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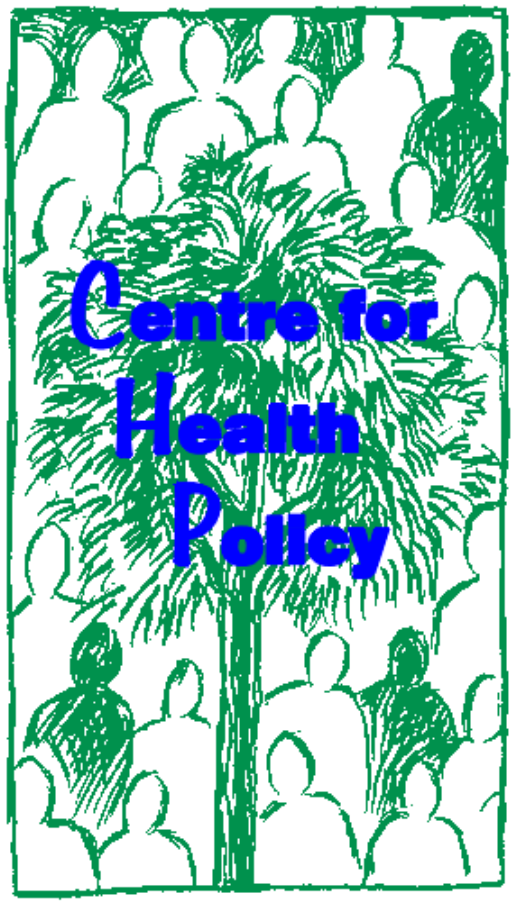

The Integration of HIV/AIDS Care and Support into Primary Health Care in Gauteng Province

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Executive Summary

Background and methods

This study aimed to assess the integration of HIV/AIDS care and support in Gauteng's primary health care (PHC) services. With this aim in mind, the research sought to provide answers to three main sets of questions. Firstly, are care and support services for people with HIV/AIDS being provided at PHC clinics, what is the quality of these services, and to what extent are these services being utilised? Secondly, are the inputs (e.g. staff knowledge and attitudes) and support systems (e.g. drug supplies), necessary for good quality, accessible HIV/AIDS care, present in the PHC infrastructure? Thirdly, what if any, systems changes are required to improve the access and quality of PHC services for people living with HIV/AIDS? This research was conducted in collaboration with, and partly funded by, the Gauteng Provincial Department of Health which is in the process of disseminating primary health care clinical guidelines in the Province.

A set of input, process, and/or output indicators were defined for the following aspects of care and support: HIV testing and counselling; management of opportunistic infections (including tuberculosis); palliative care; networking relationships ("vertically" with hospitals and "horizontally" with community-based structures); staff support systems (training, workload, morale-motivation etc.); and user perceptions.

Between May and August 2001, we visited 50 (out of a total of 405) clinics in Gauteng Province, selected through a stratified (by region) random sampling method. The facilities included community health centres and medium sized and smaller satellite clinics from both provincial and local government authorities. At these clinics we conducted a detailed audit which consisted of:

- ⇒ Semi-structured interviews with clinic managers
- ⇒ Confidential reviews of patient records and tuberculosis registers
- ⇒ Extraction of relevant data from the facility based routine health and management information systems
- ⇒ Completion of self-administered questionnaires by primary health care providers (mostly nurses).

In addition, in-depth interviews were held with 14 HIV positive service users on their experiences of public primary health care services. These informants were accessed by word-of-mouth from a network of non-governmental HIV/AIDS organisation s in Gauteng Province.

Results

The results are grouped by theme, namely, access and quality, and service delivery and staff support systems. Where relevant, findings are reported by Region (A, B, C) within the Province. Region A incorporates the Central Witwatersrand and West Rand areas; Region B the Ekhuruleni Metropolitan and Vaal areas; and Region C the Tshwane Metropolitan and Bronkhorstspruit/Cullinan areas.

Access and quality of HIV/AIDS care and support services

HIV/AIDS counselling and testing: HIV/AIDS counselling and testing services were available in all but three (satellite) clinics. Roughly half (47%) of the HIV test results were available within one week. However, testing levels were not high. A mean of only 13 people per clinic (range 1-45 per clinic) were tested for HIV in the month prior to the study visit, and of these 13, 9 people returned for their results. The reasons for testing were a combination of clinical and client-initiated requests.

Counselling was provided by professional nurses in 88% of clinics, by lay counsellors (volunteers) in 40% of clinics and by "health promoters" (auxilliary staff) in 20% of clinics. Region B made the most use of lay counselors and health promoters to provide counselling (59% and 41% of clinics, respectively). An ongoing, post VCT, counselling service was reportedly available in 81% of facilities in Regions A and B clinics and in only 50% of the clinics in Region C. However, in Regions A and B few clients were recorded as receiving such ongoing counselling (a mean of 4 and 6 per month, respectively), whereas those clinics providing ongoing counselling in Region C had an average of 38 clients receiving follow-up counselling. It thus appears that certain clinics in the Tshwane area have an established follow-up HIV counselling service.

In interviews with users, problems with confidentiality and lack of trust in health facilities were frequently cited. Providers were ambiguous on the issue of confidentiality: while 77% agreed

(in the self-administered questionnaire) that HIV patients were entitled to confidentiality, 80% also agreed with the statement: "Confidentiality is hampering our ability to get on top of the AIDS epidemic." A written policy on confidentiality was present in only 46% of clinics (24%, 71%, 50% of clinics in Regions A, B, C, respectively).

Diagnosis and treatment of opportunistic infections: Provider knowledge of the clinical illness associated with various stages of HIV was generally poor, with 25% or less able to correctly stage herpes zoster, pulmonary TB and persistent generalised lymphadenopathy (PGL). This knowledge is necessary for judging when to introduce prophylactic therapy such as co-trimoxazole. Only 15% of respondents in the self-administered questionnaire recognised a classical clinical scenario of oesophageal candidiasis and only 6.9% gave the correct management for the condition (fluconazole).

In order to confirm whether or not common opportunistic and other infections (especially in young adults) are being recognized and treated in primary health care facilities, approximately 500 recent records were scanned in each clinic. Records were assessed for the presence of the following diagnoses: candidiasis (oral, oro-pharyngeal or oesophageal), herpes zoster, diarrhoea and pneumonia. In nearly half the clinics no diagnoses of pneumonia and herpes zoster were evident in their clinical records (43% and 48% of clinics had not diagnosed pneumonia and herpes zoster, respectively). Only 33% of clinics had three or more diagnoses of candidiasis, and only 23% clinics had diagnosed it three or more times in adults. Diarrhoea was more frequently diagnosed.

There are two possible reasons for the low level of diagnoses of opportunistic infections: firstly, that health care workers do not recognise these infections because they do not have the knowledge and skills to do so, as was confirmed by the study. Secondly, that people with HIV are not using these services. Although the users interviewed were a highly selective group (open about their HIV status and part of support groups), there appears to be a high degree of mistrust of routine public sector services. People with HIV feel that they are simply not wanted at public health facilities and that their privacy and anonymity are at risk. However, when asked to estimate the numbers of known HIV positive clients they seen in the prior week, respondents to the self-administered questionnaire gave a mean of 5 clients. This suggests that primary health care services are indeed being utilised by people living with HIV/AIDS.

TB treatment outcomes: The quality of tuberculosis care was assessed as TB is one of the most important HIV-related opportunistic infections and also because TB management is an indicator of the ability of services to ensure follow-up and continuity of care. Of the 50 clinics, 41 (82%) provided TB care. Data on 501 new pulmonary tuberculosis (PTB) cases recorded in the TB registers of clinics between 1 May and 31 August 2001, were collected. The cure rate (i.e. treatment completed and negative 6 month sputum) amongst these cases was 56% and a further 7% had completed treatment without a sputum result recorded. While still below the WHO target of 85% cure rate, it was clear that the TB registers were well-established in clinics, and that services are capable of being oriented to ensure continuity of care.

The TB patient load is a good indicator of the changing clinical load related to HIV. Over a 7-month period (July 2000-January 2001), the number of visits for TB care increased by 27% in the clinics visited.

Palliative care: Eleven clinics (22%) clinics were linked to a home-based care programme, and 8 clinics (16%) had a link with a hospice. Only five (10%) clinics were dispensing morphine, which was provided through home-based care programmes linked to the clinics. Clinic managers raised several concerns about dispensing morphine, including that it would increase staff workload and be difficult to dispense without a doctor being available.

Referral and networking: Eighty six percent (86%) of clinics reported a referral/networking relationship with other health care providers or community-based groupings. Twenty-seven (54%) clinics were networking with a HIV/AIDS support group or community based counselling group. Only seventeen (34%) clinics had a formal referral relationship with a higher level of the health system – a community health centre or hospital; many of these were general rather than specific HIV/AIDS referral relationships. When asked to rank the sources of their clients with HIV/AIDS, managers cited voluntary counselling and testing (64%), followed by clinical diagnoses at the clinic (60%) as the most important sources. Referral to the clinics from hospitals and non-governmental organisations (NGOs) were uncommon.

Service delivery and staff support systems

Staff training on HIVAIDS: Of the 215 providers who completed self-administered questionnaires, 58% had received some training in HIV/AIDS; 40% had been trained in

HIV/AIDS counselling, mostly through the AIDS Training, Information and Counselling Centres (ATICCS). Only 10% of providers had had training in the clinical aspects of HIV/AIDS and management. Two-thirds (66%) of providers indicated that they wanted further training in HIV/AIDS counselling, while 49% felt they wanted to be skilled in clinical management.

Prevention of occupational injury and availability of post exposure prophylaxis: One quarter (26%) of providers completing the self-administered questionnaire reported a needle stick injury in the previous year. More than 40% of providers in each region said that they did not always wear gloves when performing invasive procedures. Post exposure prophylaxis for needle stick injury was accessible to staff in 76% of clinics (varying from 67% in Region C to 83% in Region B).

Clinical and counselling support systems: Only 36% of providers reported participating in formal group meetings for clinical or counselling debriefing at their facilities. The presence of such meetings varied from 14% in Region A to 56% in Region B. Doctor support (part-time or full-time) was present in 74% of clinics, and doctors were the most favoured source of advice on clinical management (69%), followed by a friend at work (37%) and clinic manager (28%).

Drugs and other supplies: Drug supplies were on the whole good. More than 90% of clinics had essential antibiotics in stock. However, certain drugs listed in the Gauteng HIV/AIDS clinical guidelines, namely, Cloxacillin, Imodium, Daktarin gel, Amytryptaline, DF118 and Morphine were present in only some of the clinics. The fluconazole (Diflucan) program had not commenced at the time of the field visits and the presence of this drug was therefore not assessed.

Provider morale and motivation

Health care systems are first and foremost human systems. Improving the accessibility and quality of HIV/AIDS care requires that providers change their habits, routines and perspectives and take on a new challenge. While guidelines and training are clearly necessary, provider readiness to develop HIV/AIDS services is also dependent on other factors such as the quality of the work environment, personal experiences of HIV/AIDS, and attitudes towards people with HIV/AIDS. Considerable attention was paid to assessing these factors.

Personal experience of HIV/AIDS: Personal exposure to and experience of HIV was high. Nearly three-quarters (70%) of providers who filled in the self-administered questionnaire knew or had known someone in their personal lives (i.e. not a client or colleague) who was HIV positive. That person was commonly a friend (36%), followed by an extended family member (31%) and then close family member (13%). Significantly, 80% of providers had had an HIV test. Although prompted, only a third of these were willing to give reasons for taking the test; most commonly self-initiated testing, followed by testing following needle-stick injury and for insurance purposes.

Workload and absenteeism: The mean daily load per provider was 32 patients. Workload varied significantly between regions - 31, 39, and 25 patients per provider per day in Regions A, B and C, respectively. Research had suggested that, depending on the patient profile, the daily workload should be in the range of 28-40 patients per day. All regions thus fell within the range, although one region (B) was close to the upper end of this range. Clinic workloads varied considerably, from a low of 10 to a high of 65 patients per provider per day, suggesting staffing inequities within the province.

The absenteeism rate was 5% i.e. staff were not at work as expected for one day out of every 20 days. Absenteeism was highest in Region B (7%) which also had the highest workload. Taking into account absenteeism, workload in Region B increased from 39 to 43 patients per day. Absenteeism was lowest in Region C, which also had the lowest workloads.

Burnout: Provider burnout was assessed using a scale known as the Maslach Burnout Inventory (MBI), which was completed by the 215 providers who filled in self-administered questionnaires. The inventory assesses three dimensions: emotional exhaustion, depersonalization and personal accomplishment. Of these, emotional exhaustion emerged as the most prominent dimension of burnout. Sixty-nine percent (69%) of providers had moderate or high levels of emotional exhaustion. They were much less likely to report a sense of depersonalization (28%) or low personal accomplishment (36%). An increasing HIV-related workload is likely to exacerbate the experience of emotional exhaustion.

Providers' attitudes on HIV/AIDS: By and large provider attitudinal responses towards people with HIV, were positive. For example, few providers (4%) disagreed with the statement "AIDS patients are entitled to the same care as any other patient", and most (66%) stated that they "would volunteer to care for an AIDS patient". Only 1% "would quit their jobs

rather than to care for people living with AIDS". Nevertheless, data from the service user interviews revealed that providers often have negative attitudes towards people with HIV/AIDS.

User perceptions

Fourteen in-depth interviews were completed with people who are HIV positive and living in Gauteng Province. The interviews sought to establish pathways of health service utilisation and the factors influencing these, and to understand the experiences of HIV positive people in using public health care services.

The first entry point into the health system of people living with HIV is the hospital, mainly involving tertiary or quaternary hospitals. Primary health care services are therefore bypassed in favour of specialist academic clinics and hospitals. Utilisation patterns of HIV positive service users are influenced by a number of factors. The response of individuals to their HIV positive status is a key factor – for example, in the process of coming to terms with their status, HIV positive people may seek repeated tests in the hope that they were previously incorrect. A few were tested without consent, several experienced broken confidentiality, and most complained of poor pre-and-post test counselling. The service users who were satisfied with their initial experience of care, hinted that the quality of post-test counselling was a key factor. Good counselling enabled people to come to terms with their HIV diagnosis and to overcome denial. All were members of a support group and such participation was reported as very positive.

Care was seen as positive when it was experienced as being of good technical quality, and was accompanied by a positive provider attitude, courtesy and confidentiality. By and large positive perceptions were linked to dedicated HIV clinics rather than general clinics. Common negative experiences of care in general clinics were victimisation of HIV positive users, callous treatment from health providers, poor confidentiality, overcrowding, long waiting times, limited hours of service and shortage of drugs. HIV positive users explained the providers' behaviour as stemming from lack of appropriate training, poor personal attitudes, and provider hopelessness and helplessness in dealing with HIV/AIDS.

