mentioned that when her and fellow domestic workers could not afford to pay the taxi fare, the conductor would allow them free passage, which they were to pay for the following week.

4.2.1.3) Extra Expenses due to HIV

The two additional expenses households were faced with due to HIV (or rather as a result of being aware of ones status) as reported by all respondents were food and by three respondents medication.

a) Food

Only seven respondents stated that they were able to meet their nutritional requirements – diets rich in fresh fruit and vegetables and rich in protein as shown in Graph 1. The remaining respondents reported that they only managed to eat well a few days in a week and sometimes go without eating balanced meals for over two weeks. The diets of these respondents consisted mainly of miellie pap or bread.

*Note: Employed households with poor nutrition have either: high dependency ratios, low or irregular income.

Graph 1: Respondent nutritional status of and primary sources of income. (Note: Employed refers to any household which at least one member is working)

Of the respondents who ate poorly two are formally employed, one informally, one is employed casually (every few weeks), and the rest (six) are unemployed. All have a high number of dependents (over three) or are one of a number of dependents. Of those who are unemployed one respondent receives a grant while two have another person working in the household and three have some one else receiving a grant (in all cases child support
grants). Two out of the 10 respondents also have small vegetable gardens, but as they say due to space can only grow limited amounts of vegetables, which they reported help to supplement their families vegetable intake.

Of those respondents who mention that they eat correctly, three were employed formally. Of these one household had another member of the household employed and a third receiving a grant. The other four respondents who eat well are all unemployed, in each of these households another member of the household is employed and in one another member receives a grant. Five of these respondents have lower earner to dependent ratios the other two have a higher ratio. These houses get by as the one respondents spouse has a relatively good salary (according to her), the other although his spouse works only once a week (one of the other respondents), makes sure that he eats well sometimes sacrificing her own nutrition. The latter respondent is one of those mentioned above who also grows vegetables to supplement food shortages.

**b) Medication**

Three respondents reported that medication was an additional expense due to HIV. The medication concerned was predominantly vitamins, nutritional drinks and elixirs although one respondent stated that she needed a special ointment as the Health Centre medication was not helping her with her problem and wouldn’t change her prescription (her private doctor suggested an alternative). Interestingly enough one of the three respondent who mentioned this as an extra expense did not use the medicine for herself, but rather for her spouse who is also HIV positive (in a more advanced stage, respondent mentioned above), and while he mostly fulfilled her dietary requirements she did not.

All other respondents relied on Health Centre medication as extra money was not available to spend on medication. Three respondents received additional medication from their employers when it was needed.
4.2.1.4) Informal Safety Nets Accessed

Respondents and their families made use of a range of financial support mechanisms (refer to Graph 2).

Savings clubs were accessed by seven of the respondents. Households who used this varied in their access to income. Although 13 households had income from employment – seven of which also received a grant or grants – only five of these made use of savings clubs. This is compared with two households who made use of savings clubs where the predominant source of income was welfare grants and no income from employment. Most respondents stated that they would like to use this service. To access this, however a member of the household had to have a regular income - through employment or other, e.g. a welfare grant – as a monthly contribution was required\(^{37}\), as well as available disposable income.

![Graph 2: Utilization of financial support mechanism, showing sources of income. (Note: Employed refers to any household which at least one member is working)](image)

Four respondents made use of burial/funeral policies; all had an employed household member while three also received a grant. As with savings clubs the majority of respondents said they would like to utilise this form of insurance.

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\(^{37}\) As reported by respondents.
Three respondents made use of a micro/informal-loan service. According to respondents who utilised this, the repayments on these loans were between 50 and 100 per cent over a 6 – 12 month period. They also reported can access these loans irrespective of employment situation.

Out of the 17 respondents two receive grants, one for a non-HIV disability the other due to advanced HIV infection (Cd4 <200). Although two other respondents had Cd4 <200 they did not access these. In the one case this is because the respondent does not have a Birth Certificate or Identity Book, either of which is required to access this grant. In the households of eight respondents someone else in the house receives a grant (seven child care and one old age pension). In some cases more than one grant was received (e.g. two childcare grants). All of these respondents benefit from these grants as they are received by their dependents. One respondent stated that she is in serious need for a child support grant for her two children but as she doesn’t know their fathers cannot access this: a requirement to qualify for this grant is for the father’s details to be presented.

4.2.2) External Support Mechanisms Accessed

Only one respondent reported that at one stage she made use of medical aid. This was accessed through her work and only applied for the duration of her employment with the company.

Only two respondents made use of banks for saving (refer to Graph 2). One respondent made use of financial insurance. These three respondents were according to them coping financially and all reported that they were able to meet their nutritional requirements.

Factors constraining access to the financial support mechanisms presented both informal and formal are presented in Table 5 below. The table also shows factors contributing to household and individual vulnerability.
<table>
<thead>
<tr>
<th>Dimension</th>
<th>Factors Constraining Access to Services</th>
<th>Factors Contributing to Vulnerability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial</td>
<td>Poor Health</td>
<td>Inability to Work</td>
</tr>
<tr>
<td></td>
<td>Low/ irregular/ no income</td>
<td>Low/ irregular/ no income</td>
</tr>
<tr>
<td></td>
<td>High Dependency ratio</td>
<td>Poor Nutrition</td>
</tr>
<tr>
<td></td>
<td>Extra nutritional needs/expenses</td>
<td>Inability to purchase medication</td>
</tr>
<tr>
<td></td>
<td>Extra medical expenses</td>
<td>Lack of saving options</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Lack of savings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Contribution to debt</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Further stress on already pressured livelihood activities e.g. school fees</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Extra expenses on already pressured households</td>
</tr>
</tbody>
</table>

Table 5: Summary table showing factors constraining access to financial support mechanisms and factors contributing to vulnerability.

4.3) Psychosocial coping and access to support

This section is divided into two parts, the first being the role of social networks. Social networks are comprised of immediate family, extended family, friends and community. Religious groups have been separated in some places for greater clarity although they have been included in the first section as two respondents considered members in their faith groups as part of their social networks. The second section is concerned with external support mechanisms accessed; in this section religious groups have been set apart from social networks.

Each section deals with issues of disclosure, emotional support access as well as different form of help accessed (including material and physical).

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38 These included barriers to accessing both informal and formal financial support mechanisms.
39 Low/irregular/no income as an endemic condition (i.e. not due to HIV) constrains access to financial support mechanisms as well as occurs as an outcome of poor health and the inability to work.
40 The use of micro-loans by unemployed households.
41 Community referring to neighbours adjacent and surrounding, as well as people from the Suburb.
4.3.1) Role of Informal Social Networks
4.3.1.1) Disclosure

Disclosure of HIV positive status to immediate family, extended family and friends varied greatly between respondents, in total 16 of the 17 respondents disclosed to one or more of the above (refer to Graph 3).

Graph 3: Respondent disclosure to selected confidantes.

While the majority (16) disclosed to immediate family, this was often highly selective i.e. mother only, siblings only, parents and siblings or one sibling and not the other, or to spouse only. Eight of the 17 respondents disclosed their HIV status to only one friend (two of the respondents were in a relationship with this person) one respondent disclosed to all her friends – as most of them are also HIV positive. With respect to community disclosure only three respondent were forthcoming of their status (two to fellow church goers the other to a neighbour). The main reason for not disclosing one’s status was that if one told someone that person would tell someone else, and so on, till most people who know you and even those who don’t, will be aware of your HIV positive status. Following on from this respondents said that people would treat them badly if they knew:

"...people won’t talk to me..." (Respondent 4 11/08/05);

Note: these values are not congruent with number of respondents who disclosed their HIV status due to the fact that multiple answers were given.
"...if I tell them when we fight they will bring it up (in a bad way)" (Respondent 5 11/08/05);

"...my boyfriend will stand on the street and swear at me." (Respondent 14 1/09/05);

"...can't tell them (friends/neighbours) my status when they drink they will talk everything and I don't want to stress, they might even hurt me" (Respondent 14 1/09/05)

Some respondents spoke from experience:

"when he finds out his sister is HIV positive he's shouting and treating her badly”
respondent 17 (8/09/05)

This respondent was explaining how her father treated his sister when he found out she was HIV positive. This was also brought to my attention by a HIV – resident in Delft who said that at a Shebeen she frequents the owner will not allow an HIV positive women to use his crockery or cutlery and that she must take her own, she was also ridiculed by the community (pers com. 11/08/05).