Recommendations

All clinics should be providing a package of good quality care to people with HIV. In Gauteng this package includes:

- Voluntary counselling and testing
- Prevention, diagnosis and treatment of opportunistic infections, including tuberculosis
- Mother-to-child transmission prevention
- Referral "upwards" to hospital care and "outwards" to support groups, community and welfare structures and home-based care
- Palliative care and support to home-based care.

The study found that certain aspects of this package are available and that an infrastructure on which to build care and support services exists. However, quality of care is often poor and services are not widely trusted by patients. Providers are mostly not trained and inducted into providing this care. People with HIV are made to feel guilty for utilizing services. The available evidence also suggests that support for providers is often lacking and desperately needed. This is compounded by the fact that HIV personally affects the majority of these providers. Although considerable networking is occurring at community level, referral systems between levels of care are poorly developed.

While some care for people with HIV/AIDS is being provided, it has not been conceptualized and established as a particular kind of service in the same way that other chronic diseases such as tuberculosis, diabetes and hypertension exist in the health system. Care is fragmented and ad hoc and continuity of care appears largely absent in the province's PHC infrastructure. It is therefore not surprising that patients gravitate towards the specialist HIV clinics linked to academic hospitals.

PHC services should aim to provide continuity of care for individuals from the point at which they are diagnosed across the continuum. This includes not only voluntary counselling and testing and treatment of opportunistic infections, but also follow-up counselling and support, "wellness" management, (e.g. nutrition, cotrimoxazole prophylaxis) referral to welfare and other support structures, hospitals and community-based organisation s, and palliative care. Care across the continuum needs to be supported by systems for follow-up and monitoring of individuals and their families e.g. through special record-keeping. To achieve continuity

also requires that people with HIV trust clinics and providers. These are essential pre-conditions if PHC services are to have a future role in the provision of long anti-retroviral therapy. Possible actions to achieve this are listed below.

Ensure adequate staffing:

- ✓ Monitor workload and equity of staff distribution and address needs of clinics with large workloads
- ✓ Define future staffing requirements in the light of growing needs and develop an incremental plan to increase staffing to PHC services.

Increase capacity for HIV counselling and testing*.*

- ✓ Explore ways of promoting the effective use of volunteers – look at dedicated nursing staff to work alongside volunteers and health promoters in providing counselling
- ✓ Increase the capacity of counsellors through continuous training
- ✓ Provide debriefing support for counselors and a counselling support infrastructure
- ✓ Institute processes for quality assurance in HIV/AIDS counselling and for monitoring of utilisation of counselling services.

Improve clinical skills

- ✓ Adequate management of HIV/AIDS in primary health care clinics requires that providers are trained in comprehensive clinical skills. This will promote the appropriate detection and management of HIV/AIDS related opportunistic infections at the primary health care level. Ideally this training should be integrated into the undergraduate curriculum of health professionals and in post-basic primary health care training programs.

Additional training

- ✓ Promote training in palliative care, including how to network with community-based organisation s.

Guidelines and protocols

- ✓ Develop and distribute guidelines on clinical management (already developed in Gauteng), counselling, palliative care, support for home-based care and referral, and on systems for the continuum of care for HIV/AIDS.

Improve referral and networking

- ✓ Identify and address key barriers in referral between clinics and hospitals
- ✓ Strengthen networks between clinics and home based care organisation s
- ✓ Promote networking with community based care and support groups in order to build trust and communication. Make information on entitlements and expectations available to communities.

Enhance support systems to address issues of provider morale and motivation

- ✓ Define the role of clinic managers in providing support for providers
- ✓ Consider ways to monitor stress and burnout amongst providers and deal with the sources thereof
- ✓ Increase the availability of formal clinical and counselling support for staff through institution of a counselling support infrastructure, debriefing opportunities within the clinics, and clinical support by trained practitioners.

Monitoring and evaluation of HIV/AIDS care in the primary health care clinics

- ✓ Define specific indicators to measure quality and utilization of HIV services in the primary health care setting
- ✓ Develop tools for HIV quality monitoring at district level, to be integrated into quality improvement systems
- ✓ Institute systems for periodic monitoring to measure uptake and quality of HIV/AIDS services.

To achieve the above requires a process of negotiation and coordination between a wide variety of actors and authorities at provincial, regional and local level. The report identifies these various actors as well as the challenges to implementation and suggests mechanisms to address these.

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1 Introduction

1.1 Study background

South Africa has had one of the fastest increasing HIV rates in the world (Williams and Campbell, 1998). In 2000, 22.4% of women attending government antenatal clinics nationally were HIV positive compared to 2.4% in 1991 (Department of Health, 2000). Estimates are that 20% of the adult population is infected with HIV, with 1 500 new infections occurring daily (UNAIDS, 2000). Approximately 280 000 people are thought to be presently in the AIDS phase of illness and sharp increases are expected in the next few years (Love Life and ABT Associates, 2000). By 2005, 504 000 South African children will have lost their parents to AIDS (Baleta, 1998), and by 2015, more than 30% of all children between the ages of 15 and 17 will have lost their mothers (Bradshaw et al, 2002).

The AIDS epidemic will dramatically affect South Africa's social welfare and health care systems. In the early 1990's it was estimated that by the year 2000, between 19 and 49% of the national health care budget would be spent on providing care to people living with HIV and AIDS (PWA's) (Broomberg, 1991). More recent modeling work suggests that if current levels of care are maintained, public sector health care costs will have doubled by the year 2010 (Steinberg et al, 2000).

The largest health system impacts of HIV-related illnesses occur at hospital level. In 1999, the Gauteng provincial government estimated that 30% of patients in the adult medical wards of public hospitals had HIV related illnesses (personal communication, Dr Liz Floyd). In Kwazulu-Natal, 54% of admissions to the medical wards of King Edward Hospital in Durban were HIV positive, and of these 84% had AIDS (Colvin et al 2001). In order to address these impacts, alternative models of care have been proposed: these include community and home-based care, "step-down", hospice type of care and building the capacity of primary health care services to provide ambulatory care and support to people with HIV. Apart from their role in protecting hospitals, primary health care services clearly also have other roles in relation to HIV/AIDS care and support: maintaining continuity of care, providing ongoing support and counselling, "wellness" management, treatment and follow-up of tuberculosis and ensuring a continuum of care with other providers. In addition, if the many calls for greater access to anti-retroviral drugs in the public sector are to materialize, the PHC infrastructure will be the major vehicle through which this will happen.

In its five-year HIV/AIDS and STD Strategic Plan for South Africa (Department of Health, 2000) the national government has identified the following care and support goals:

- Provide treatment, care and support services in health facilities (includes treatment of opportunistic infections, drug supplies and guidelines)
- Provide adequate treatment, care and support in communities (develop, implement and increase acceptability of models of community/home-based care)
- Improve access to voluntary testing and counselling
- Develop and expand the provision of care to children and orphans.

The Gauteng government has developed its own five-year AIDS Strategy for the Province (Floyd and Simon, 1999, Floyd and Molekwa, 2000). Key components of the strategy include mobilisation, prevention, care and inter-sectoral action. As part of its AIDS Strategy, the Gauteng government has developed a care policy around the notion of the continuum of care (Gauteng Provincial Government, 1999). It includes:

- Support for people with AIDS (in communities, support groups, counselling)
- Care services: medical (clinics, hospitals, TB) and palliative (home care and terminal/respite care facilities)
- Families and orphans: social support and grants
- Referral systems.

Co-ordinated intersectoral action through local government is key to the implementation of care and support policies (Floyd and Simon, 1999). Promoting and supporting community-based activities and universal access to primary AIDS care are the crucial building blocks of an AIDS care strategy. The Gauteng AIDS Directorate is currently developing and supporting the establishment of home-based care programmes in all districts of the Gauteng Province, and plans to ensure access to home-based care for 80% of the population by 2003 (Floyd and Molekwa, 2000).

In early 2000, it was estimated that only 50-60% of Gauteng's clinics provided AIDS care. The aim is to increase this to 90% of clinics by 2004/5. It is anticipated that AIDS care will become an integral part of primary health care services and will include the following package of services (personal communication, Dr Liz Floyd):

- Counselling (pre and post test, ongoing and bereavement)
- Diagnosis (including testing)

- Primary AIDS care, including prophylaxis
- TB treatment
- Palliative care
- Referral (first level hospitals, TB hospitals, hospices, home-based care, support groups, welfare services)
- Support to home-based care (referrals, supplies, management support)
- Prevention of occupational exposure and post exposure prophylaxis.

As part of achieving the above, the Gauteng AIDS Directorate has developed a series of guidelines for primary health care providers. These include adult and paediatric HIV/AIDS medical care, voluntary counselling and testing, and palliative care guidelines. The purpose of these guidelines are three-fold: to increase access to primary HIV/AIDS care, to promote quality of care by defining the minimum package of expected care and to reduce the burden of HIV/AIDS care on hospitals.

Evidence suggests that passive distribution of guidelines does not ensure their uptake, and that this process often requires interventions to address barriers to effective implementation (Makella and Thorsen, 1999). These barriers potentially include: lack of technical skills and knowledge to identify and manage HIV related illnesses, active avoidance by health care workers due to fear and stigma linked to AIDS, lack of organisational support systems, inadequate resources e.g. drugs, inadequate management systems, limited in-service training, poor staff morale and motivation, increased stress and burnout, as well as lack of proper consultative process in the development and implementation of guidelines. Gilson (1997) highlights the importance of involving a variety of interest stakeholders including front line providers in the processes of developing and implementing policy, and using these as means to better inform and mobilise their support in this regard.

1.2 Provider stress and burnout

Health care workers who work with HIV/AIDS patients are faced with enormous psychological and physical challenges in providing care, which may result in the phenomenon of burnout. Maslach (1982) defines burnout as emotional exhaustion, depersonalisation, and a sense of low personal accomplishment that occur amongst individuals working with people. Burnout results from a discrepancy between the demands of

a job and the ability of an employee to meet these demands (Miller and Bor, 1991). Stress and burnout amongst health care workers who work with people living with AIDS has been associated with fear of contracting the disease, and as a consequence of this fear, health care workers display a tendency to avoid HIV positive patients (Bellani et al, 1996, Nesbitt et al, 1996). Burnout impacts negatively on the provider-user interaction and leads to lowered productivity levels due to sickness leave (Hiscox, 1991).

Bellani et al (1996) identify the following stressors linked to burnout of health care providers in HIV/AIDS care: continued exposure to death and dying, sense of helplessness and ineffectiveness due to inadequate expertise to deal with or care for PWA's, increased workload, and coping with inadequate resources. Other burnout related stressors are linked to the health care provider work environment, including role confusion, and lack of work autonomy and control. Different stress levels in doctors have been associated with various sizes of health care settings (Firth – Cozens, 2001). For example, staff who work in bigger organisations have been found to be more stressed compared to those who worked in smaller organisations.

The presence of both formal and informal workplace support networks reduces the levels of burnout and stress amongst caring professionals. (Bellani et al, 1996, Nesbitt et al, 1996). Better mental heath outcomes amongst doctors have been associated with organisation al systems which ensure co-operation, open communication, performance monitoring, more training and staff self-determination (Firth–Cozens, 2001). A critical element in minimising burnout and its effects on health care provided is the development of appropriate staff support systems e.g. "caring for the carers" programmes.

1.3 Provider attitudes

Positive and accepting health care worker attitudes towards people with HIV/AIDS are essential to successful HIV/AIDS care (Fusilier et al, 1998). Health care workers with negative attitudes are less likely to spend time in caring for patients with AIDS and this tends to reduce the quality of health care they provide (Fawcett 1993). In the late 1980s 85% of US nurses were said to have fearful and negative attitudes toward AIDS (Prince et al (1989) cited in Fusilier et al, 1998). In a study that compared the attitudes of nurses in Zimbabwe and the US, it was found that although the Zimbabwean nurses perceived themselves to be at higher risk of occupationally acquired HIV infection, 93% said that they "should be

required to work with HIV/AIDS patients", compared to only 77% of American nurses. Adelekan et al (1995) found that a third of the nurses and a quarter of the doctors in a Nigerian teaching hospital said they would be hesitant to treat a person with AIDS. In South Africa, 79% of medical officers and 69% of medical registrars working with paediatric patients in three academic hospitals in Cape Town felt that they should have the right to refuse to treat HIV-infected patients. However, the majority of respondents said that they did not spend any less time with the HIV-positive patients than with other patients (Fransman et al, 2000).

While some have found that improved knowledge amongst health care workers is a strong predictor of positive attitudes and appropriate professional behaviour in dealing with AIDS (Gordin et al 1987, cited in Adelekan 1995), others have suggested that knowledge-based programmes are not adequate to bring about change in AIDS-care intentions or behaviour (Fusilier 1998).

1.4 Study aim and objectives

The Gauteng AIDS Programme has identified a need for operational research to inform the process of implementing the HIV/AIDS care guidelines in primary health care clinics. This research has been designed to address this need – it aimed to evaluate the response of Gauteng's public primary health care clinics to HIV/AIDS, specifically to assess the extent to which HIV/AIDS care is integrated into primary health care services. With this aim in mind, three sets of questions were at centre of the research. Firstly, are care and support services for people with HIV/AIDS being provided at PHC clinics, what is the quality of these services, and to what extent are these services being utilised? Secondly, are the inputs (e.g. staff knowledge and attitudes) and support systems (e.g. drug supplies), necessary for good quality, accessible HIV/AIDS care, present in the PHC infrastructure? Thirdly, what if any, systems changes are required to improve the access and quality of PHC services for people living with HIV/AIDS?

The specific objectives of the study were to assess:

- The range of services for HIV/AIDS care and their utilisation and quality, currently provided at public sector primary health care clinics and health centres in Gauteng Province

- Clinic and health centre staff skills, perceptions, and attitudes towards providing HIV/AIDS services in general and, more specifically, in the use of treatment guidelines for HIV/AIDS care
- Support systems in place for primary AIDS care (including staff training and support/ supervision, drug supplies, referral networks etc.)
- Service user perceptions of HIV/AIDS care at clinics and health centres.

2 Methods

2.1 Study design

A descriptive cross-sectional study was conducted, drawing on both qualitative and quantitative research approaches.

2.2 Sampling

The study population included all primary health care clinics, their staff and users in Gauteng Province. Using a list of local authority and provincial government clinics in the Province as a sampling frame, a self-weighting, stratified random sample of 50 clinics was selected. Stratification was done according to the current "health regions" in the Province, namely Region A (Central Witwatersrand and West Rand); Region B (Ekhuruleni and Vaal) and Region C (Tshwane/Bronkhorstspruit-Cullinan). The clinic sample was represented by community health centers, PHC clinics and satellite clinics. Mobile facilities were excluded.

2.3 Measurement

2.3.1 Indicators

A series of input, process and output/outcome indicators were defined for the research. They are listed in Table 1 below.

2.3.2 Tools

Data collection involved the following:

- Semi-structured interviews with the facility/clinic manager at each of the clinics sampled. The following information was gathered through the interviews: service provision and ulitisation, staff workload, staffing levels, staff turnover, HIV/AIDS services including counselling and testing, staff support systems, and networking role of the clinic. The interviews also gathered information on managers' perceptions of barriers and opportunities in implementing HIV/AIDS primary health care clinical guidelines. Each interview took, on average, an hour and half to complete.

- Examination of routine data from the health and management information systems, including the Minimum Data Set (MDS) returns, absenteeism records, and blood tests files.

- Self-administered questionnaires were distributed to all the primary health care clinicians (i.e. mostly nurses) at the clinics sampled. 215 completed questionnaires were returned.

- Reviews of clinical records of patients to determine whether or not common opportunistic and other infections (especially in young adults) are being recognised and treated in primary health care facilities. Approximately 500 recent records were scanned in each facility. As each facility tends to have its own filing system, the sampling procedure was defined on the day of the fieldwork. For example, if records were filed chronologically according to date of attendance, they were sampled consecutively going backwards; if filed alphabetically, then there was an initial random selection of starting points and the most recent files obtained from the drawers. Of the 50 clinics visited, 40 had clinical records available at the facility. These records were scanned for the presence of a diagnosis, and the age of the patient and the treatment recorded for the following conditions: Diarrhoea, Pneumonia, Candidiasis (oral, oro-pharyngeal, oesophageal), Herpes zoster, Tuberculosis and Genital ulcers.

- Reviews of the tuberculosis registers in 36 clinics.

- In-depth interviews with 14 HIV positive service users on their experiences of using primary health care clinics. These service users were purposefully selected from a network of HIV/AIDS non-governmental organisations.

Table 1: Indicators measured

Aspect of care and support	Input	Process	Output	Measurement tool
Counseling and testing	❑ % clinical staff trained in HIV counselling ❑ Testing facilities (on-site, distant) ❑ Turn around time of HIV test results	❑ Procedures for HIV counselling and testing ❑ Informed consent policy ❑ Written confidentiality policy	❑ Number of HIV tests done in the last month ❑ Number of patients counselled pre-test, post-test and ongoing over past three months	❑ Clinic manager interview schedule ❑ Routine data ❑ Self-administered questionnaire
Management of opportunistic infections	❑ % staff trained in clinical management of HIV/AIDS ❑ % staff with knowledge and skills to recognise and manage opportunistic infections ❑ Availability of drugs to treat opportunistic infections	❑ Recognition and treatment of opportunistic infections i.e. herpes zoster, pneumonia, diarrhoea, oesophageal candida and TB	❑ PTB treatment outcomes ❑ Number of patients receiving ongoing care	❑ Self-administered questionnaire ❑ TB register and patient record reviews ❑ Drug check list ❑ User interviews
Palliative care	❑ Presence of morphine in clinics ❑ Networking with community-based care structures	❑ Capacity to deliver morphine ❑ Staff attitudes towards morphine delivery ❑ Support to home-based care		❑ Clinic manager interview schedule ❑ Self-administered questionnaire ❑ Drug check list
Networking and referral	❑ Presence of referral and networking relationships	❑ Successes and difficulties in referring patients		❑ Clinic manager interview schedule
User satisfaction		❑ Perception of and degree of trust in services	❑ Continuity of service utilisation	❑ User interviews
Support systems	❑ Staff work load ❑ Availability of support system for debriefing purposes ❑ Availability of post exposure prophylaxis	❑ The functioning of the support systems available ❑ Sources of advice in dealing with work problems	❑ % staff with needle stick injuries in the last year ❑ Staff stress, burnout, absenteeism and turnover	❑ Clinic manager interview schedule ❑ Self administered questionnaire ❑ Routine data

2.3.3 Planning and fieldwork

Several planning meetings were held with the Gauteng AIDS Directorate during the initial phase of the research, when indicators and research implementation processes were agreed upon. The research tools were pre-tested for face validity at a primary health care clinic in Soweto. This pilot was also used by the researchers as an orientation to the organisation and functioning of clinic services in Gauteng Province.

Two fieldworkers were employed to assist with data collection. The principal researcher (PM) trained the fieldworkers. The training provided an orientation to the study purpose, data collection tools, conducting interviews and research ethics. Regular meetings were held between the principal researcher and the fieldworkers to review data collection process and to discuss problems pertaining to fieldwork as they emerged.

2.4 Data analysis

Quantitative data were analysed using SPSS, using both descriptive and analytical statistics. One way analysis of variance (ANOVA) was used to compare means between and within the regions. Results are presented mainly according to Region (A, B, C). In certain instances, Region A and B are further disaggregated to local government health area (i.e. Central Witwatersrand, West Rand, Ekhuruleni and the Vaal). Where appropriate, results are also compared by authority responsible for the clinic (i.e. local authority or provincial government). Content analysis of qualitative data was conducted to identify common and divergent themes.

The study assessed issues linked to provider morale and motivation such as workload, absenteeism rate, stress and burnout, as well as personal experiences of HIV/AIDS outside the work context. In order to assess burnout amongst the clinical providers, the Maslach Burnout Inventory was used. Masclach identifies three components of burnout: emotional exhaustion, depersonalisation and personal accomplishment. Scores are calculated for each component based on responses to a series of closed-ended questions.

2.5 Ethical considerations

All the research participants were provided with a clear purpose of the research and were given an opportunity to decide on whether or not they wanted to participate in the research. Anonymity and confidentiality was also assured to all participants i.e. no names were recorded. Permission to conduct the research was obtained from each of the regional offices of the three health regions in the Gauteng Province. The Committee on Research on Human Subjects at the University of the Witwatersrand gave ethical approval for the research (Clearance number: M01-01-21).

2.6 Study limitations

The extent of the integration of HIV/AIDS care into primary health care was limited by the lack of standardized and routinely collected data specific to this condition. The study was thus unable to measure continuity and follow-up of HIV positive clients. Similarly, it was difficult to measure the uptake of VCT in some clinics. Utilisation had to be assessed indirectly e.g. through user and provider interviews.

3 Results

3.1 Clinics studied

Table 2 represents the categories of clinics studied. Two-thirds (66%) of the clinics were (medium sized) “PHC clinics”, and 22% were (large) Community Health Centres. One clinic only provided TB care and was categorised as such.

Table 2: Clinics studied and respondents to self-administered questionnaires

Clinic Type	Region A	Region B	Region C	Total
Community Health Centres	4	6	1	11
Satellite clinic	3	1	1	5
PHC clinic	14	10	9	33
TB clinic			1	1
Total	21	17	12	50
Number of respondents to self-administered questionnaire	68	72	75	215

Out of the 50 clinics visited, 48 returned completed provider questionnaires giving a total of 215 questionnaires. Apart from 5 medical practitioners and one dentist, all the respondents were nurses. Region C had a significantly higher number of senior professional nurses responding compared to Region A and B ($p = .002$), which probably corresponds to the profile of nursing staff in clinics.

3.2 Profile of providers

All but 17 respondents to the self-administered questionnaire were female (91.7%), and two-thirds (64%) were married (Table 3). There were no differences in the mean age, number of children and the number of school going age children of the providers between and within the regions.

Table 3: Demographic characteristics of the providers completing self-administered questionnaires (n=215)

	Region A	Region B	Region C	Total
Gender N (%) *(*N=204*)*				
Male	3 (4.6)	5 (7.1)	9 (12.9)	16 (8.3)
Female	62 (95.4)	65 (92.9)	61 (87.1)	188 (91.7)
Age in years				
Mean (95% CI)	42.9	43.2	42.8	43.0
SD	7.6	7.4	7.5	7.5
Marital status N (%)				
Married	42 (63.6)	41 (58.6)	50 (66.6)	133 (63.0)
Number of children				
Mean	2.0	2.1	1.3	2.1
SD	0.85	1.0	1.1	1.0

Training in primary health care (PHC) is critical in enabling the comprehensive treatment of illnesses (both acute and chronic) and promotes the effective management of HIV/AIDS related illnesses. Sixty three percent (63%) had received training in PHC. There were no differences in the proportion of providers trained in primary health care between regions (Table 4). The majority (80%) had worked in other health care settings. The mean length of years of experience was 10 years and 4 years in the current clinic.

Table 4: Professional training and experience (self-administered questionnaires)

	Region A	**Region B**	**Region C**	**Total**
Number and % of providers who have received training in PHC (n=201)	38 (59%)	42 (63%)	46 (66%)	126 (63%)
Number and % of providers had had worked in other health care settings (n=205)	51 (77%)	56 (84%)	56 (79%)	163 (80%)
Length of time working as a health provider Mean in years SD	9.5 6.3	10.4 8.5	10.5 7.3	10.2 7.4
Length of time working in current clinic Mean in years SD	5.0 5.5	4.8 6.3	5.5 4.8	5.1 5.5

Participation in professional and other organisations was not high amongst providers in this study: only a third (31%) indicated membership of a professional organisation /association or service network/forum. Of the 47 providers who provided information on the type of organisation that they belonged to, half (53%) were members of a union or professional association, 21% participated in a local service network or service forum and 28% were active in a local community based structure or NGO.

Providers were engaged in a multitude of clinical duties, with more than half (60%) being involved in routine curative care, and 22% reporting involvement in HIV/AIDS counselling (Table: 5).

Table 5: Profile of provider activities (self-administered questionnaires, n=202)*

Activities	**%**
Minor ailments -curative	60%
Family planning	30%
Immunisation/child health	24%
TB care	23%
HIV/AIDS counselling	22%
STD care	22%
Administration (e.g. compilation of statistics)	14%
Clinic management	17%

* nurses had more than one possible role so responses add to more than 100%

3.3 Utilisation of services

In order to measure utilisation of services we collected data from the MDS register at the clinics for the months of July 2000, October 2000 and January 2001. Table 6 presents monthly means and percentages of total head counts constituted by selected services. In so far as utilisation data are accurate, general patients appear to make up the largest proportion of the patients (from 32% in region A to 53% in Region C). Chronic diseases, including tuberculosis count for 12%-16% of total head counts.

Table 6: Utilisation patterns by type of service and region (mean of three months 2000/1)

Mean number and % of total headcount of patient visits per clinic by type of service in a month	**Region A**	**Region B**	**Region C**
"General" patients	1793 (32%)	2021 (37%)	2104 (53%)
Maternal and child health	819 (15%)	1462 (27%)	1373 (35%)
Tuberculosis	211 (4%)	325 (6%)	226 (6%)
Chronic diseases (hypertension and diabetes)	449 (8%)	539 (10%)	288 (7%)
Total headcount	5638	5465	3937

TB 'headcounts' (i.e. attendance, not cases) over the seven month period between July 2000 to January 2001, increased by 27%, possibly indicating the increasing TB load resulting from the HIV epidemic (Figure 1).

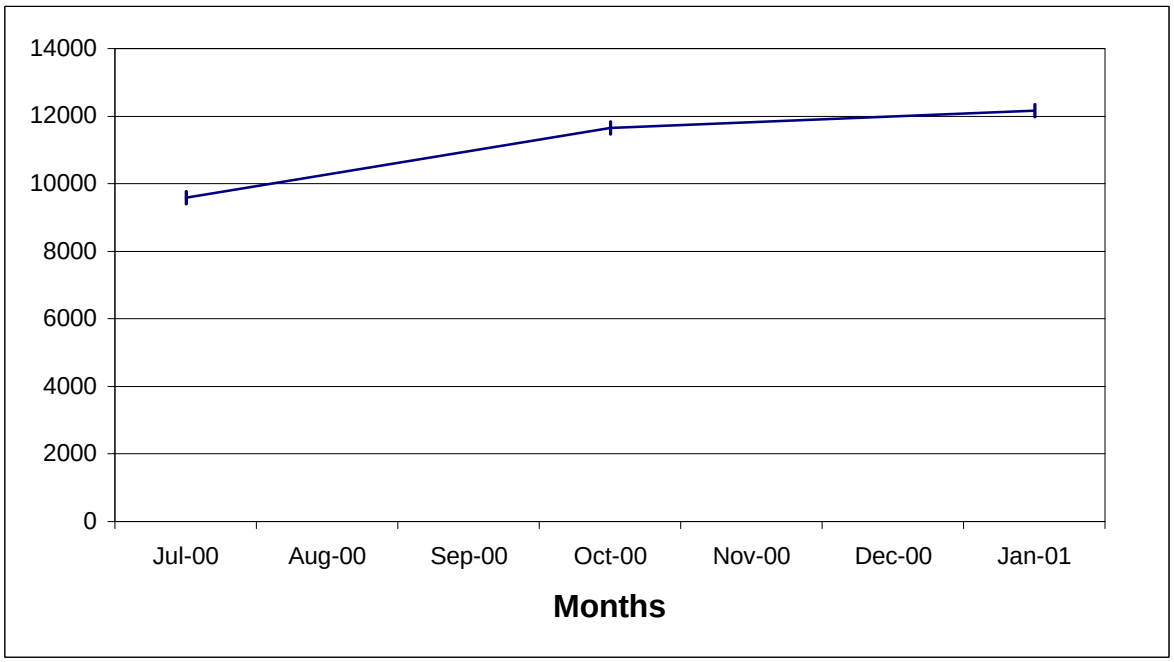


Figure 1: TB 'headcounts' for 40 clinics in Gauteng Province

3.4 Availability and quality of HIV/AIDS care and support services

3.4.1 HIV/AIDS counselling and testing

Only three clinics, in Region A, did not provide any HIV/AIDS counselling and testing services (Table: 7). Two of these clinics were satellite clinics and their staff reported a lack of capacity to run the services, because they had never being given relevant training. Another clinic had a problem of supply of blood tubes. HIV testing levels did not vary dramatically between and with the regions, with clinics reporting a mean of between 11 to 15 (range 1-45) people testing for HIV in the month prior to data collection.