The above factors were aggravated by alcohol consumption:

"... in my place every time they are drunk, maybe when my friends are drunk they will tell everyone." respondent 5 11/08/05);

"...when drunk people may not talk to you...” (Respondent 6 16/08/05).

While this is the case many, who disclosed their status to immediate family reported that they were treated positively. One respondent however mentioned that her sisters were initially angry when she disclosed, as they rely on her very strongly for financial security (as she was the only member of their family with stable employment). She recalled however that soon after this they became supportive of her, they also care for her when she is ill.

The other respondents however did not allude to the initial response of their families but rather their present attitudes toward their condition which was generally supportive.

In general a high level of mistrust surrounded most of respondents relationships even within their own families. One respondent did not disclose to anyone stating:
"ons bruin mense is anders, kan vir niemand vertrou nie, ek praat met niemand oor hierdie dinge nie..."^43 (respondent 12 /08/05)

This respondent believed that coloured people have a deep seated problem, as they could not be trusted, the respondent in question is also from the group termed ‘coloured’.

4.3.1.2) Forms of help accessed

a) Physical and material support accessed

Respondents predominantly accessed help^44 from friends (9 of the cases). Help from immediate family was rarely solicited (seven of the cases) and extended family even less so (four of the cases). Graph 4 shows the types of support accessed and who provided it to the respondents.

Graph 4: Number of times different types of support were accessed^45 and the sources of this received support^46.

The areas respondents required most help with was for food, ten respondents obtained food or money for food. The second most requested assistance was for child care. It is interesting to note that friends provided more assistance with child care than did family,

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^43 Us coloured people are different, can’t trust anyone, I don’t talk with anyone about these things.
^44 Respondents were asked as to whether they or a household member had solicited help from relatives, members of their community and/or friends in the last six months.
^45 Refers to help accessed in the last six months.
^46 Note these values are not congruent with the number of respondents who accessed support due to the fact that multiple answers were given.
both immediate and extended. Household labour assistance was solicited by only eight respondents. Clothing was not always asked for; respondents mentioned that they were mostly given the clothes without asking. With respects to the category other this referred to items such as toiletries, appliances and money for electricity.

Five respondents mentioned that they were not granted help when asked (these times the help asked for included food, money for food, or money for other expenses):

"Sometimes I ask my friends, but they say no, life is not good" (respondent 8 16/08/05)

"...here (Delft) neighbours take you down, down, down, in Eastern Cape you can go to your neighbours, its where we belong, they know you from when you’re young..." (respondent 10 18/08/05)

In comparison to child care support accessed over the last six months (seen in Graph 4), mainly of friends, long term child care was to be predominantly taken over by immediate family (Graph 5).

Three out of the nine of these individuals were also HIV positive (two spouses and one sibling) one is planning to go for a test and another respondent has not yet disclosed to his spouse. In total therefore a possible five out of the nine members of immediate family who were to care for the children of respondents were HIV positive. One of these

Graph 5: Sources of support for long term dependent care

Three out of the nine of these individuals were also HIV positive (two spouses and one sibling) one is planning to go for a test and another respondent has not yet disclosed to his spouse. In total therefore a possible five out of the nine members of immediate family who were to care for the children of respondents were HIV positive. One of these

47 Multiple answers were given by some respondents as they were not sure which of their confidants would take on the guardian role
respondents reported that she and her sister, both HIV positive, were already looking after their older sister’s child. Their sister had died due to HIV/AIDS related illness (each of them is responsible for the children when the other is ill, as they cannot afford to send the children to crèche).

Two respondents who stated that their children could look after each other in the case of illness, in both cases the oldest child was above 18 years of age.

b) Emotional Support Accessed
With respects to emotional support, more respondents discussed worries related to HIV with their families (11) than their friends (8, two were in a relationship with this person). Only two respondents discussed issues related to HIV with extended family. One respondent discussed issues with a fellow church goer. Eight of the 17 respondents did not discuss HIV related concerns with the same people that they would discuss other personal issues with. This was for a variety of reasons including that of disclosure concerns and the fear of exclusion (2):

“...at your back people will talk and you'll fell alone (if one discloses ones status)” (respondent 10 18/08/05);

Other factors affecting discussion of HIV related concerns with respondents’ usual confidantes included: the nature of the relationship (i.e. due to the nature of the disease some respondents were not comfortable to talk with a parent about it or a spouse, especially if infidelity had occurred) (2); and preferring not to dwell on HIV status (2):

“...don’t wanna think of these things, don’t wanna stress for that thing...” (respondent 5 11/08/05);

None of the respondents’ family makes use of the family counselling services provided by the hospital.
4.3.2) External support mechanisms accessed

This section is broken into two sections the first being disclosure and emotional support accessed and the second the forms of help granted. In each section the role of employers, religious organisations and community organisations has been presented.

4.3.2.1) Disclosure and emotional support accessed

a) Role of Employers

With respects to employer disclosure, of the five formally employed respondents three disclosed their status to their employers. One respondent said that she thinks people don't disclose because they will be fired:

"I've heard that some people lose their jobs and some people are fired..."

(Respondent 4 11/08/05)

When asked if she personally knew of any one she replied that she had just heard about it. Another respondent confirmed this belief:

"...I'm scared to tell employee they'll chase me away" (Respondent 11 18/08/05)

The three respondents who disclosed their status to their employers were met with much support. Emotional support was given when respondents found out their status and one respondent was encouraged to get tested by her place of employment. A health worker visited the latter’s place of employment every month, and employees were encouraged to ask him/her questions. Two of the respondents’ employees took them for counselling when they found out that they did not receive counselling, prior or after being tested. One of these respondents recalled that after she was told her status she was convinced she was going to die. After being counselled by her employees family doctor (private) she recalled that her whole outlook changed and that she realised if she took care of herself she could live a long healthy life.

One of the unemployed respondents was encouraged by her previous place of employment to get tested by her work through her union – South African Clothing and Textile Workers Union (SACTWU) Health Centre. On testing positive she received medication as well as counselling - of which she had unlimited access for both her and
her family. Her family did not attend any counselling sessions however. Since she stopped working she no longer had access to these services.

b) Role of Religious Groups
Ten respondents attend some form of religious worship; only two however disclosed their status. The two respondents who disclosed their status to their Church community recalled that they only came across supportive attitudes. One stated that after each service people from her church who are HIV positive meet and exchange experiences and information.

One respondent stated that she gets much emotional strength from her worshipping rituals (although she had not disclosed her status). These spiritual practices are both physical and mental. The respondent mentioned that she would like to consult with the doctor as to the possible harm the physical practises may incur, but that she did not feel comfortable to do so. This respondent also said that she watches a religious programme produced by the Universal Church, she commented that once she had phoned in and they prayed for her. Her spiritual endeavours, she remarked

"...make(s) me feel better; even Health Centre medicine doesn’t make me feel that good" (respondent 5 11/08/05)

c) Role of Community Organisations
Only one respondent attended a support groups which was facilitated by the Treatment Action Campaign, he commented that he attended these meetings even before being diagnosed with HIV. Another respondent reported that she had previously attended one on one counselling sessions facilitated by Sothemba. Both respondents no longer use these services. While the one respondent stated she no longer required the services of a councillor, the other respondent stated that he would like to attend the TAC support group but that it had ended.

48 Undertakes Spide whereby one drinks five litres of water and then must vomit it up.
49 A non-governmental organization concerned with the provision of emotional support and information to PLWHA as well as advocating equitable access to Anti-retroviral treatment.
50 A non-governmental organization providing support both physical and emotional to people infected and affected with/by HIV/AIDS
Although seven respondents mentioned that they would like to attend support groups, none attended the group sessions facilitated by local NGO’s or individuals. This was because respondents either had no knowledge of them, they were at inopportune times or places and/ or respondents did not know who to contact to find out about them. Through participant observation as well as discussion with health care workers it was found that they too were unaware of who provided what in the community. These individuals were also not privy to the details of these types of services available in the Health Centre— both in terms of those run by the Health Centre as well as those run by other facilitators.