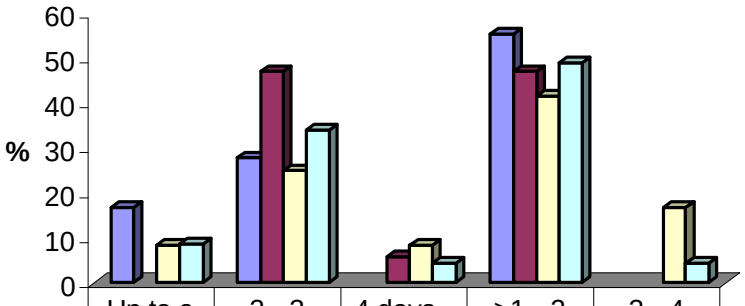
An ongoing counselling service for HIV positive people was more commonly reported in the clinics of Region A (81%) and B (81%) than C (50%), although those clinics in Region C that did provide the service currently had a higher number of clients (mean 38) in ongoing counselling than clinics in Regions A (mean 4) and B (mean 6). From the MDS register, it appeared that clinics in Region C were providing more “special” counselling (including for child abuse and rape cases) than clinics in other regions.

Table 7: HIV counselling and testing services

		Region A N=21	**Region B** N=17	**Region C** N=12	**Total** N=50
HIV Testing	Number and % of clinics providing HIV testing	18 (86)	17 (100)	12 (100)	47 (94)
	Mean number (range) of HIV tests per clinic done in the last month	14 (2-41)	11 (3-45)	15 (1-37)	13 (1-45)
	Mean number per clinic of people returning for their results	6	9	11	9
HIV Counselling	Number and % of clinics providing pre and post test HIV/AIDS counselling	18 (86)	17 (100)	12 (100)	47 (94)
	Number and % of clinics providing ongoing counselling for HIV/AIDS*	17 (81)	15 (81)	6 (50)	38 (76)
	Mean number of HIV clients receiving ongoing counselling per clinic providing ongoing counselling (at the time of visit)	4	6	38	11
	Mean number of "special counselling" clients per month per clinic**	23	23	68	36

* Obtained from HIV counselling records ** Based on MDS register

The quality of HIV testing can be assessed based on a number of criteria such as privacy and confidentiality in the process of testing, as well as the turn around time of receiving test results. Overall 47% of clinics received their test results within one week (Figure 2). Region B was more likely than other Regions to receive test results within one week (P =0.011). Onsite testing was available in 3 (6%) clinics, 2 were pilot VCT sites and one was a pilot MTCT site. Two clinics in Region C waited for 3 or more weeks for test results.



	Up to a day	2 - 3 days	4 days - 1 week	>1 - 2 weeks	3 - 4 weeks
Region A	17	28		56	
Region B		47	6	47	
Region C	8	25	8	42	17
Total	9	34	4	49	4

Figure 2: Turnaround time of HIV test results

A variety of people were used to provide HIV/AIDS counselling (Table 8). Professional nurses provided HIV/AIDS counselling in 76% of clinics, volunteer lay counsellors assisted in 40% of clinics; health promoters (employed auxiliary workers) in 20% of clinics and nursing assistants in 14% of clinics. The use of auxiliary workers and volunteer/lay counsellors was more common in clinics of Regions A and B than clinics of Region C.

Table 8: Categories of counsellors present in clinics by region

Category of counsellor	Region A N=21	Region B N=17	Region C N=12	Total N=50
Professional nurse	16 (76%)	17 (100%)	11 (92%)	44 (88%)
Enrolled nurse	1 (5%)	3 (18%)		4 (8%)
Health promoter	2 (10%)	7 (41%)	1 (8%)	10 (20%)
Nursing assistant	6 (29%)		1 (8%)	7 (14%)
Lay/volunteer	8 (38%)	10 (59%)	2 (17%)	20 (40%)
Other*	3 (14%)		1 (6%)	4 (8%)

*Clerks, social workers and priests

A written confidentiality policy was available in 46% of clinics, mostly as part of a VCT policy. However, this varied considerably by region: 24%, 71% and 50% of clinics in Regions A, B, C respectively. When asked to describe counselling procedures in the clinic, on the whole, clinic managers showed some awareness of the need for privacy and confidentiality such as keeping files locked in a filling cabinet and disclosing HIV test results only to the person

concerned. Comments included “it is the nurse’s obligation to maintain patient confidentiality” and “confidentiality is part of patient’s rights”.

However, providers’ responses to statements on confidentiality in the self-administered questionnaire suggested contradictory attitudes. For instance, even though 77% of providers agreed that with the statement that “HIV positive patients are entitled to confidentiality”, 80% thought that “confidentiality was hampering our ability to get on top of the HIV/AIDS epidemic”.

Problems with confidentiality emerged strongly in the interviews with service users (see later). The common problems cited by users included: disclosure of their HIV positive status to other people without consent, lack of privacy in the clinic consultation, and providers “gossiping” to others about their HIV positive status.

3.4.2 Diagnosis and treatment of opportunistic infections

3.4.2.1 Recognition of opportunistic infections

Patients clinic records were reviewed to assess whether or not HIV/AIDS opportunistic infections were being recognised in clinics. In the 40 clinics where these were available on site, the records of about 500 recently seen patient were scanned for the presence of a diagnosis, and the age of the patient and the treatment recorded for the following conditions: diarrhoea, pneumonia, genital ulcers, suspected tuberculosis, oral candidiasis and herpes zoster. The first four represent infections commonly seen in primary health care settings in people both with and without HIV, whereas the last two (oral candidiasis and herpes zoster) are infections more specific to people with HIV, especially when they occur in young adults.

A maximum of three entries were made for each condition.

Table 9 shows the frequency of recognition of each diagnosis in the forty clinics assessed.

Table 9: Frequency with which various infections were recognised (n=40 clinics)

	Frequency of recognition				
Diagnosis	**0 (%)**	**1 (%)**	**2 (%)**	**3 (%)**	**Total**
Pneumonia	17 (43)	6 (15)	5 (13)	12 (30)	40 (100)
Diarrhoea	3 (8)	6 (15)	2 (5)	29 (73)	40 (100)
Herpes Zoster	19 (48)	11 28)	5 (13)	5 (13)	40 (100)
Oral candidiasis	11 (28)	5 (8)	11 (28)	13 (33)	40 (100)
Oral candidiasis (>15 years)	9	2	6	9	26
Suspected TB	9 (23)	12 30)	2 (5)	17 (43)	40 (100)
Genital ulcers	6 (15)	3 (8)	4 (10)	27 (68)	40 (100)

No diagnoses of pneumonia and herpes zoster were observed in 43% and 48% of clinics respectively. Genital ulcers and diarrhoea were more frequently diagnosed. Only thirteen clinics had evidence of three or more diagnoses of oral candidiasis, and only 9 clinics had diagnosed it three or more times in adults. Only 12 clinics had 3 or more diagnoses of pneumonia.

The mean, median and range of ages at diagnosis of each of conditions are given in Table 10. Where infections are being recognized, the age profile is typical of the age group at risk of HIV. This suggests that young adults with HIV-related infections are attending clinics for care.

Table 10: Mean, median and range of ages (in years) at diagnosis

Diagnosis	Mean	Median	Range
Pneumonia	22	26	1-50
Diarrhoea	21	24	< 1 -86
Herpes Zoster	31	30	3-58
Oral Candidiasis	23	23	<1-59
Suspected TB	36	34	8-65
Genital Ulcers	29	28	18-68

Of those with the diagnosis of diarrhoea, 34% were prescribed an antibiotic. Of the 52 pneumonia cases reviewed, 6 (12%) were referred to hospital, and of the remaining 46 cases treated at clinics, only two did not receive antibiotics. By far the most common antibiotic prescribed for pneumonia was amoxycillin (in 36 cases). Of those with the diagnosis of genital ulcer, 51% received the recommended combination of drugs (Benzyl penicillin and Erythromycin).

From the file review it appears that the "newer" opportunistic infections are not being diagnosed in many clinics. The possible reasons for this are firstly, that people with opportunistic infections are choosing to utilise higher levels of care, perhaps because they perceive their problem to be more serious than that which can be dealt with at PHC facilities or general lack of trust of these services; or secondly, that staff in facilities are not recognising infections (also a strong possibility – see knowledge and skills assessment below). When specifically asked in the self-administered questionnaire, providers estimated seeing a mean of 5 (range 1-71) known HIV cases in the prior week. Assuming these estimates to be correct, it suggests that some degree of utilisation of services by people with HIV/AIDS is occurring.

3.4.2.2 Clinical knowledge and skills of providers

The clinical knowledge and skills of providers were evaluated in the self-administered questionnaire. Providers were asked to assess five statements concerning clinical aspects of

HIV/AIDS as either true or false; answer questions on a clinical scenario; and link clinical conditions to the WHO HIV staging system.

The responses to the true/false questions are presented, by region, in Table 11. Knowledge about the treatment of diarrhoea in HIV positive children was poor with only half of all respondents giving the correct answer.

Table 11: Clinical knowledge about HIV/AIDS (n=215)

Statement	Correct response	Providers who gave the correct response: n (%)			
		Region A	Region B	Region C	Total
HIV infected children with diarrhoea should routinely receive antibiotics	False	32 (47.1)	42 (58.3)	34 (45.3)	108 (50.2)
BCG should be given to asymptomatic HIV-infected children	True	36 (52.9)	44 (61.1)	42 (56.0)	122(56.7)
Cotrimoxazole helps to prevent the occurrence of PCP pneumonia in HIV infected people	True	51 (75.0)	49 (68.0)	47 (62.6)	147(68.4)
Shingles (herpes zoster) usually occurs on both sides of the body	False	50 (73.5)	54 (75.0)	50 (66.6)	154 (71.6)
The treatment of TB is the same whether a person is HIV-infected or not	True	56 (82.3)	58 (80.5)	48 (64.0)	162(75.4)

A summary measure of knowledge levels was derived from the five statements where knowledge was considered poor if zero, one or two correct answers were given, fair if three or four answers were correct and good if all answers were correct (Table: 12). The majority (56.7%) of respondents fell in the “fair knowledge” category. Only 16% of respondents provided correct answers for all five statements, while 28% had poor knowledge levels. Differences in knowledge levels between regions did not reach statistical significance (p=0.23).

Table 12: Clinical HIV/AIDS knowledge levels as assessed by correct responses to five true/false statements

Knowledge levels	Region A n (%)	Region B n (%)	Region C n (%)	Total n (%)
Poor: 0/1 or 2 correct answers	16 (23.5)	18 (25.0)	25 (33.3)	59 (27.4)
Fair: 3 or 4 correct answers	45 (66.2)	39 (54.2)	38 (50.7)	122 (56.7)
Good: 5 correct answers	7 (10.3)	15 (20.8)	12 (16.0)	34 (15.8)

To assess their ability to diagnose and manage oesophageal candidiasis, providers were presented with the following clinical case scenario: `A thirty-year old HIV positive man presents to you complaining of weight loss and difficulty and pain on swallowing. What would be your first diagnosis and how would you manage him?'.

The results are summarised in Table 13. A very low proportion (15%) correctly diagnosed oesophageal candidiasis, while an additional 17% diagnosed oral candidiasis. Nearly 45% gave another or incorrect diagnosis. Other diagnoses included tonsillitis (12.3%), HIV/AIDS (10.4%), cancer of the oesophagus (9.8%) and TB (7.4%).

Table 13: Skills of primary health care providers in the diagnosis and management of oesophageal candidiasis by region (n=215)

		Region A n (%)	Region B n (%)	Region C n (%)	Total N (%)
Diagnosis	Oesophageal candidiasis	8 (11.76)	14 (19.4)	10 (13.3)	32 (14.9)
	Oral candidiasis	16 (23.5)	16 (22.2)	5 (6.7)	37 (17.2)
	Other/incorrect diagnosis	27 (39.7)	30 (41.7)	37 (49.3)	94 (43.7)
	Don't know/ missing	17 (25.0)	12 (16.7)	23 (30.7)	52 (24.2)
Management	Fluconazole/Diflucan	1 (1.5)	3 (4.2)	11 (14.7)	15 (6.9)
	Oral antifungal	8 (11.8)	9 (12.5)	4 (5.3)	21 (9.7)
	Other/incorrect management	24 (35.3)	43 (59.7)	30 (40.0)	97 (45.1)
	Don't know/missing	35 (51.5)	17 (23.6)	30 (40.0)	82 (38.1)

One quarter of respondents did not know and/or did not respond to the question. Less than 10% gave the correct management. Other intervention approaches given included: counselling (10%), sputum investigation (7%) and education on lifestyle changes (6%).

Providers were asked to state the WHO stage of five clinical conditions associated with HIV/AIDS. This knowledge is important, for example, for knowing when begin cotrimoxazole prophylaxis. Correct knowledge of the clinical stage of disease is presented in Table 14.

Overall, the knowledge of the clinical illnesses associated with the various stages of the disease was poor, with 25% or less of the providers able to correctly stage herpes zoster, pulmonary TB and persistent generalized lymphadenopathy (PGL). Only 20% of respondents were aware that PGL occurred early in the illness and approximately one third of providers knew that Kaposi's Sarcoma was a sign of advanced disease.

Table 14: Knowledge of WHO staging system for infection and disease (n=215)

Clinical condition	WHO clinical stage	Knowledge of stage	Region A (n=68)	Region B (n=72)	Region C (n=75)	Total
Herpes Zoster	Stage 2	Correct staging	18 (26.5)	22(30.6)	11(14.7)	51(23.7)
		Incorrect staging	33(48.3)	30 (41.7)	26(34.7)	89(41.4)
		Don't know/missing	17(25.0)	20(27.8)	38(50.7)	75(34.8)
Pulmonary TB	Stage 3	Correct staging	17(25.0)	24(33.3)	13(17.3)	54(25.1)
		Incorrect staging	33(48.5)	21(29.2)	24(32.0)	78(36.3)
		Don't know/missing	18(26.5)	27(37.5)	38(50.7)	83(38.6)
Persistent generalised Lymphadeno-pathy	Stage 1	Correct staging	18(26.5)	22(30.6)	7(9.3)	47(21.9)
		Incorrect staging	33(48.5)	32(44.4)	30(40.0)	95(44.2)
		Don't know/missing	17(25.0)	18(25.0)	38(58.7)	73 (33.9)
Kaposi's Sarcoma	Stage 4	Correct staging	25(36.8)	30(41.7)	17(22.7)	72(33.5)
		Incorrect staging	13(19.1)	21(29.2)	27(22.7)	51(23.7)
		Don't know/missing	30(44.1)	21(29.2)	41(54.7)	92(42.8)
Severe weight loss with diarrhoea	Stage 3	Correct staging	11(16.2)	11(15.3)	11(14.7)	33(15.4)
		Incorrect staging	40(58.8)	42 (58.3)	26(34.7)	108(50.2)
		Don't know/missing	17(25.0)	19(26.4)	38(50.7)	74 (34.4)

3.4.2.3 Tuberculosis treatment outcomes

Forty (41) of the 50 clinics provided TB care, and all had TB registers. Of these 41 clinics, 1 had only recently started providing TB care and a further four had incomplete data recorded in their TB registers. Data from 36 clinics are thus available. Field workers were instructed to record data (sputum results at 2 and 6 months; and outcomes) for all new pulmonary TB cases (PTB - code 011) registered between 1 May and 31 August 2000, up to a maximum of 20 cases. Also noted was the total number of new PTB (011) cases in May 2000. Data on 501 cases were thus recorded. Of these, 398 (79.4%) had 2-month sputum results and 256 (53.5%) had 6-month sputum results recorded. To calculate outcomes the 58 cases transferred out or recorded as not having TB were excluded, leaving a total of 443 cases. Because in some clinics data were recorded for only 20 cases and not all the new cases over the four-month period, a weighting procedure was done, using the total number of new cases in May 2001. The outcomes are recorded in Table 15 below.

Table 15: Recorded PTB outcomes (weighted) for 501 cases reviewed

Indicator	**N (weighted)**	**%**
Cases with no outcome recorded	51.6	11.6
Cured	249.8	56.4
Treatment completed	31.6	7.1
Died (TB and not TB)	24.2	5.5
Treatment interrupted	65.4	14.8
Failure	5.5	1.2
"Discharged"	15.4	3.5

A fair number of outcomes were recorded as "discharged", not one of the official outcomes. All such cases with a negative 6-month sputum result were recoded as "cured". For the remainder it was not possible to interpret the outcomes and they have been left as is.

From the above it can be seen that cure rates currently stand at 56.4%. If treatment completers are added to this, 63.5% of new PTB cases are receiving a full course of

treatment. Of concern are those 11.6% of cases with no outcome recorded and the 3.5% whose outcomes were inaccurately reflected as discharged.

Table 16 gives the weighted outcomes by local government area (including both provincial and local government clinics). Although based on a small sample of cases (36), the West Rand area appears to have the best treatment outcomes and the Pretoria area the worst.

Table 16: Recorded TB outcomes (weighted) for 501 cases reviewed by local government area

Indicator	West Rand (n=36)	Central Wits (n=149)	Ekhuruleni (n=76)	Tshwane * (n=100)	Vaal (n=82)
Cases with no outcome recorded (%)	12.6	5.0	10.3	20.4	13.8
Cured (%)	79.7	62.3	57.1	32.4	64.1
Treatment completed (%)	0	4.0	6.3	18.6	2.8
Died (TB and not TB) (%)	0.6	7.1	6.3	1.8	8.5
Treatment interrupted (%)	7.3	16.0	12.0	20.9	10.9
Failure (%)	0	1.0	1.8	2.6	0
"Discharged" (%)	0	4.7	6.3	3.5	0

**Includes Bronkhorstspruit/Cullinan*

3.4.3 Palliative care

Nine clinics (18%) were engaged in a networking relationship with home-based care programmes, in which clinics provided these programmes with medication and supplies support. Only five clinics were dispensing morphine, through home-based care programmes linked to the clinic. Although a number of clinics had schedule 5 or higher drugs in the interviews with clinic managers, they thought that dispensing morphine would add to the workload and be difficult to dispense without a doctor present. Some were concerned about the habit-forming possibilities of the drug. Concerns were also raised about facilities to ensure that the drugs were always locked in a safe place.

3.4.4 Referral and networking

Managers were asked to rank the most common sources of HIV patients in their clinics. Of the six possibilities provided (diagnosis at the clinic, VCT, referral from hospital, referral from NGOs, antenatal clinics, other), clinical diagnosis at the clinic and voluntary counselling and testing were the most common first and second rankings. Thirty (60%) managers interviewed ranked patients diagnosed at the clinic on clinical grounds as the first and second most common sources; and 32 (64%) identified voluntary counselling and testing as the first or second. Referral from hospitals and NGOs were uncommonly cited as sources of patients and this possibly highlights the lack of formal interaction between the clinics and hospitals.

When managers were asked to list all the networking and referral relationships of the clinic, 17 (34%) reported a referral relationship with a higher level of the health system (community health centre or hospital). Many of these referral relationships were not specific to HIV/AIDS. Clinic managers highlighted several difficulties that providers encounter when referring patients to other health facilities and service providers. These difficulties included the following:

- ✓ A lack of knowledge on other providers within the vicinity of the clinic
- ✓ Lack of referral guidelines
- ✓ Patients being turned back from the hospitals
- ✓ Lack of feedback on the outcome of the referral
- ✓ Lack of transport for patients.

Almost all the clinics (86%) were involved in some form of a networking relationship with HIV/AIDS organisations in their catchment areas. More than half (54%) the clinics were linked to a local HIV/AIDS support group or community-based counselling activity, eleven (22%) clinics were linked to home-based care programmes, and 8 (16%) to a hospice (Figure 2).

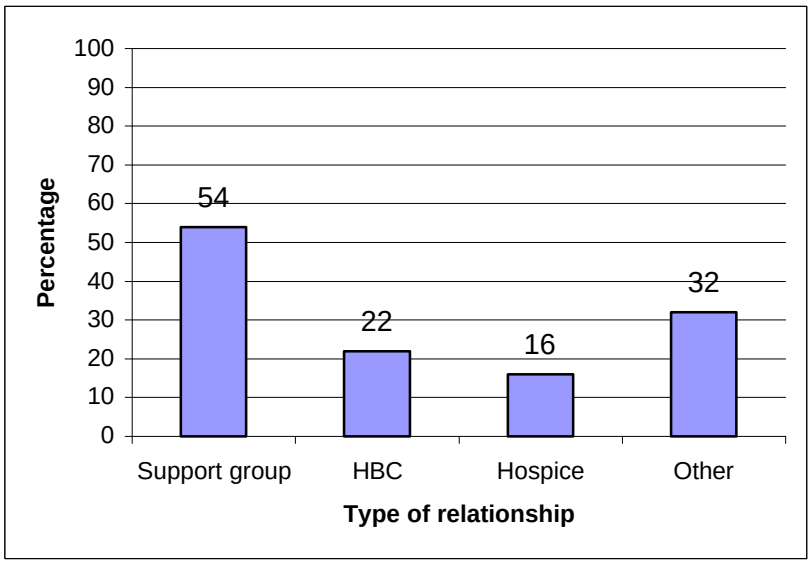


Figure 3: Networking relationships of clinics

3.5 Support systems for service delivery

3.5.1 Prevention of occupational injury and availability of post exposure prophylaxis

Twenty-nine percent (29%) of providers reported a needle-stick injury in the past year and 73% were concerned about contracting HIV in their places of employment (Table 17). Sixty-one percent (61%) always wore gloves when performing invasive procedures, and almost all (98%) providers reported always putting sharps in a specified container.

Table 17: Occupational exposure and universal precautionary measures

	Region A n (%)	**Region B** n (%)	**Region C** n (%)	**Total** n (%)
Providers reporting a needle stick injury policy in their clinic (n=203).	59 (91%)	63 (93%)	67 (96%)	189 (93%)
Providers who had had a needle stick injury in the past year (n= 207).	21 (32%)	19 (27%)	19 (29%)	59 (29%)
Providers concerned about contracting HIV in their workplace (n=201).	46 (72%)	54 (81%)	46 (66%)	146 (73%)
Providers always wearing gloves when performing invasive procedures (n=202).	34 (54%)	42 (61%)	47 (67%)	123 (61%)
Providers always putting sharps in a specified container (n= 203).	63 (94%)	66 (99%)	69 (99%)	198 (98%)
Clinic managers reporting access to PEP (n=50).	15 (71%)	15 (83%)	8 (67%)	38 (76%)
Clinic managers reporting availability of PEP on the clinic premises (n=50).	13 (62%)	9 (50%)	7 (58%)	29 (58%)

Nearly all (93%) providers reported a needle-stick injury policy in their clinic. However, only 76% of clinics had access to post exposure prophylaxis (PEP) and 58% had PEP available on the clinic premises. In situations where providers had to be referred somewhere else to access PEP, the clinic managers were often uncertain about what procedure to follow in cases of needle-stick injury after working hours.

3.5.2 Training in HIV/AIDS

Information obtained from the provider questionnaire indicated that 58% of providers had received training in HIV/AIDS (Table 18). Most commonly providers were trained in counselling (40%). Only 10% of providers had been trained in clinical aspects of HIV/AIDS and management.

Table 18: Training in HIV/AIDS (n=215)

Training course	Region A n=68	Region B n=72	Region C n=75	Total n=215
% providers received any training in HIV/AIDS	49	67	58	58
% providers trained in "basic HIV/AIDS"	12	35	16	21
% providers trained in counselling	37	47	37	40
% providers trained in clinical skills	4	18	7	10

Analysis of HIV/AIDS training by authority managing the facility (local government or province) did not show any marked differences, with 60% of local government and 53% of the provincial government staff being trained in HIV/AIDS. Sixty eight percent (68%) of providers in Region B thought that the training they received in HIV had been effective in equipping them with skills to manage HIV/AIDS, compared to 52% in Region C, and 39% in Region A. On the issue of additional HIV/AIDS training needed by providers, two thirds of providers (66%) wanted to be further skilled in HIV counselling, and 49% wanted skills in clinical management.

3.5.3 Support systems for clinical and counselling debriefing

Information on the available support systems in clinics for provider debriefing was gathered from both provider self–administered questionnaires and clinic manager interviews. Twenty-eight (56%) clinic managers reported that counselling support systems were available for staff in their clinics. However, only 36% of respondents to the self-administered questionnaires indicated that they participated in “meetings at this clinic to discuss issues and problems related to providing care to HIV/AIDS patients”. Region B and C clinics were more likely (56% and 42% respectively) than clinics in Region A (14%) to hold such meetings.

Seventy four percent (74%) of clinics had some form of doctor support, mostly on a part-time/sessional basis.

Providers were asked to rank sources of advice they would use if they needed clinical advice at work. The majority indicated the doctor at the clinic (69%) as their first most preferred source of advice in dealing with clinical issues, followed by a friend at work (37%) then clinic managers (28%). For personal problems, 52% of providers indicated that they would approach their manager or supervisor for assistance, possibly indicating some degree of trust.

3.5.4 Delivery of drugs and other supplies in clinics

The availability of key drugs listed in the PHC AIDS guidelines was assessed in the clinics visited (Table 19). Except for cloxacillin, over 90% of clinics had essential antibiotics in stock, including drugs to treat STDs. The combination Anti-TB drug myrin was present in only 83% of clinics although this may be a reflection of the number of clinics providing TB care. Three quarters of the clinics in Region B and C and only 40% of clinics in Region A had amitryptaline in stock, one of the drugs listed in the PHC HIV/AIDS clinical guidelines. Other drugs listed in the guidelines and not universally available in facilities included imodium; daktarin gel, betnovate ointment and amphotericin B. Five clinics had morphine in stock which they were dispensing for palliative home based care. The presence of Diflucan (fluconazole) or nevirapine was not assessed as neither of these were as yet introduced into services at the time of study.

Table 19: Availability of key drugs and supplies by region*

Item	Region A	Region B	Region C	Total
Cotrimoxazole tables (n=48)	18 (90%)	17 (100%)	10 (91%)	45 (94%)
Cotrimoxazole syrup (n=48)	20 (100%)	17 (100%)	10 (91%)	47 (98%)
Amoxacillin tablets (n=48)	19 (95%)	16 (94%)	10 (91%)	45 (94%)
Cloxacillin tablets (n=47)	13 (65%)	9 (56%)	11 (100%)	33 (70%)
Myrin tablets (n=46)	16 (84%)	16 (94%)	6 (60%)	38 (83%)
*Benzathine penicillin injection (n=48)***	*19 (95%)*	*17 (100%)*	*9 (82%)*	*45 (94%)*
Erythromycin tablets (n=47)	*18 (90%)*	*15 (94%)*	*11 (100%)*	*44 (94%)*
Amitryptaline tablets (n=48)	8 (40%)	13 (77%)	8 (73%)	29 (60%)
Metronidazole tablets (n=47)	*19 (95%)*	*16 (100%)*	*11 (100%)*	*46 (98%)*
Ciprofloxacin tablets or equivalent (n=48)	*18 (90%)*	*16 (94%)*	*10 (91%)*	*44 (92%)*
Immodium tablets (n=48)	4 (20%)	2 (12%)	7 (64%)	13 (27%)
Mycostatin ointment (n=47)	19 (95%)	16 (94%)	10 (100%)	45 (96%)
Daktarin gel (n=47)	8 (40%)	15 (88%)	8 (73%)	31 (65%)
Amphotericin B (n=35)	3 (18%)	2 (18%)	3 (43%)	8 (23%)
Betnovate ointment (n=47)	14 (74%)	11 (65%)	8 (73%)	33 (70%)
DF118 (n=48)	1 (5%)	0	0	1 (2%)
Morphine (n=48)	3 (15%)	1 (6%)	1 (9%)	5 (10%)

* sample sizes given with each item
** STD drugs in italics

3.5.5 Provider morale and motivation issues

3.5.5.1 Personal experiences of HIV/AIDS

Most (70%) providers across the regions knew or had known someone in their personal lives who is infected with HIV or has AIDS. Of the 144 providers who knew someone infected with HIV, 113 provided details of their relation to the infected person(s) (Figure 4). This person was most commonly a friend (36%) or an extended family member (31%), followed by an immediate family member (13%) or work colleague (13%).

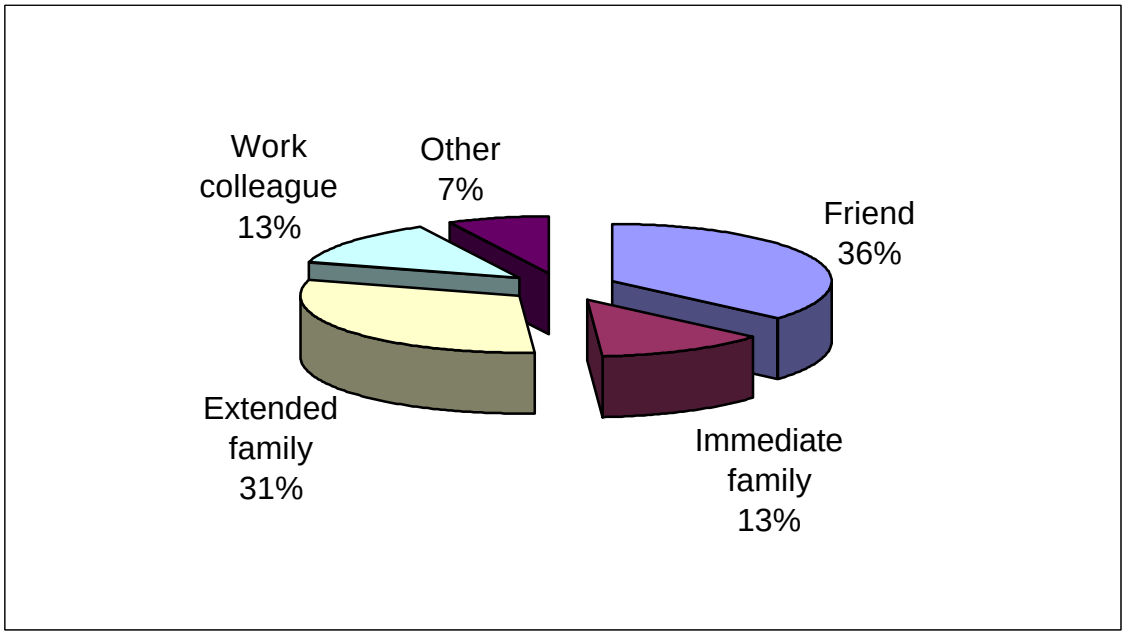


Figure 4: Relations of HIV positive people known by providers

One hundred and sixty-two (80%) providers had had an HIV test, and 5% had tested for HIV more than once for HIV. Fifty-one provided information on why they had been tested (Figure 5). Voluntary, self-initiated testing was the most common reason given for doing an HIV test followed by needle-stick injury and applications for insurance policies.