1.3.2.2) Forms of Help Granted

a) Role of Employers
Respondents who disclosed their status said that their employees would buy them medicine (not provided by the hospital) if/when they requested it. These respondents also said that while at work their employers provided food for them which they found very helpful – especially as two of these respondents were the sole breadwinners and money for food was sometimes scarce.

b) Role of Religious Groups
One of the two respondents who disclosed her status mentioned that she was given food by fellow members of her parish. One respondent who had not disclosed his status had previously received food through the Muslim Zakar Fund\textsuperscript{51}. He said that his household had only made use of it once. He stated that his wife was not happy to use this service as she did not want to ‘look poor’ to her community (Respondent 12 30/08/05).

Although other religious groups offer food programmes as well as skills sharing no respondents made use of these services. All stated that they did not know who provided these or what was available.

\textsuperscript{51} The respondent mentioned that all Muslim people were to contribute a set percentage of the salaries, to this fund to provide food for people in need. Anyone, irrespective of religious persuasion may make use of this fund.
c) Role of Community Organisations

The only two forms of community support accessed (non-emotional) were for food and home-based care. One respondent had previously made use a food outreach programme provided by Grace House (only once) – where fruits and vegetables were given out – and another respondent received soup from a soup kitchen established by Sothembá.

Although only two respondents made use of these services eight of the respondents said that if they knew of these services they would utilise them, while three said that they knew of them but did not use them (refer to section 4.4)

One respondent mentioned that home-based carers had visited her when she was very ill (in the early stages of her illness).

A summary of the factors constraining accessibility of psychosocial support both formal and informal are shown in Table 6 below. Factors contributing are also present.
Dimension | Factors Constraining Access | Factors Contributing to Vulnerability
---|---|---
Psychosocial | Stigma | Negative Experiences |
| | Disclosure fears | Stress due to disclosure concerns |
| | Negative experiences of disclosure | Inability to access social networks
| Alcohol Abuse | Fear of exclusion | Poor integration into established external support mechanisms |
| | Fear of physical safety (if disclose) | |
| Informal Safety Networks | Perceived racial factors | |
| | Endemic poverty - inability of connections\(^{52}\) to provide assistance | |
| | Overburdened connections | |
| | ........................................... | |
| External Support Mechanisms | Poor knowledge of assistance available | |
| | Poor service integration | |
| | Poor accessibility of external support mechanisms | |

Table 6: Summary table showing factors constraining access to support mechanisms and factors contributing to vulnerability.

\(^{52}\) Connections being one friends, family or any other close individual one would usually count on for assistance in adverse situations.

\(^{53}\) This was both because of poor disclosure as well as inability of connections to assist.
4.4) Access to Healthcare

4.4.1) Role of Informal Social Networks

Primary care giving, with respects to long term situations, is anticipated to be predominantly from immediate family (Table 7). As one respondents whose sister-in-law assists her when ill (cares for and assists in household chores) mentioned:

"I'm not free to ask her (sister-in-law)... my brothers’ wife is not my sister or my brother" (respondent 16 8/09/05)

A few respondents echoed this sentiment in preferring immediate family as their primary care givers.

In the majority of cases there were a range of possible negative consequences for the caregiver (Table 7) as reported by the respondent. These included possible loss of employment or decreases in pay (due to care giver absenteeism and inflexible working conditions), early withdrawal from school – in the one case where this was mentioned it was the withdrawal of the female child; and extra burdens on already pressured families\(^\text{54}\). A further problem included extra stress on HIV positive caregivers\(^\text{55}\).

The second most predominant source of care was respondents themselves. Three respondents did not have anyone to care for them in the event of prolonged illness.

Friends and neighbours were the second source of care, while only one respondent would be looked after by her extended family.

\(^{54}\) Families already affected by illness and or financial problems mostly due to unemployment and a high numbers of dependents.

\(^{55}\) This was not alluded to by the respondents but is a logical conclusion as the care giver will have not only her or himself to look after as well as other family members (especially in female headed households, or if the carer is a women) but also a demanding client???
<table>
<thead>
<tr>
<th>Number of Respondents</th>
<th>Source of Care</th>
<th>Factors affecting care</th>
<th>Profile of care givers</th>
<th>Possible negative outcomes for care givers &amp;/or respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Immediate Family</td>
<td>• 8 of 11 - Employed</td>
<td>- absenteeism from work may result in loss of pay or loss of employment</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• High number of dependents</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1 of 11 - Attends school</td>
<td>- extra burden on an already pressured family</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 4 of 11 HIV positive</td>
<td>- absenteeism from school</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>- primary care giver in need of care</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>Self Care</td>
<td>• 2 of 3 with dependents</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Friend</td>
<td>• 1 of 2 - Self-Employed</td>
<td>- cannot always be present (because self-employed)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• 1 of 2 - Respondents employer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Neighbour</td>
<td>• 1 of 2 – neighbours health not good</td>
<td>- inability to provide quality care</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Extended Family</td>
<td>• Unemployed</td>
<td>- Extra burden on an already pressured family</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>• High number of Dependents</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 7: Primary sources of respondent care, possible negative consequences for care givers fulfilling this role and for respondents.

4.4.2) Role of Formal Healthcare Facilities

4.4.2.1) Discovery of HIV positive status and Emotional Support Accessed

Most respondents (13) found out their HIV status through VCT at Delft Day Hospital. Three respondents were tested by doctors at Nyanga Day Health Centre and one in an emergency situation (she was very ill) at Tygerberg Hospital. Most (12 out of the 13) of those who went through VCT undertook both pre- and post-counselling sessions, one

56 Note these numbers are not congruent as multiple answers were given by respondents, especially when they were not sure who would act as their primary care giver.

57 This was as described by respondents, answers have been reworded e.g. if told child will stay home to look after the respondent it was reported as absenteeism from school.
respondent mentioned however that she received no post-test counselling. All respondents who found out their HIV status at Nyanga received no pre- or post-test counselling – the respondents were just given a little information regarding the use of condoms. The respondent who attended Tygerberg Health Centre received a little counselling from the doctor and nurse who told her she was HIV positive, they instead told her to go for counselling at the Health Centre close to her.

Since initial testing only seven respondents returned for counselling, three at Delft Health Centre with councillors, one at Bellville Health Centre which she sourced herself, and one at Table View Health Centre (on suggestion of employee, see section 4.3.2.1a). Of the seven who returned to the Delft Health Centre only two went for more than two sessions (not including VCT). Two respondents received counselling through their place of employment (see section 4.3.2.1a).

Counselling services are provided at Delft albeit not always reliably\(^{58}\), and various barriers exist, inhibiting utilization of these services (discussed in section 4.4). No respondents made use of support groups available at the hospital.

4.4.2.2) Post – VCT Access of Formal Health Care Facilities.

Respondent utilisation of the Health Centre facility was biased as all respondents were contacted within the outpatient setting. The level to which respondents interacted with this service varied however. Nine of the seventeen gave reasons that would prevent them from seeking treatment (ill and in general). Four of these were related to accessibility and 5 to accommodation.

One respondent utilises a Sangoma\(^{59}\) together with a conventional doctor but has not told the conventional doctor this, although she would like to. Three respondents who made use of traditional healers said that they would not go to these, as, in the words of one respondent; “...this thing needs a doctor (referring to an academic one)....” (respondent 8 16/08/05)

The following section is divided into the five determinants of access, namely affordability, accessibility, accommodating, availability and acceptability. The results

\(^{58}\) During some Health Centre visits the councilors who were my main contacts were sometimes out for the day with no previous warning, the doctor also commented that this was not uncommon.