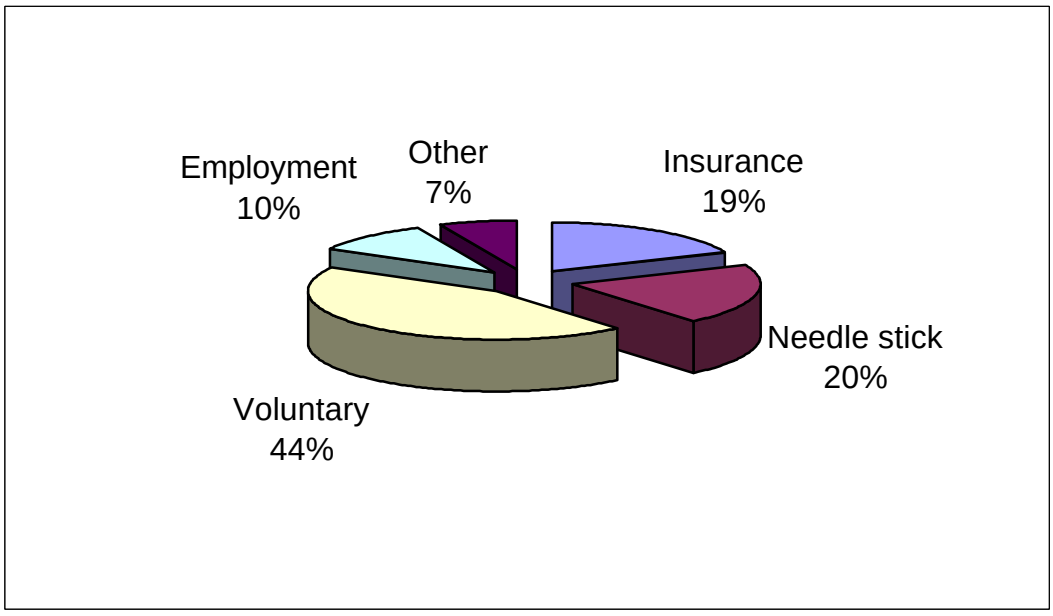


Figure 5: Reasons for taking HIV test

3.5.5.2 Workload

The mean daily load per provider was 32 patients (Table 20). Workload varied significantly between regions – 31, 39, and 25 patients per provider per day in Regions A, B and C, respectively. Research had suggested that, depending on the patient profile, the daily workload should be in the range of 28-40 patients per day (Rispel et al, 1996). All regions thus fell within the range, although one region (B) was close to the upper end of this range. Clinic workloads varied considerably, from a low of 10 to a high of 65 patients per provider per day, suggesting staffing inequities within the province.

The absenteeism rate was 5% i.e. staff were not at work as expected for one day out of every 20 days. Absenteeism was highest in Region B (7%) which also had the highest workload. Taking into account absenteeism, workload in Region B increased from 39 to 43 patients per day. Absenteeism was lowest in Region C, which also had the lowest workloads.

Table 20: Workload, absenteeism and turnover*

	Region A	Region B	Region C	Total
Mean patient load per day per staff member (full-time staff only)	39	42	26	37
Mean patient load per day per staff member (full-time and part-time staff)	31	39	25	32
Mean absenteeism of professional nurses (%) (absent/expected workdays %)**	5	7	2	5
Mean daily workload taking into account absenteeism	33	43	25	35
% of clinics reporting professional nurses leaving in the last year.	48	67	42	40
% of total professional staff who have left the service in the last year.	16	8	9	11

* Workloads were calculated as follows: total head counts were extracted from the MDS register for three months (June 2000, October 2000 and January 2001); total staff days for a three month period were calculated for each clinic, using the assumption (taking leave into account) of 56 working days per 3 months of a full-time equivalent staff member. Days contributed by part-time doctors and nurses were added in a second calculation. Total staff days were then divided into total head counts to give a daily workload. As managerial staff were not separated from clinical staff, workloads may be underestimated.

** Absenteeism rates were obtained from registers in clinics

Forty percent (40%) of clinics reported at least one staff member leaving in the last year; 11% of the professional nursing staff establishment had left the clinics in the prior year.

3.5.5.3 Job stress

A series of items based on a simplified version of the Karasek Job Strain model was assessed in the provider self-administered questionnaires (www.workhealth.org/strain/jsquest.html). The items combine aspects of job demand (e.g. workload) with job control-latitude and workplace social support. Responses in each category were somewhat mixed and at times contradictory (Table 21), suggesting low internal validity of the tool. While the majority (81%) of providers stated that they had to work very hard, only 56% felt that they were asked to do an excessive amount of work. Over half (54%) said they did not have enough time to complete their work. While 72% of providers indicated that they have a lot of say about what happens at work only 39% felt they had a lot of freedom to decide how to do their work. Scores were generally fairly high on items of social support.

Table 21: Job stress/strain (n=215)

% providers responding yes to following statement:	%
Job demands	
I have to work very hard	81
I am asked to do an excessive amount of work	58
I do not have enough time to get my work done	46
Job control	
I do not have a lot of repetitive work	41
My job allows me to be creative	52
My job allows me to learn new things	79
I have a lot to say about what happens at work	72
I have a lot of freedom to decide how I do my work	39
Social support	
I work with helpful people	81
I work with people who take a personal interest in me	67
My supervisor is helpful	75
My supervisor is concerned about my welfare	60

3.5.5.4 Provider burnout

In order to assess burnout amongst the clinical providers, the Maslach Burnout Inventory was used. Masclach identifies three components of burnout: emotional exhaustion, depersonalisation and personal accomplishment. Scores are calculated for each component based on responses to a series of closed-ended questions. The burnout profile includes high scores on the emotional exhaustion and depersonalisation subscales and low score on the personal accomplishment. More than two-thirds (69%) of providers scored moderate to high burnout on the emotional exhaustion dimension (Table 22). This dimension includes the extent to which, for example, providers feel “used up” or “emotionally drained” or “at the end of their rope” from their work. Only 28%

had moderate or high scores on the depersonalisation dimension, in which providers indicate the extent to which they, for example, have become “callous towards people”; and 36% had moderate to high burnout scores on the personal accomplishment scale (e.g. extent to which providers feel they “deal effectively with problems”).

Table 22: Level of burnout amongst providers (n = 215)

Item	Low (%)	Moderate (%)	High (%)
Emotional Exhaustion	65 (30%)	46 (21%)	104 (48%)
Depersonalisation	156 (73%)	25 (12%)	34 (16%)
Personal accomplishment	137 (64%)	35 (16%)	43 (20%)

3.5.5.5 Providers attitudes to HIV/AIDS

By and large providers attitudinal responses towards HIV/AIDS were positive (Table 23). Few providers (8%) strongly disagreed or disagreed with the statement that “AIDS patients are entitled to the same care as any other patient” and most (66%) would volunteer to care for an AIDS patient. A tiny proportion (2%) of providers indicated that they would quit their jobs rather than to take care for people with HIV/AIDS. About a quarter of providers (24%) strongly agreed or agreed with a statement that “a primary health care provider should be discharged if she refuses to take care for an HIV positive patient”.

Table 23: Provider attitudes (n=215)

% providers agreeing or strongly agreeing with the following:	A n=68	B n=72	C n=75	Total n=215
AIDS patients are entitled to the same care as any other patient	95	97	94	96
I would volunteer to care for an AIDS patient	68	62	72	66
I will quit my job rather than to care for people with HIV/AIDS	4	2	1	1
If I had to treat HIV/AIDS patients I would feel uneasy about doing so	16	5	12	10
A primary health care provider should be discharged if she refuses to care for an HIV positive patient	25	20	24	24
Health care workers have the right to refuse to work with AIDS patients	13	18	20	17
Most AIDS patients are not necessarily	65	61	58	61

responsible for their own illness				

3.6 Communication channels

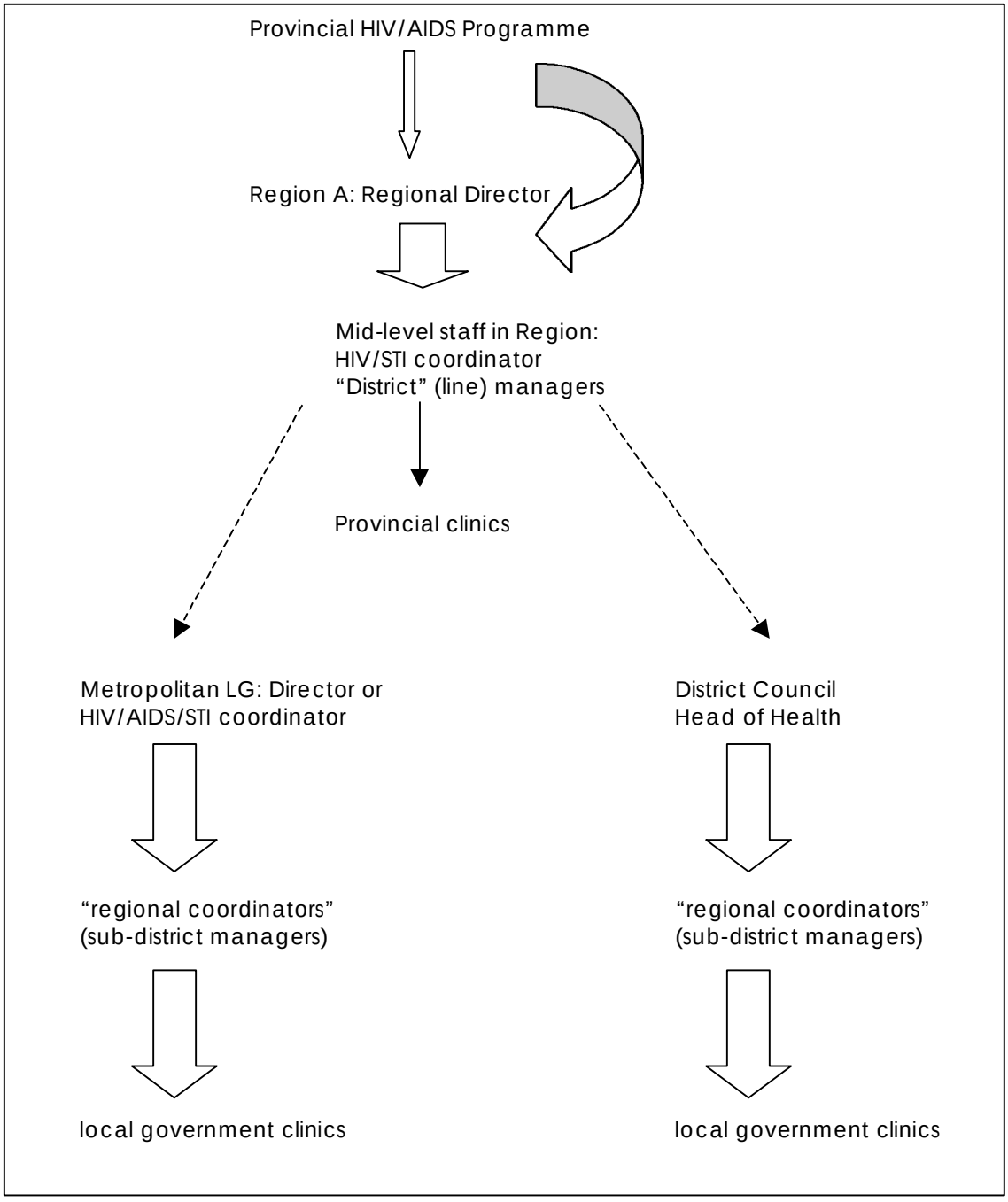
Figure 6 below gives an outline of communication channels up to facility level in Gauteng's three Regions based on experiences in obtaining approval from various authorities during the course of the research. The obstacles encountered are likely to be similar when implementing strategies to improve the integration of AIDS care and support into primary health care. They provide important insights into the systems hurdles which need to be over come in order to effect changes at the level of service delivery.

Our experiences during the research were as follows:

- Communication within authorities is better than communication across authorities – potential blocks exist at every one of the interfaces within the province.
- Communication between the provincial HIV/AIDS Programme and the Regional HIV/AIDS coordinators is regular. However, communications have to pass through the Regional Manager and any contact with facilities has to be approved by the Director's office at the regional office. Thus to get approval for the research we had to liaise with the Director's office. This involved sending the proposal with a covering letter explaning the research and arranging a follow-up meeting.
- The Regional HIV/AIDS coordinator (in Provincial Region A,B,C) is a critical "node" of communication. This person is generally overloaded and unable to adequately manage tasks. This is a key bottleneck in the system.
- There appear to be inadequate formal mechanisms of communication between the provincial regional office and local government in at least two of the three regions. The approval process for the research had to be initiated separately with each of the local authorities. In one region contact with local government was facilitated by the regional office which convened a joint local government-provincial meeting.
- With respect to HIV/AIDS issues the key person to liaise with in the metropolitan councils is the head of health services in the local government (Tshwane and Ekhuruleni) or the HIV/AIDS coordinator (Johannesburg). In the District Councils, which are smaller, it is the head of health services.
- There is still considerable instability in the senior echelons of metropolitan local government, with acting heads of health services in all three metropolitan authorities at the time of research.

- Everything that happens in the local government clinics is mediated through the "regional coordinators" – the sub-district level general managers (i.e. not specifically HIV). This managerial layer appears to be more stable than that of the senior managers and is a key layer to target for implementation of new systems during a period of restructuring.
- Communication on HIV/AIDS tends to be top-down, with few mechanisms or opportunities for getting formal "bottom-up" communication into programme priorities and planning.