\(^{59}\) A traditional healer.
from this section related to constraints in accessing healthcare services as well as effects of this on vulnerability are displayed in Table 8.

a) Affordability

With respects to affordability none of the respondents paid in money or in kind for the services they utilized\(^60\).

b) Accessibility

Although none of the respondents paid for Health Centre services this did not completely eliminate financial constraints to access. Respondent access to the Health Centre is influenced by financial wellbeing as well as availability of transport. For financial reasons six of the 17 respondents’ primary means of reaching the Health Centre is by foot (they cannot afford to take public transport). Four of the aforementioned respondents noted that if they were too ill to walk to Health Centre for a treatment they would not be able to go. This was because two were not on a taxi route and therefore this option was not available to them and the other two would not be able to afford a taxi. The other two respondents whose only option is to walk reported that they would walk even if sick. In total three of the respondents who walked could not make use of public transport regardless, as they are not on a taxi route. Walking respondents have an average walking time of 40 minutes to the Health Centre and back home.

While 11 of the respondents make use of taxis to get to Health Centre this is not constant and depends on their financial situation at the time.

Two respondents take over an hour to reach the hospital\(^61\) due to the taxi rank being far from them and due to the constant stops and waiting involved in taking this form of transport\(^62\). One of these respondents however stated that this would not prevent her from seeking treatment even if ill. She noted, however that she has not been very ill yet.

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\(^{60}\) This is in accordance with the South African Bill of Rights which stipulates that each South African citizen has a right to basic health care.

\(^{61}\) These two respondents live far from the Health Centre but as their local Health Centre does not offer the services they need, in terms of medication and HIV/AIDS counselling they attend Delft Health Centre.

\(^{62}\) Only when the taxi is full or has a sufficient number of passengers will it go and even then it may make several stops.
With respects to support groups one respondent mentioned that she did not attend these as she lived far from the Health Centre and the sessions were held at the end of the day. As she was apprehensive taking public transport late at night she could not attend these.

c) Accommodating

Five of the seventeen respondents reported that if feeling unwell they may not go to Health Centre because of the time it takes to be seen. One respondent stated:

"...when I don't feel well I just want to sleep...and must wait too long (at the Health Centre)" (Respondent 16 8/08/05)

Another respondent told of one of his experiences waiting at the Hospital:

"...you have to wait so long...the one time I got too hungry and left...that food they give doesn't seem right" (Respondent 10 18/08/05)

For some respondents it is not a problem to return to the Health Centre another time, for others however it is: Respondent 16 who has a one month old baby remarked that it is not easy for her to come on another day if she misses an appointment as first she must come to make an appointment (the Delft Health Centre does not allow for phone appointments to be made) and then only can she see a doctor.

Another respondent told of how she would have to stay absent from work if she needs to come to the Doctor and how sometimes this is not possible, she told of one case where she missed her appointment because:

"Service is slow and I would have to come for the whole day and miss work ..." (Respondent 4 11/08/05)

The same respondent spoke of her experience when she was unwell and came to the Health Centre for treatment without an appointment:

"...(I) was very sick ...waited from 6:30/7:00 and only got seen at 14:00" (Respondent 4 11/08/05).
She commented that she would not seek treatment without an appointment, but would rather try to go to a private doctor.

Of those respondents who said that the time they wait would not put them off from coming one remarked:

“...we wait a long time, but they help you” (Respondent 15 6/08/05)63

With respects to the centre’s counselling and support groups three respondents reported that the times of these services clashed with their work responsibilities and they could therefore not attend.

d) Availability

None of the clients reported that issues surrounding availability would put them off seeking health care. Seven recounted instances where they did not receive medication but were told to come back the next day. For three of them this was a problem as it meant they had to take another day off work. Another respondent recalled how she had a persistent problem that the Health Centre did not help her with and when she tried to discuss this with her nurse was just told to continue the treatment. She did continue, but to no avail as the problem persisted. It was not so much that the treatment had failed that made her unhappy but that she felt her complaint was not taken seriously. This respondent recalled another aggravating experience that made her unhappy with the service at the hospital:

“...the Doctor told me I must get six packets of medicine, the pharmacy only gave two, when I asked them why they said I must ‘just go’...I told them I would go back and tell the doctor... ” (Respondent 17 8/09/05) they then gave her the correct medication. This was a problem of both medication availability as well as service provider acceptability. The respondents’ main concern was that the doctor prescribed the correct amount of medication for the month. As she was employed it was very inconvenient for her to return for her medication and in the past when this happened (i.e. she ran out of medication) she couldn’t always return.

Another respondent told of how once when coming for an appointment the doctor and nurse were not there and she left without being seen by any health professional.

63 This same respondent takes over an hour to reach the hospital, which she views as part of her exercise.
In a similar vein one respondent recalled a time when he needed to see a doctor and was told by the nurses to wait for his Health Centre day, he also left without treatment.

The predominant reason why clients did not access counselling, or support groups was that they were not made aware (according to them) of these services. When interviewing councillors the same response was given; they were not aware of available services in the Health Centre or in the community. Other members of the HIV/AIDS Health Centre were also not aware of where and when these support mechanisms were available (this was also as councillors kept their own times, which were subject to change without prior notice).

e) Acceptability

While no respondents stated that they would stay away from the Health Centre due to issues related to acceptability, two respondents reported that they were not comfortable attending the HIV/AIDS Health Centre as there is no privacy. One respondent noted that if one goes in for an appointment ‘in that room’ people know you are HIV positive. These respondents also mentioned that they do not attend counselling for those reasons although both said that they would like to receive it. One of these respondents said:

“...too many people there (outside the room) and if you go inside they know you’re HIV positive, and if they see you with the councillor they know you’re HIV positive” (Respondent 16 8/09/05)

Along the same lines one respondent told how on going to receive her medication the person dispensing the medicine (she was not sure of his position) enquired as to what the medication was for in front of everyone who was waiting with her in line, although all he had to do was read her folder. This respondent also commented:

“I know that I’m HIV positive but that doesn’t mean everyone must know”
(Respondent 17 8/09/05).

This respondent was referring to an experience with a nurse whereby the nurse had been quite outspoken of her (the respondents) status, in front of other clients and Health Centre staff. Other respondents also mentioned that they were not happy with their health care workers, one respondent mentioned that her doctor treated her ‘like a child’, and another that nurses are often abrupt and not very polite. One respondent said:
"Some nurses (they) make you angry, they even make you say a word you don’t want to say." (Respondent 10 18/08/05).

With respects to language the study biased English speaking respondents (in addition all spoke either Afrikaans or Xhosa), these respondents mentioned that they were able to converse with health care workers. The one respondent however who spoke no English, commented that so far he had been lucky, as there has always been a Xhosa speaking nurse around when he has seen a doctor (only speaks English). On observation it was noted that where an Afrikaans or Xhosa speaking nurse was not present the doctor had much trouble conveying his message to clients. This is of particular concern as most client seen by the HIV and AIDS Health Centre doctor are already advanced in the disease and it is important they understand what is happening to them.

One respondent reported that she would like to discuss her physical practices with her doctor, but did not feel comfortable to do. The same respondent also made use of a Sangoma and although she also wanted to discuss this with her doctor she was afraid to do so. She was not the only respondent who did not feel comfortable with their doctor. One respondent stated:

"...he makes you feel like a child" (Respondent 1 5/08/05).

It should be noted that respondents are seen by a range of doctors, for HIV as well as non-HIV illnesses. Only two respondents commented that they would prefer to see the same doctor.

Table 8 shows a summary of the factors constraining access of healthcare, as well as possible vulnerabilities incurred.
<table>
<thead>
<tr>
<th>Dimension</th>
<th>Factors Constraining Access</th>
<th>Factors Contributing to Vulnerability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare</td>
<td><em>Accessibility</em> – transport issues; financial constraints</td>
<td>Low utilisation of Health Care facilities</td>
</tr>
<tr>
<td></td>
<td><em>Accommodation</em> – long waiting time</td>
<td>Poor utilisation of palliative treatment services</td>
</tr>
<tr>
<td></td>
<td><em>Acceptability</em> – privacy issues, poor relationships with health care providers</td>
<td>Possible and reported poor treatment adherence</td>
</tr>
<tr>
<td></td>
<td><em>Availability</em> – unreliable medication provision</td>
<td>Incomplete disclosure of sexual and other behaviour to health care workers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Possible need for personal expenditure on medication64</td>
</tr>
</tbody>
</table>

Table 8: Summary table showing factors constraining access to formal healthcare and factors contributing to vulnerability

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64 As previously mentioned households relied on Health Centre medication as most did not have money to spend on medication, having to buy their own – if not provided – would place further stress on already stretched finances.
4.5) Access to Information

This section is divided into three parts. The first reports on respondent attitudes toward information, the second the role of informal safety networks, and the third external support mechanisms accessed.

4.5.1) Respondent attitude toward information

Most respondents attempted to keep themselves well informed as can be seen from Table 9. For most respondents obtaining much information about the disease was very important. One respondent told of how she visits her cousin unfailingly every Sunday to watch 'Siyangoba' which she says gives her very important information on how one with HIV/AIDS should live and look after oneself. As he is not privy to her HIV status she pretends to visit him\(^65\). Those who strove to be well informed were generally more positive in interviews. While those who didn’t often seemed more resigned:

"Ek het so slegs gevoel dat ek nie belangestel het nie (I felt so bad that I really didn’t care)" (Respondent 12/08/05) ...when talking about his status\(^66\); or in denial:

"I’m not really sure that I’m HIV positive that’s why I delay to support myself" 
(Respondent 6/16/08/05).

While the latter respondent receives much information (see Appendix 1) she applies what she knows to her sister as she is in advanced stages of HIV, rather than herself. One respondent mentioned that she can barely afford necessities such as food for herself and her children let alone buy the things needed for herself, so she doesn’t worry with these ‘other things’.

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\(^{65}\) This respondent reported that she has seen families turn against a fellow family member who is HIV positive.

\(^{66}\) He also admitted to not giving up his bad habits such as smoking, which he says won’t make a difference, although he is also an asthmatic.
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Table 9: Respondent source of information (grey areas signal usage).

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67 Private doctor
4.5.2) The role of Informal Social Networks

Three respondents obtained information about HIV/AIDS from their family, of these three two are also HIV positive and give information based on experience. Two received information from a friend or friends: one has many friends who are HIV positive and they share information. The other respondent does not know where her friend gets her information. For the latter respondent this friend serves as her primary source of information.

4.5.3) External Support Mechanisms Accessed

The source most drawn on for information was reported as being the councillors, as can be seen in Graph 6. This was in spite of the fact that the majority of respondents accessed these only for Pre- and post-counselling (VCT) sessions (only two respondents said that they have continued with counselling sessions).

Graph 6: Source of respondent information.

According to respondents the first counselling sessions (VCT) provided much useful information. This included information regarding: safe sex practices; dietary requirements and good nutrition; healthy living - no smoking or drinking, exercise; and
legal rights (only two respondents mentioned this). Contact details for support groups were also provided; this was reported by the two respondents who attended more than two counselling sessions.

The second most used information source is pamphlets/magazines. Most respondents found them easy to understand and pertinent in the information they provided. Respondents mostly obtained these from the hospital, others from organisations such as ‘Love Life’ (at the Hospital, only one respondent received this through her daughter from school). Not all respondents found these helpful due to low literacy levels. The number of respondents who obtained useful – with respects to HIV – information from television and radio were the same (9). Some of the information received from these sources include: information on Health Centre visits and their importance; names of useful medicines; new medication available; nutritional guidelines for people with HIV/AIDS; and Human Rights. With respects to medication available one respondent enquired during the interview if it is true that a new HIV and AIDS injection is being produced which can rid the body of the virus. This respondent had seen this on the News.

One respondent commented on a soap opera character in a South African television series, this character she said:

"...is a very strong person...in the way she handled things...she doesn’t feel ashamed of herself" (Respondent 4 11/08/05)

Another respondent said that she regularly watched “Soul Buddies” with her children and that it helps them and her deal with her illness and understand it. Respondents without a television did not always have access to one, through their social networks. This was partially due to the fact that they did not want to watch programmes related to HIV and AIDS in case they were suspected of being HIV positive. Two respondents had recently burgled: in both cases their televisions and radios were stolen. One respondent mentioned that she cannot always buy electricity as it is not always available; another said that as her home burnt down she now resides in a temporary housing site. This site does not have electricity. Therefore although the aforementioned respondents are in possession of a television they cannot always watch programmes on it.

68 In many interviews respondents could not always remember exactly what information they were given by the different sources.
69 Isindingo – the character “Nandipa” disclosed her HIV status on “Air".
Only six respondents reported that they got much information from doctors. This is because most clients will see the Health Centre Clinical Nurse practitioner if they are in the early stages of HIV. At each check up the Health Centre Clinical Nurse Practitioner will determine clients CD4 count (through blood tests). During this time the Nurse will also remind clients of correct eating, use of condoms, and general healthy behaviour. This was not captured well in the questionnaire and respondents too did not voluntarily recall this when information provision was discussed. This may be due to the fact that this goes by unnoticed by respondents as it is so much a part of each appointment.

Only five respondents obtained information from Newspapers, although all reported that this was not constant, but when given was useful.

Three respondents mentioned that what they had previously learnt at school had become useful to them; this was mainly about finding out one’s HIV status, diet and the use of condoms.

Support groups yielded much less information to respondents. Seven respondents wished to attend these, but for a variety of reasons didn’t (refer to section 4.4.2.2) Those two respondents who used them – both no longer attend as they have come to an end in both cases – commented that they provided much useful information especially through informal discussion with other members in a welcoming, encouraging environment.

Only one respondent made use of a helpline. This was an enquiry made with regard to a health issue she felt the Health Centre was not able to assist her with as all their efforts had previously failed.

A religious group provided information to only one respondent, at her Parish PLWHA meet after the religious service, socialise and exchange information. As mentioned by the previous two respondents who attended support groups she found this a comfortable environment within which ideas and experiences could be exchanged.

The one respondent, who received information from the library, received it through her daughter who brought home interesting information that the library made

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70 The respondent couldn’t remember the name of the particular helpline.
71 She was told by her Doctor that if her infection was not treated it may reach full blown cancer and that having HIV increases this risk.
available. In this way she made contact with a councillor whose address and number was on one of the documents.

One respondent reported that she gets much useful information off the internet, which she accesses at her work. No other respondents had access to this.

The factors affecting access to information and factors contributing to vulnerability are summarised in Table 10.

<table>
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<tr>
<th>Dimension</th>
<th>Factors Constraining Access and Utilisation</th>
<th>Factors Contributing to Vulnerability</th>
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<tbody>
<tr>
<td>Information</td>
<td>Low literacy levels</td>
<td>Inadequate knowledge of HIV</td>
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<td>Unsafe conditions – theft</td>
<td>Incorrect HIV related information</td>
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<td>Mistrust of information regarding the treatment of HIV</td>
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<td>Poor relationships with health care workers</td>
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Table 10: Constraints affecting access to and utilisation of available information, and factors contributing to vulnerability.
Chapter 5

5.1) Discussion

This study investigated the levels of support accessed by PLWHA and their households. Three objectives relative to this question were investigated. The first objective was to identify what support mechanisms households were accessing, the second to investigate factors constraining access and the third how the findings of the first two objectives affect the PLWHA and their household.

The discussion of the findings is presented in five parts, congruent with the five focus areas, namely: financial resources; access to healthcare; psychosocial support; access to information; and environmental factors.

Although the Progression of Vulnerability (Blaikie et al. 1994) provided a useful framework, highlighting possible areas of vulnerability for PLWHA and their households, it was limited in its application for the findings. An altered DFID framework (refer to Figure1), illustrates how the findings of access to support mechanisms interact with livelihood assets and individual and household vulnerability (refer to Figure 4 below). The original DFID framework placed too little emphasis on the factors constraining access of transforming structures and in its focus on strengths. This framework also places too little emphasis on weaknesses which have the potential to underestimate the severity of a situation. The two frameworks together served to overcome these constraints, one highlighting vulnerabilities and the other revealing interactions and important dimensions (assets and transforming structures.). An overview of the findings are presented in the altered DFID framework in Figure 4 below.