*Figure 6: Communication channels in Provincial Regions, Gauteng Province**



* Arrows indicate extent and quality of communication – the thicker and more solid the arrows, the better and more formalized the channels

3.7 Service user perceptions

3.7.1 Introduction

Fourteen HIV positive service users were interviewed in-depth on their experiences of using the primary health care clinics, including the public hospitals. All of the service users were based in the Gauteng province and they were purposefully selected from a network of HIV/AIDS non-governmental organisations. All the interviews were tape-recorded with the consent of the individual respondents. Each interview took an average of an hour to complete. The nature of the interviews or discussions was informal, based on a guiding list of questions rather than a structured questionnaire. The intention of the interviews was to allow users to describe their own experiences of accessing and using health services, reflecting on both positive and negative experiences. Interviews with HIV positive service users focused on their experiences of being HIV positive as well as their experiences of using public sector HIV/AIDS services. All the interviews were conducted from the user service organisation s or their homes. Data from 13 interviews were included in the overall analysis, since the tape of one interview was damaged. The demographic details of the service users are included in Box 1.

Box 1: Demographic details of HIV positive users interviewed

- 14 respondents: 6 male and 8 female
- Average age 35 years
- 11 never married
- mean of two children per person
- 13 had achieved high school education
- On average each had known about their HIV status for 3.4 years, but this ranged from 6 months to 6 years across the whole group

3.7.2 Pathways in accessing health care

All service users had been in contact with the health services, mostly when they were first tested for HIV. Six service users were using primary health care services at the time of data collection. The following table illustrates pathways of nine service users who had a contact with more than one health care facility, since they had been diagnosed with HIV. Most service users used tertiary hospital as their first entry point into the health care system. Only two users used the service of a private doctors and one had used that of a

traditional healer. Three users subsequently used primary health care clinic as their second point of contact in accessing health care. Overall, these respondents had, since diagnosis, used a minimum of two and a maximum of eight different service providers in their search for care and assistance. The users' pathways illustrate that most users bypass the primary health care clinics in their first to their third attempt in seeking health care. This possibly points to the fact that service users access health services during late stages in their illness and when in need of high level medical care.

Half (7) of the service users themselves initiated the action that led to their HIV positive diagnosis. A school pupil, for example, had presented him/herself for an HIV test after participating in a peer counselling programme. The rest, however, decided to have a test because of their own concerns about their health and slow process of recovery from other illnesses. As one respondent who had been admitted to a TB hospital explained, "*I stayed there for sometime and I realised that I was not getting better. They were not telling me what was wrong with me, but I knew I had TB and I did not know what else I was sick from. So I requested people who came to the hospital to teach us about AIDS, that they should arrange an HIV test for me. I wanted to know where I stand in terms of my health. So they agreed, then I signed with the social worker, the doctor and the doctor's assistant that they should take my blood for testing. So the doctor took my blood and he told me to wait for the results".*

Among the other seven respondents, four had effectively been persuaded to have an HIV test by medical professionals – for example, whilst attending for antenatal care. One person had even been asked to decide whether or not have a test in the presence of other patients. Two respondents stated that they had neither been asked nor given consent for a test to be conducted, nor had anyone else in their family given consent. As one explained *"I collapsed at work when I heard that my wife and I were to separate. When I collapsed I was not sick and there was nothing wrong with me. I think it was issues of stress and that's when they took my blood for testing before, without getting consent from me. It was when I regained consciousness that I was told I was HIV positive".*

Table 24: Service user pathways from time of diagnosis to interview[1]									
User	Facility 1	Facility 2	Facility 3	Facility 4	Facility 5	Facility 6	Facility 7	Facility 8	Date of diagnosis
1	Hospital	Clinic	Traditional healer						1996
2	Hospital1	Hospital2	TB hospital	Clinic1	Clinic2	TB clinic	Clinic3		2000
3	Hospital1	TB hospital	Hospital1	Hospice	TB clinic	Clinic			1998
4	Private doctor1	Private doctor2	Hospital1	Private doctor3	NGO clinic	Hospital1	Clinic1	Hospice	1995
5	Clinic1	Different private doctors	Clinic2 and hospice						2000
6	Hospital1	Psychiatric hospital	Hospital1	Hospice/clinic					1995
7	Hospital1	HIV clinic							1995
8	Clinic1	Clinic2	HIV clinic						1998
9	Hospital1	Hospital2							1997
Note: all interviews conducted February/March 2001									

While twelve of the fourteen interviewees had been asked for their consent before HIV testing, eight maintained that they had not received pre-test counselling. *"They just asked me if I knew about AIDS. Then I said not exactly, because that is what everybody talks about. Then they asked me why I wanted to do an HIV test. I gave them the reason. They did not do any counselling".* Those who had been counselled generally indicated that they were given information on HIV and the meanings of the negative and the positive status.

3.7.3 Factors influencing Utilisation of Health Services

3.7.3.1 Personal responses to HIV positive status

One of the key factors underlying utilisation of health services was clearly the respondents own responses to their HIV positive diagnosis. Three respondents indicated, for example, that they had presented themselves several times for HIV testing. As one explained, *"I went for another test because I believed that sometimes it happens that things might change. So when I went to get my results, I found out that my status hadn't changed."*. The service user who had visited most providers since the time of the initial diagnosis also indicated that she had been tested seven times for HIV and had used various health facilities to confirm her HIV status. Such behaviours are presumably linked to the individuals' own, understandable denial, of the diagnosis.

For some people, the initial HIV positive diagnosis was clearly a very difficult thing with which to come to terms. Two people talked about losing their will to live and even contemplating committing suicide after they were diagnosed HIV positive: *"I felt that I was dead already, because I told myself that ok, it was the end of the world. I will no longer live like a human being. Those are the things that were happening to me at the time".* Another said that he become very angry towards women because he understood that his wife had infected him. A fourth said that she used to get drunk as a means of ignoring and forgetting the diagnosis.

Others were more accepting of their situation and themselves. Some responded to their diagnosis by getting involved in activities that could empower themselves and the wider HIV positive community*. "I extended my hand to TAC and the AIDS Consortium and NAPWA. Since then I never looked back. I have grown many people who some I still meet even today".*

All respondents had disclosed their status to their families. For one the shock of being diagnosed HIV positive had only been made worse by his/her family's responses. *"My aunt used to say, there is AIDS. If it happens that someone in this house goes to the hospital or clinic to do an HIV test and that person is positive she will kick him or her out of the house. She chased me away after she found out".*

However, all service users interviewed belonged to a support group. Such groups were seen, at a minimum, as a way of preventing boredom. More positively, they were also seen as important because they provided material support such as clothes and food, as well as emotional support that helps people to cope. *"The group helps and we share ways of coping, how to be confident about yourself, we talk about various ways the HIV virus is contracted so that people could know how to cope with this disease".* Support groups had even provided some service users with a base from which to conduct HIV/AIDS education activities in the wider community. Those who had become activists often seemed able to draw on wider networks of support than others: *" I get support from my family, friends, and neighbours, the PWAs support group, schools, teachers, churches. Yes I have strong support and a lot of support. There is a shop owner who is providing me with groceries every month. Sometimes if I need sort of cash, she gives me. Then I do whatever I need to do, I appreciate. Then there is a doctor she is assisting during test, even to the extent that if I need medication she can buy it for me".*

3.7.3.2 Initial experiences of care

A second important factor underlying service users' utilisation of health services is their initial experience of care. In addition to whether they are consulted about the first test, three key issues of concern to users are:

- whether they are told their test results
- the confidentiality with which their test results are treated and
- the nature of the counselling they receive at the time of their test.

Several interviewees indicated that they were not told the result of their HIV test when returning to the facility to collect it. Consequently, they had gone on to visit several facilities in order to get a final diagnosis.

Three of the respondents clearly felt undermined by the behaviour of the health professionals they met at the time of their first test. One of those tested without consent, commented *"And when I looked around every member of the ward knew about my HIV status. Really it was not good at that time. Even now, you see, when a person knows something about you, you can see his or her reaction from the beginning. Yes, the way they look at you, you see, you know these things and then obviously, he will ask you so many things, you will end up running from people".*

Finally, the majority of service users had been given post-test counselling. Its importance in enabling people to come to terms with their diagnosis was indicated by those who were satisfied with the counselling they had received. They indicated that the counselling was critical in helping them cope and in enabling them to overcome denial. One respondent described the importance of his relationship with his post-test counsellor:
" The counsellor was good, I still had that denial. I could not agree with all the things and it was difficult to be in the position the counsellor was expecting me to be in. It took me three months because the counsellor had patience. She made follow–ups and she encouraged me in many things, she arranged courses for me to attend, like counselling course, basic HIV/AIDS course. So when I did the course my relationship with my counsellor was so good because she encouraged me in many things ".

However, counselling experiences were more often rather negative. Explaining her dissatisfaction with counselling and the communication around her test, one interviewee said *"The doctor called me to his room, and he told me the results, he was with a nursing sister, he did not tell me that I was HIV positive, he told me that I had AIDS and that I was going to die, just like that and then after I was shocked and I did not want to answer him – he told me that there was no cure for AIDS"*.

3.7.4 Positive experiences of care

Perceptions of the care received after the initial interaction with the health system continued to influence patterns of health care use. Those who had positive experiences of a particular facility were, therefore, continuing to make use of it because they had been given treatment and care that met their expectations. *"It is better, I am lucky, because I haven't got that sick, because I go to the clinics. At least at the clinic where I go for treatment, I can say its better because they have patience for people, they try very hard, they don't talk without paying attention".*

As Box 3 indicates, the positive attitudes and approach of providers was seen to be a very important element of well-perceived care. Two people felt that they were treated well because their health providers had received specific HIV/AIDS training. Another valued the courtesy and confidentiality of her current clinic, having been subjected to considerable harassment at the clinic she had previously visited. Some were, finally, happy just to be able to get appropriate medication. Unfortunately, many of the positive accounts related to experiences in dedicated HIV clinics, rather than general clinic services.

Box 2: Positive experiences of services

"The doctors there [at the HIV clinic] are, they give support. It is the doctors with HIV training. They know everything. If you've got this they will give the right medicine, if you've got anything they will give you a right tablet for that".

"She tries by all means to do whatever, because others don't give you injection they just say I will give you…".

"When I first went to see her she tried by all means, for me to get injections, tablets and became alright. So now I am all right. When it is coming to going to these other clinics, even if I have headache, a very bad one I wont go to them, I will go to this doctor. I saw that she has a lot of patience. Lets say she knows that one needs to understand a sick person. So she tried in the way she knows".

" The [HIV] clinic is right because everybody feels free. Everything is confidential. Doctors treat patients equally. There is no such a thing that you the best and you not the best. Everybody feels free because sometimes they offer lunch to the patients and their treatment is right. They make sure when you leave you are right and satisfied about the treatment".

" I haven't experienced any problems because when I go there they give tablets".

3.7.5 Negative experiences of care

Although service users reported positive experiences, negative experiences were more commonly identified. Health care providers were often seen to victimise HIV positive people and to treat them callously. Service users reported that they often disclosed their HIV positive status to health providers in order to get appropriate medical treatment but only ended up being blamed. As Box 4 indicates, such attitudes only contribute to the despair some feel on hearing their diagnosis. It was also said that nurses frequently accused people

living with AIDS as being "*always sick"* and patients were often told *"you will be like this forever…But I asked isn't there something we could get from the clinics?".* Overall, the perception of service users was that health providers in clinics *"…don't care about people. They are not quick in providing treatment no matter how sick a person is".*

Box 3: Callous attitudes

I found a certain doctor. He asked me what was wrong and I told him that I was not shocked or had a headache or something, may (be) it was the symptoms because I was HIV positive. He said to me I am going to die a terrible death. I have sinned. I have to pray to God for forgiveness because I was sleeping around. I was very angry because I did not expect that from a doctor, a professional doctor, how can?. I am expecting that when I see him I should see life. I mean I am depending on the doctor, not to swear at me. Then I went to the matron. Actually I went to see a certain Sister who is the friend to the sister I usually see when I come to the clinic. The two of them give right treatment. Then I went to her and she said, no its wrong, how about you go to the matron. I knew each and every right of HIV positive people. I thought I could take the story to the newspapers and I will make this doctor's life very miserable right now. Because there is no person who deserves to be HIV positive and there is no person who is suited to be HIV positive. So she said I should speak to the matron first. Then I went to the matron and we then went to that doctor, when we confronted the doctor, he denied. He said he was talking to me as a father and then I said to him as your real daughter I did not expect that from you. How do you expect me to feel when you tell me that I am going to die? I don't want you to tell me that … even though I am going to die, I want you to tell me that I am going to live.

Service users also reported poor confidentiality as being part of the negative attitudes of health care workers towards HIV positive patients. Three service users talked explicitly about confidentiality being broken when they visited clinics and hospitals for treatment. One described how nurses gossiped about her because she was HIV positive and felt that their behaviour had been abusive. *"When you go to the clinic, you will see Sisters nudging at each other talking about you. They speak with their eyes. So that is abusive".* Another explained how consultations are conducted without privacy, *"… while the door is open, knowing that it is not okay. Knowing very well that the door should be closed during consultation".* A third related how, on admittance to hospital, a nurse read her clinical notes and discovering that she was HIV positive, shouted *" Shoo! You HIV positive AIDS"* in the presence of other people. The same person clearly expressed the need for confidentiality. *"What if I don't want my status to be known? What if one of my neighbours was admitted at the hospital and was listening?"*

Other problems identified included: overcrowding in clinics, long waiting times, limited hours of service, and, a very common complaint, lack of drugs: *"Here everyday sometimes they don't give us tablets, they just tell us that they are finished. They tell us that we should go to the other clinics"*. Such problems sometimes generated horror stories. For example, *"I won't count how many people died at _____ hospital. When I was admitted there, I used to see people dying because there is a shortage of tablets"*. Criticisms of hospital care were particularly strong and included long waiting times, poor facilities (such as clothing) and poor treatment (Box 5).

Box 4: Negative experience of hospital care

There is a patient who also attends here. He was in ward 16 and he was treated badly and we were even considering suing that Sister. That patient was made to sleep in the bed with a plastic, there were no sheets, he was not even given a blanket to sleep with. He had to bring his own blanket. He was weak and had diarrhoea. His wife came to the hospital everyday to wash and feed him. He could not even walk, he could not get medical treatment because he could not walk. He was not able (to) stand up and fetch the treatment. That Sister did not want other patients to help him, he could not eat, he spent three days without food. His food was put on the trolley, they told him to get up and get the food. He could not walk, not that he did not want, he couldn't walk. No one had time for him, may be because he is HIV positive. His wife was helping him. We got a complaint from her. She told us that she found her husband sleeping in a messy bed. She was with their two children and the very same sister said to her you should not touch that child you will infect her. Imagine just because she touched someone who is HIV positive, meaning that you will infect the child with the virus.