The study has several limitations, namely: low respondent participation, language bias and lack of privacy for interviewing sessions\(^\text{72}\) (refer to section 3.1.2.8). These prevent the findings from having the rigor necessary to make generalized predictions or conclusions. The value of the findings of this qualitative study revolved around their elucidation of issues related to support mechanisms access in resource poor settings. As with other qualitative studies investigating support mechanism access (Arntz, 2002 and

\(^\text{72}\) This was of specific concern in the section on healthcare part of the questionnaires as patients were interviewed in the Health Centre setting (HIV/AIDS Health Centre) and the answers may have been biased, this was quite apparent in that most if the respondents who reported problems with health care workers were often those interviewed in private spaces of the Health Centre.
Figure 4: A summary of the findings showing the interaction between the individual and household vulnerability context as it interacts with possible transforming mechanisms (which are a function of available support mechanisms and the factors constraining usage). These two dimensions articulatate at the household level, represented here as livelihood assets.
Power 1998), the study revealed important needs for infected as well as affected individuals.

The findings that follow illustrate an overall under-usage of available support mechanisms. Reasons for poor utilisation in each dimension vary, factors common to all include: stigma, poor service integration, endemic unemployment and gaps in service provision. These and more factors are unpacked in the following passages.

5.1.1) Financial Resources

Findings from this study, with respects to financial needs, are congruent with those of the literature review, e.g. Baigis - Smith et al (1995), who found that the most pressing needs for HIV positive individuals were financially orientated. These needs were related to income/financial resources and employment. Similarly the most pressing need of respondents and their households were financially related, firstly with respect to nutrition, secondly to daily living, and thirdly with respects to medication. It was important to note that respondents, even before knowing their HIV status or getting ill as a result of it – were not coping financially.

With respects to nutrition only seven respondents reported that they met their nutritional requirements (as suggested to them by the Health Centre). In this study ability to obtain adequate and sufficient food depended on three factors: high dependency ratio’s (i.e. earner to dependent); low/irregular/no income (from employment, welfare or others); and informal employment. All of these decreased or yielded too little money available for spending. Unfortunately the respondents who could not meet their nutritional requirements did not meet the standards for accessing nutritional assistance programs linked to the Health Centre, that is to say they were not malnourished and sick ‘enough’.

As all these respondents reported that their primary food source was either miellie pap or bread and that they sometimes had to eat less or skip meals, their nutritional levels are probably quite low. As previously mentioned nutritional status greatly affects the immune system which in turn leads to further replication of the HI virus (Haddad & Gillespie

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73 Possible diversion of expenditure to food, medication or other HIV related expenses.
74 Daily doses of fresh fruit and vegetables LYNDAL put this sooner
It is therefore likely that these respondents will progress more quickly than those who stated they meet their necessary nutritional requirements. This finding was commensurate with other studies of household income and nutritional status whereby nutritional spending was the first to come under strain during times of financial stress in already financially stressed households (Booysen 2002), in these studies malnutrition often resulted. The reality of this is that in need and only partially malnourished individual must wait for inevitable malnourishment before receiving assistance.

The findings also alluded to the issue of intra-household differences in access to resources. This was commensurate with studies that investigate asymmetrical access to resources, whereby factors such as gender and age determine access (Posel 1997). In this study another factor was added to the aforementioned, namely sickness. In two households there was a bias as to who received what food; in both cases it was the sicker member (also HIV+) that had first access to quality food. In one context this was the respondents’ sister while in another the respondent’s spouse. As mentioned by Booysen et al (2002) as food gets diverted to certain household members and as household spending on food decreases (especially where the sole breadwinner is the PLWHA or the primary care giver) malnutrition in other household members may occur. It is for this reason that poor access to and insufficient numbers of food programmes available is of great concern, as it affects the individual as well as the household.

The saving mechanisms mostly used were informal. Only two respondents made use of banks for saving and one made use of financial insurance. All of these respondents received regular income and welfare grants, two had more than one earner and all exhibited low dependency ratios.

Not all respondents qualified for a disability grant although four were already feeling the affects of the disease due to decreased earnings. Each of these respondents suffered from

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75 It is worrying to note that this is a cyclical pattern for the dietary intake and disease are the primary determinants of nutritional status, which in turn affects disease progression (Hudspeth 2003).
76 Research from Côte d’Ivoire and Thailand have shown that more money is spent on healthcare for men living with HIV/AIDS than on women with HIV/AIDS (Department of Housing in van donk no.7).
77 Although this is the case the members were still not necessarily constantly meeting their nutritional requirements.
78 In turn this makes them more vulnerable to illness as well as possibly involved in dangerous practices for fast money (drugs, promiscuous sex get references).
problems often reported by PLWHA, including: decreased endurance, physical mobility and sensory perception (Bennett 1988 and Walent 1992 both in Baigis–Smith)

There was generally low utilisation of informal financial support mechanisms. Arntz (2002) noted that poor accessibility of informal safety networks further undermines the ability of PLLWHA and their households to cope with the increasing needs associated with HIV. Seven of the thirteen households made use of informal savings clubs and only four made use of informal burial and funeral policies (refer to Graph 2 section 4.2.1.4). It was interesting to note that it was not just sufficient and constant disposable income that allowed for the use of saving support mechanisms but also the disposition of the recipient. This was made apparent as four of the seven respondents who made use of savings clubs reported that they ate poorly, which means that expenditure on food was sacrificed for savings. In general however it was households with one or more formally employed members, who also received welfare grants and had low dependency ratios that made use of savings support mechanisms. The majority of households did not however fit this profile and accordingly did not make use of these. This meant that the most available of financial safety nets were not available to them.

With respects to usage of micro-loans it was worrying to note that one household that received no income from employment or from welfare grants was making use of micro-loans. This is worrying as studies have shown that usage increases as the disease progresses with a corresponding increase in household debt (Pryer 1988). Where there is an inclination to use these, this possibility always exists. Inability to payoff loans – due to illness79 of the sole breadwinner – and increased usage of microloans will increase the chances of households accruing debt

Limited accessibility of informal safety networks undermines the ability of poor urban residents to pursue different livelihoods options (UNDP 2004). Cox et al. (1997) reported that poverty could increase by 25% in a sample of private transfer recipients if their private safety nets were removed. The impacts of lack of access to these networks on PLWHA, is therefore even more severe due to the increased demands of the illness.

79 A decrease in income occurs as a result of morbidity and mortality, not only in losing a bread-winner but also due to funeral costs (Bachmann & Booysen 2003).
On a community level the decreased use of informal safety mechanisms has the ability to undermine the social capital of the community. Dersham and Gzivishvili (1998) findings have shown that the number of households who are food, economic and shelter vulnerable in the general population will increase on average by 4 per cent for each loss of an informal network member. The inability of respondents to contribute to informal exchanges will therefore in the long run undermine the ability of their social networks to provide help.

5.1.2) Access to Health Care
The expected loss of income due to carer responsibilities is anticipated to compound financial stress. Most respondents reported that they had someone to care for them in the event of prolonged illness. Their expected primary care givers exhibited a combination of unemployment or informal employment, high dependency ratios as well as HIV infection. The quality of care therefore, may be undermined by monetary stress, other familial obligations or sickness (especially where HIV +). Accessing this support mechanism may in due course increase respondent vulnerability, due to poor quality care.

Three respondents reported that they would have to look after themselves, in the event of illness. It is people like this who have little or no access to primary care that the government suggests should benefit from home-based carer services.

Three home-based carer NGO’s are currently active in Delft. Presently each of these NGOs cares for approximately 25 individuals. The awaited increase in HIV related morbidity will according to the Home-based care co-ordinator call for a greater demand for home based care than they will be able to supply (pers com, 21/09/05). She added that while HIV morbidity is pressing, individuals with other illnesses also require care and this she said is an example of how HIV and AIDS will slowly erode the health system, through the pressure it will place not only on health care workers but also on non-HIV ill patients. She further commented that although the aforementioned NGO’s are in a process of recruiting and training new home-based carers this increase in personnel is unlikely to be sufficient to deal with the projected HIV and AIDS health care needs.

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80 A higher number of carers may have been infected than reported, as their status may not be known to respondent or they may have not been tested.
81 These are Koinonia, Tygerberg Hospice and Ma Afrika Tikkun.
With respects to access to formal healthcare, as this service is free it lessens the burden of the illness with respects to financial strain. Bachmann and Booysen (2002) highlight the importance of free government Health Centres and Health Centres in providing care and in avoiding poverty or barriers to access caused by user charges (also Booysen et al 2002). Access however as shown in this study was restricted due to accessibility and accommodation. This is of special concern as PLWHA are at grave risk from other communicable diseases around them and also from disease causing organisms we carry in our bodies, which their immune systems cannot hold in check (Hewitt 1997). PLWHA may be severely or completely vulnerable to otherwise treatable diseases. They are at unusual risk from new strains of disease notably tuberculosis (Hewitt 1997). It is therefore important that they seek treatment and adhere to treatment regimes. It has been shown that prompt diagnosis and treatment for TB\(^2\) can extend the lives of PLWHA by up to two years.

During interview sessions it was also found that respondents had questions related to HIV although when asked why they did not ask the health care workers, many just brushed the question aside, except those that expressed dissatisfaction with service providers. Ntuli et al (2003) reported that after having negative health care experiences, patients may feel disempowered and unsure of what measures to take to improve/control their health conditions. This is in part due to the very personal nature of the disease.

It is for this very complex nature of HIV that counselling is so important. Miller and Bor (1991 see Irinoye) noted several concerns of PLWHA, which include: doubts surrounding family and friends willingness to give support, possible rejection by family and friends, problems concerning work and finances as the disease progresses and meeting basic needs. These concerns as well as others are dealt with during counselling thereby helping the individual to come to terms with not only their current situation but also to help them prepare for the uncertainty of their future (Irinoye 1999). Many respondents verified the above concerns and eight respondents expressed interest in attending counselling sessions. For a variety of reasons however, including formal health care accessibly as well as issues around stigma and knowledge of what was available,

\(^2\) As was previously mentioned TB is the leading cause of death in PLWHA in developing countries (Global AIDS-Care-Watch 2005).
respondents did not attend counselling. Stigma was revealed as an aspect of health seeking behaviour through the need for privacy required by some respondents. The benefits of counselling include enhancing life quality and limiting progression of the virus through stress management, information sharing as well as assistance in effective communication (Irinoye 1999). These benefits were therefore denied these respondents (for personal as well as interpersonal reasons).

The use and need of public transport to reach the Delft Health Centre poses as a problem for two reasons. The first is due to an increase in already pressured household expenses and the second with respects to health. Some respondents reported that they must walk far to reach a taxi pick up point and sometimes wait extended periods for a taxi to arrive. This they reported was especially inconvenient in winter. As PLWHA are at grave risk when they catch infections this has the ability to affect the rate of progression of HIV due to illness undermining their immune systems.

5.1.3) Psychosocial Support
The greatest non-monetary need of respondents was that of food provision. Help received from informal social networks corresponded to this (refer to Graph 4). It was mostly the friends of respondents who provided nutritional support as well as all other types of assistance. This contrasted with long term support provision. Long term care for both respondents (primary care) and dependent was to be mostly undertaken by immediate family (refer to Table 8 and Graph 5). As stated by Arnall (2004) “…informal community arrangements work well under certain circumstances but begin to breakdown under periods of prolonged or widespread stress”. Informal safety nets, therefore pose limited usage to PLWHA. This is because as the disease progresses periods of illness will increase in frequency, duration and severity, and this drastically increasing the levels and types of assistance needed (Whiteside 2002).

Respondents even before reaching this level of need were not always able to access help from their social networks. Several respondents reported that even if they could or did ask for help from members of their social network these members were not

83 Van Niekerk (2001) discusses how the need for privacy and confidentiality with respects to HIV infection arises in large due to the stigma surrounding HIV and AIDS.
always able to comply. Endemic unemployment and poverty therefore undermined the ability of social networks to yield support. As Arnall et al (2004) found community wide threats can have a severe impact on people’s ability to engage in safety net transfers. In the South African context many of these difficulties stem from the country’s structural unemployment crisis (Arnall 2004).

Social network access for emotional support was also underutilised. The reason for this was a lack of disclosure, which was rooted in fear of exclusion and personal safety as well as off-putting personal and hearsay experiences. As reported in the literature review the sexual mode of transmission means that HIV is highly stigmatised by among other things moral judgement (Holdon 2003). This was mostly apparent in the low respondent disclosure in religious settings as well as the differential disclosure within social settings, in particular immediate family.

Although ten respondents attended religious services only two disclosed to fellow members of their faith group. Most of these respondents reported they would like to speak to the leaders of their faith groups. Puchalski and Sandoval (1995) state that the moral judgement connected with HIV and AIDS may lead religious PLWHA to the belief that they are punished by God and in this way feel isolated from their spirituality. Puchalski and Sandoval (1995) reported that the benefits of spiritually (in such inclined individuals) are an important factor in coping with pain, in dying and in bereavement. The active practice of spirituality can help PLWHA cope with the uncertainty of their illness, instil hope, bring comfort and support from others (from fellow faith group members) and bring resolution to existential concerns, particularly the fear of death. As one respondent commented:

“...make(s) me feel better; even Health Centre medicine doesn't make me feel that good” (respondent 5 11/08/05)

This respondent was referring to her physical and mental religious practices. The full value of spiritual guidance and practice in individuals who did not disclose excluded them from the full benefits of this form of support.

The lack of access to informal psychosocial support was not offset by the utilisation of formal support mechanisms. In total only two respondents benefited from food programmes although 12 respondents expressed a need for them. Similarly (as
stated above) only two respondents made use of emotional and material support from their religious groups. No respondents made use of support groups although 8 respondents said they would like to join support groups so that they could meet other HIV+ individuals. Respondents often reported that they would like to have someone to talk to, that can understand what they are going through.

It was problematic to note that one reason preventing respondents from accessing these formal support mechanisms revolved around general poor knowledge of what services were available both in the community and the hospital. The concerning issue is that healthcare providers, according to the Delft Health Care Facility Manager, should all at least be aware of what is services are offered in the Health Centre. Where applicable healthcare workers should also be privy to community related hospital initiatives, such as support groups and food programmes. The majority of members of the HIV and AIDS Centre where not privy to services available however. These individuals are often the sole connection the respondents had to accessing this type of information. It was not only the clinic however that revealed poor service integration other organisations active in the area also did not have knowledge as to who offered what service in the community.

5.1.4) Access to Information
Van Niekerk (2001) referred to HIV as a complex problem \textsuperscript{85} one in which the whole is more than its constituent parts. This is relevant with respects to access to information. As stated by MacKian (2002) there is a gap between ‘what we know’ and ‘what we do’. It is not only the ‘acquisition of\textsuperscript{86}’ but also the ‘acting on’ information that pose as problems in this study.

With respects to the former, factors inhibiting access to information included personal (such as poor literacy and negative attitudes) and interpersonal (inability to access available support\textsuperscript{87} and poor relationships with service providers) factors. Other factors included issues such as poor access to television and radio (both personal and

\textsuperscript{85} A complexity refers to a kind of problem that has no clear cut or self-evident answer, but also may not be successfully addressed even through an analytical approach wherein we distinguish parts and a whole, often with the expectation that addressing the part will fix the whole (van Niekerk 2001).

\textsuperscript{86} Acquisition is made up of the availability and acceptability of information.

\textsuperscript{87} Certain respondents reported that they would not watch HIV and AIDS programmes at their friends’ houses, as the friends may suspect that they are HIV positive.
interpersonal support affected this) and poor knowledge of where to get information (especially with respects to respondents who were not comfortable with healthcare workers – refer to section 4.4.2.2).

Stigma effected both information acquisition (where respondents felt that their HIV status would be discovered if they attend counselling sessions or even if they go to the HIV and AIDS clinic) as well as the acting out of what was learnt.

Although not part of the study it was found that the acting out of known information had definite social dimensions. This was related to stigma, as previously reported (e.g. not accessing known support available due to privacy issues), but also to the need to fit into social groups. This was highlighted in respondent alcohol consumption\(^88\), where respondents drank knowing that it would have negative affects it on their health.

Information acquisition therefore highlighted ways in which social capital (with respects to issues of trust and memberships of groups) interacts with access to information. In this study access to information was, among other things, a product of social capital (disclosure concerns related to stigma inhibits utilisation), accessibility of health care, access to finances (e.g. to have money to take public transport to the Delft Health Centre, or buy a television etc) and personal factors (e.g. illiteracy).

It is worth noting that three respondents had previously received HIV education while at school. Another respondent was a member of the Treatment Action Campaign even before being HIV positive\(^89\).

In no small way this illustrates that one of the barriers to enhancing the abilities of PLWHA and their households to cope with the virus, is that of complexity. Complexity of personal relationships, interpersonal as well as institutional and socioeconomic factors the list could go on.

\(^88\) Alcohol usage seemed to 'affirm' place in social networks, especially with the male respondents.

\(^89\) It is possible that he was already infected before joining the group however.
5.1.5) Environmental conditions

"In cities the ratchet effect\textsuperscript{90} will be generated and felt by people living having to live with multiple risk types – crime, violence, disease, unemployment pollution... as well as environmental hazard"

Pelling 2003

As previously stated HIV is a complex problem. The four areas above highlight this but are far from the only interactions that make poor PLWHA and their households vulnerable to the impacts of the disease and increase their general vulnerability.

Of the 17 individuals interviewed, 14 reported unsatisfactory living conditions as a result of their dwellings physical structure, three of these respondents resided in RDP homes. Winter posed the worst time, where respondents reported that rainwater and wind would enter their dwellings through holes in the roof, window frames and under their doors. This together with poor nutrition and cramped living conditions puts not only the HIV positive member of the household at risk from sickness but all household members. As noted the bouts of illness following HIV infection increase both in severity and duration as the disease progresses (Hewitt 1997). The increased risk of infection\textsuperscript{91} together with poor conditions will therefore greatly reduce the ability of recovery from the myriad opportunistic infections.

The overcrowded living conditions (GLTY Plan 99 Sout 1999) in Delft compound this problem as overcrowding aids the spread of infectious disease (Hewitt 1997) and generates other risks. Seven of 17 respondents made use of paraffin for heating. Not only has paraffin usage (especially the long exposure due to paraffin heating) been linked to health hazards (asthma and other ailments) but also physical hazards (fires). The latter is compounded by overcrowding.

With respects to the social environment only three respondents complained of theft. Many respondents however alluded to or stated outright that should their neighbours and other Delft residents find out their status it would be very unpleasant to

\textsuperscript{90} The ratchet effect of vulnerability is a result of frequent exposure to risk, where each exceeding event reduces the resources a group of individuals have to resist and recover from the next stress (Pelling 2003).

\textsuperscript{91} Many studies point to the link of illness, the poor quality housing and overcrowded living conditions in peripheral urban areas (Pelling 2003).
live in the area. This is because residents would ignore them, possible swear at them or even physically hurt them.

Even those residents who are not HIV positive commented:

“I feel safe... but face reality there’s lotsa shebeens and Gangsterism...” (pers com 11/08/05).

Alcohol as already mentioned further causes a hostile environment, this was even true with respects to friendships where many respondents stated that they don’t trust their friends when they are drunk.

Ultimately this results in a social environment that in an inadvertent way discourages disclosure and as seen from the above sections inhibits access to a range of available support mechanisms. The bulk of support is therefore carried by the immediate family or in cases where individuals do not disclose, to themselves.

5.2) Conclusion

This study has investigated the access, by disadvantaged PLWHA and their households, of available support mechanisms. Its objectives were to identify what support mechanisms are accessed, what constrains usage of available mechanisms and the ways in which these contribute to individual and household vulnerability.

The study sample was purposely skewed toward poorer HIV positive individuals and their families. As such it has highlighted possible problems faced by such groups. This study has shown that unquestionably there is under usage of available support mechanisms as well as constricted usage; for reasons closely related to the stigma and fear that surrounds HIV. On the side of the establishment, insufficient provision of safety networks including: welfare grants, food parcels and quality healthcare – as according to the patients charter further undermined respondents’ and their household’s ability to withstand the increasing impacts of HIV. Poor health care cannot be viewed solely as a problem with healthcare workers per say. The overburdened public healthcare sector is charged with the care of thousands of PLWHA. Unless the capacities of this sector are improved – especially human resources and improved infrastructural conditions – care of PLWHA will continue to be substandard.

92 As as determined by at least one respondent or through investigation
The findings of this study point to the fact that any plans to assist PLWHA to cope with their illness cannot fail to take into account the broader socio-economic and environmental conditions within which PLWHA are situated. HIV as a complex problem cannot be addressed in pieces, treating the symptoms and not the cause. The endemic unemployment, low literacy levels, over consumption of alcohol as well as a myriad unsafe conditions will continually undermine efforts to slow progression, and maximise health of disadvantaged PLWHA. As the study and literature review highlighted these affects are not contained by the individual but spill over into the household/family as well as the greater community increasing impoverishment and susceptibility to new infections.

Ultimately if real progress is to be made inequalities need to be addressed and the stigma surrounding HIV and AIDS quelled. The poor usage of support mechanisms reflects both these aspects.

5.3) Recommendations for further research

The findings highlight several avenues for future research. The first relates to the sustainability of support mechanisms, both informal as well as formal. Where support mechanisms are found to have the potential to assist PLWHA and their households cope as the affects of HIV are increasingly felt, these should be supported by government, NGOs and CBOs. This would have the capacity to take strain off the overburdened health care system as well as integrate PLWHA and their households into their communities.

This leads to the second area of pressing concern: stigma. As the study showed stigma has the ability to undermine accessibility of available services. It is suggested that an investigation into the various way stigma manifests, within the individual, the family and all the way up to the government is undertaken. Although this is a mammoth task, to dissolve the stigma and misinformation surrounding HIV and AIDS would clear the many bars preventing PLWHA from living healthy productive lives.

Thirdly a study investigating the constraints to effective service integration would serve to highlight areas where communication could be improved between service providers. Although the study paints a worrying picture it is important to note that there are support mechanisms available, the task now is to make them accessible to those most excluded from them.
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I hereby request your participation in the study which I am undertaking. This study aims at assessing levels of support provided by local institutions to HIV/AIDS infected individuals and how this impacts on their households.

As a participant you are required to attend one interview in which I will be present and perhaps also a translator depending on your comfort. Interviews will be undertaken between August – September 2005.

Recognisably this is a very personal issue and all information provided will be treated with the strictest confidentiality. No names or identifying characteristics will be given in the final report and a copy of the final report will be presented to the Delft Community Health Centre on completion.

Your contribution would be greatly appreciated and highly valued.

Yours truly,

L. Pottier

Participant:

Appendix A
Stages of HIV infection

**Stage 1:** The initial ‘window period’ period, by the end of which an HIV test can detect antibodies. Individuals are particularly infectious during this stage, and often have an illness resembling influenza.

**Stage 2:** The asymptomatic stage, when individuals have no symptoms of HIV infection, except perhaps swollen glands, although they are infectious.

**Stage 3:** The phase of symptomatic HIV infection, characterised by the onset of opportunistic infections and cancers that the immune system would normally prevent.

**Stage 4:** Progression to AIDS, which may be diagnosed by blood tests, or clinically.

(Source: Holden 2003)
Delft Fact Sheet

Appendix C

Chart 1: Individual monthly income for person weighted in Delft

Chart 2: Annual household income for household weighted Delft
Chart 3: Highest education level for person weighted Delft

Chart 4: Mode of travel