3.7.6 Explaining experiences of care

Training and personal attitudes were the main factors identified by service users as explaining positive health care provider behaviour. Being HIV positive was also seen as supporting better behaviour. An AIDS activist also noted that people living with HIV/AIDS could encourage better attitudes. *"So we need to teach them and to do so is to involve them. We can do something, mm like changing attitudes, to do this I feel if they can work with somebody who is open, during their spare time, that person can play a bigger role. So if the government can employ someone who is positive in each clinic and every clinic, then this could take us somewhere. For this issue of virus and other issues because we are trained not only for HIV or AIDS".*

More generally, however, health care providers' behaviour was seen to reflect a sense of helplessness and hopelessness about how to deal with HIV/AIDS (Box 6). Several service

users thought that nurses attitudes could be attributed to fear of contracting HIV themselves or the need to deny their own vulnerability. *"They are so ignorant, they say it will never happen to them. Many of the nurses become volunteers in Hospices for HIV/AIDS people, they should know that anybody can be HIV positive. They think because they are nurses it will never happen"*. At the same time, service users recognise that their own behaviour may exacerbate poor attitudes. *"You find that sometimes we are wrong. Sometimes we need to change our attitude because now we are aware that the nurses are not right and we also have an attitude. We don't treat people right. We don't treat nurses right. Sometimes you find a good nurse and you find that our attitude towards that nurse is not right. That is not right."*. Other less frequently identified factors were the high levels of utilisation and overcrowding in some clinics.

Box 5: The hopelessness of service providers

"Because you see the message is the same, there is no medication [referring to the anti- AIDS drugs]. Even now if you can go to the local clinic more especially... they will tell you that, hey... there are Sisters I know who tell their clients that even the immune booster wont help you".

"Last time when I was admitted at _____, I had short breath. so the nurses looked at the doctor and they said we are tired of you, you know that there is no cure for AIDS".

Nurses usually question HIV positive patients presenting at the clinics for treatment, asking them "*What must we do? There is nothing we can do".*

3.7.7 Conclusions

As can be expected, users want a health service that treats them promptly and with courtesy, listens to and assesses their problem competently and thoroughly, and provides them with appropriate treatment. From the interviews, it is clear that users will try out the different services available to them, until they find the one that best matches these expectations. In places where choices are limited, people may simply carry on going to the same facility until they receive some sort of satisfaction. In the case of people with HIV, the process of coming to terms with being HIV positive may itself involve multiple visits to different facilities. These various patterns of service utilisation may, however, not correspond to the most efficient use of resources - dissatisfaction with a service may lead to increased and less rational forms of utilisation. Thus meeting the needs of users is not only a good in itself, but also has implications for efficiency. A negative reception and poor attitudes of staff severely undermine people's trust in a service. Many users, especially people with HIV, feel that they

are simply not wanted at health facilities and that their privacy and anonymity are at risk. In Gauteng Province, people with HIV have thus naturally migrated to the specialist HIV clinics, where both the human and technical quality of care are perceived to be better. While respect for consent procedures is apparent in primary health care settings, many health workers still do not know how to provide adequate post-test counselling, and often convey the impression that nothing can be done about HIV. If primary health care services are to play a meaningful role in AIDS care and support, there needs to be a reorientation of the approach to people with HIV.

Where clinic services are experienced positively users will willingly attend these services. The category of professional (nurse or doctor) appears to matter less than the quality of the attention given to patient needs. The increased presence of trained counsellors (including lay counsellors) and HIV support groups linked to primary health care facilities was seen as very important. This infrastructure could be of value in managing other health problems, such as mental illness and violence against women.

Respondents expressed great concern on the amenities and professionalism of staff in public hospitals. Thus, the quality of a primary health care service is not seen as separate from the quality of hospital care. Hospitals represent moments of greater patient vulnerability and places where catastrophic, life threatening illnesses are dealt with. Good quality hospital care is therefore more important for users than primary health care.

4 To what extent are HIV/AIDS care and support functions integrated into primary health care services?

For the purposes of this research, integration was conceptualised as the extent to which primary health care clinics were providing HIV/AIDS care and support services within the pre-existing package of primary health services. This involved not only assessing services within facilities but also the extent to which primary health care clinics were integrating with other organisations in the provision of HIV/AIDS care and support. The latter focused on referrals between levels of care i.e. between clinics and hospitals, as well as networking of clinics with non-governmental organisation s or local community structures.

The findings of the study suggest that this is some degree of integration of HIV/AIDS care and support into primary health care services, using the criteria established by the Guateng Province. Moreover, a relatively well functioning infrastructure (both physical and human) is established in the clinics and workload appears to fall within acceptable norms, although there was wide variation both within and between regions in workloads.

Almost all the clinics (94%) provided an HIV testing and counselling service, although there were significant variations in the turn-around time of test results. For example, 49% of clinics had to wait for more than a week for HIV test results. Utilisation of the HIV testing infrastructure, however, seemed low, although in the absence of clearly defined norms, such a judgment is hard to make.

Although professional nurses (88%) were the main providers of HIV/AIDS counselling in the clinics, their role as counsellors is hindered by lack of time and training in counselling skills. Forty percent of front-line providers who completed the questionnaires were trained in HIV/AIDS counselling. Nursing assistants and health promoters also played an important counselling role. In the interviews with users, the poor quality of pre and post test counselling was raised as a major issue. Forty-six percent (46%) of clinics had a written confidentiality policy available at the clinic – regions varied in their availability of such policies. The self-administered questionnaires highlighted contradictory provider attitudes towards confidentiality, and in the interviews with HIV positive service users

problems around privacy and confidentiality were raised, largely involving disclosure of test results without user consent. Lack of privacy and confidentiality resulted in a lack of trust in health services and tendency for users to “shop around” for good quality services. These problems limit continuity of care and follow-up of HIV positive service users. Although the experience was not universal amongst all users, discrimination by providers and stigma attached to HIV/AIDS were main barriers to accessing care. Effective integration of HIV/AIDS into the primary health care level therefore requires that users have trust in the services. Trust develops where continuity of care is possible and where providers display positive attitude towards users and maintain user confidentiality.

Developing the skills of professional nurses to diagnose and treat HIV/AIDS opportunistic infections is one of the important pre-requisites for integrating HIV/AIDS care and support into PHC services. Even though 63% of front-line providers were trained in primary health care, provider clinical knowledge and skills were weak. Very few (10%) had received specific training in clinical management of HIV/AIDS. The review of patient clinic records showed that it was not common for clinics to recognise opportunistic infections. Provider knowledge of staging the HIV/AIDS disease was also poor. TB services were generally well established and integrated into clinics, with standardised registers to monitor follow-up and continuity of care of service users. However, in most cases TB services were offered as a vertical service within the clinic. Increasing training and availability of HIV/AIDS primary health care clinical guidelines will promote recognition and proper treatment of opportunistic infections. However, effective implementation of treatment guidelines should be accompanied by ongoing support systems for provider clinical support and debriefing.

Adequate management of HIV/IADS opportunistic infections also demands the existence of a well-established system to deliver drugs in an uninterrupted manner. Certain essential antibiotics were available in almost all the clinics, including cotrimoxazole tablets, cotrimoxazole syrup and ciprofloxacin tablets. However, certain drugs listed in the Gauteng Provincial Primary Health Care HIV/AIDS clinical guidelines were either not available or only available in selected clinics.

Twenty-two percent of clinics were linked to a home-based care programme, although only 5 clinics (10%) were dispensing morphine to such programmes.

A clear pattern of referral between various levels of care is key for integrated primary HIV/AIDS care and support. In this research there was generally poor formal referral relationship between hospitals and clinics. In the interviews with service users it was apparent that this situation resulted in problems around continuity of care and loss of HIV positive service users to follow-up. In the main, clinics (86%) had established networking relationships with NGOs and community-based structures in their areas. However, regional variation in terms of developed networks with NGOs was evident, possibly linked to leadership and commitment at the local level.

Support structures to provide staff with opportunities for debriefing are essential to deal with psychosocial consequences of providing care and counselling. The existence of formal structures to provide providers with opportunities for debriefing was weak in clinics, although there were regional variations in the existence of these structures. Thirty-six percent (36%) of providers reported participating in formal group meetings at facility level for debriefing purpose. Yet the need for more effective systems of provider support was evident in the high level of emotional exhaustion reported. Although needle-stick injuries were common, access to PEP was not universal.

In sum, while there is considerable potential for creating a coherent system of AIDS care and support within primary health care services, the study concludes that, at present, these are ad hoc and fragmented, and often of low quality. The notion of a multi-faceted and comprehensive service, designed to ensure continuity and follow-up through a continuum of care has yet to be established within the primary health care infrastructure. While clinical training and distribution of guidelines will improve quality, clearly more is needed if PHC services are to make a real difference to the lives of people with HIV/AIDS and play a meaningful role in promoting equity, efficiency and sustainability of HIV/AIDS care and support.

The implementation process is hampered by the lack of coordinated planning mechanisms and formal communication channels between provincial and local authorities.

Table 25 summarises the barriers to the integration of HIV/AIDS care and support into PHC, at both the “facility” and higher, “systems” levels.

Table 25: Barriers to the integration of HIV/AIDS care and support into PHC

Issue	Facility level barriers	System level barriers
Human resources	❑ Disparities in the distribution of workloads between facilities and regions ❑ High staff turnover ❑ Staff absenteeism ❑ Stress and burnout amongst providers ❑ Helplessness and hopelessness towards people with HIV	❑ Need for additional posts ❑ Inadequate staff support systems ❑ Absence of clear policies and systems for the comprehensive management of people with HIV across the continuum, including appropriate monitoring and follow-up systems
Drug supply	❑ Key drugs not available in all the clinics	❑ Several drugs listed in the clinical guidelines not available at facilities ❑ Lack of policies and procedures for distributing morphine
Diagnosis and testing	❑ Some users report being tested without consent ❑ Some users report being tested without counselling ❑ Perceived lack of confidentiality of test results.	❑ Disparities in the turn around time of test results ❑ No mechanism to monitor the levels of testing in the clinics
Counselling	❑ Providers report a lack of time and skills in HIV counselling ❑ Less than half providers trained in HIV counselling ❑ Users report highly variable quality of counselling ❑ Ongoing counselling not part of a continuity of care	❑ Limited follow-up support for staff ❑ Lack of standardised information system for monitoring counselling. ❑ Availability of provider support -system for debriefing is not universal
Management of opportunistic infections	❑ Provider clinical knowledge/skills are generally low ❑ Poor recognition of opportunistic infections ❑ Prevention of opportunistic infections not on the agenda	❑ Limited access to clinical management skills training
Networking	❑ Poor referral/ networking between clinics and hospitals ❑ Primary health care clinics are sometimes bypassed by users in favour of secondary hospitals	❑ Poor referral/ networking with the hospitals ❑ No information base for NGO networking/referral ❑ No feedback mechanisms on referrals

5 Recommendations

PHC services should aim to provide continuity of care for individuals from the point at which they are diagnosed across the continuum. This includes not only voluntary counselling and testing and treatment of opportunistic infections, but also follow-up counselling and support, "wellness" management, (e.g. nutrition, cotrimoxazole prophylaxis) referral to welfare and other support structures, hospitals and community-based organisation s, and palliative care. Care across the continuum needs to be supported by systems for follow-up and monitoring of individuals and their families e.g. through special record-keeping. To achieve continuity also requires that people with HIV trust clinics and providers. These are essential pre-conditions if PHC services are to have a future role in the provision of long-term anti-retroviral therapy.

Below are some suggested actions and recommendations to achieve this.

Ensure adequate staffing:

- ✓ Monitor workload and equity of staff distribution and address needs of clinics with large workloads
- ✓ Define future staffing requirements in the light of growing needs and develop an incremental plan to increase staffing to PHC services.

Increase capacity for HIV counselling and testing*.*

- ✓ Explore ways of promoting the effective use of volunteers – look at dedicated nursing staff to work alongside volunteers and health promoters in providing counselling
- ✓ Increase the capacity of counsellors through continuous training
- ✓ Provide debriefing support for counselors and a counselling support infrastructure
- ✓ Institute processes for quality assurance in HIV/AIDS counselling and for monitoring of utilisation of counselling services.

Improve clinical skills

- ✓ Adequate management of HIV/AIDS in primary health care clinics requires that providers are trained in comprehensive clinical skills. This will promote the appropriate detection and management of HIV/AIDS related opportunistic infections at the primary health care level. Ideally this training should be integrated into the undergraduate curriculum of health professionals and in post-basic primary health care training programs.

Additional training

- ✓ Promote training in palliative care, including how to network with community-based organisations.

Guidelines and protocols

- ✓ Develop and distribute guidelines on clinical management (already developed in Gauteng),counselling, palliative care, support for home-based care and referral, and on systems for the continuum of care for HIV/AIDS.

Improve referral and networking

- ✓ Identify and address key barriers in referral between clinics and hospitals
- ✓ Strengthen networks between clinics and home based care organisation s
- ✓ Promote networking with community based care and support groups in order to build trust and communication. Make information on entitlements and expectations available to communities.

Enhance support systems to address issues of provider morale and motivation

- ✓ Define the role of clinic managers in providing support for providers
- ✓ Consider ways to monitor stress and burnout amongst providers and deal with the sources thereof
- ✓ Increase the availability of formal clinical and counselling support for staff through institution of a counselling support infrastructure, debriefing opportunities within the clinics, and clinical support by trained practitioners.

Monitoring and evaluation of HIV/AIDS care in the primary health care clinics

- ✓ Define specific indicators to measure quality and utilization of HIV services in the primary health care setting
- ✓ Develop tools for HIV quality monitoring at district level, to be integrated into quality improvement systems
- ✓ Institute systems for periodic monitoring to measure uptake and quality of HIV/AIDS services.

Coordinated planning and communication

- ✓ Focus on getting the buy-in and developing the capacity of the sub-district managers (referred to as “regional coordinators”) in local government
- ✓ Establish and agree on formal systems of communication between provincial and regional HIV/AIDS coordinators and key people in local government
- ✓ Build the capacity (staffing and skills) of the Regional STI/HIV coordinators
- ✓ Build capacity (staffing and skills) at provincial level for proactive programme planning
- ✓ Establish a forum where provincial HIV/AIDS/STI managers, regional HIV/AIDAS/STI coordinators and sub-district managers can meet to discuss policy and plan activities on a regular basis.

References

Adelekan, M.L., Jolayeni, S.O., Ndom, R.J., Adegboye, J., Babatunde, S, Tunde-Ayimode, M., Yussuff, O., Makunjuala, A.B. (1995) Caring for People with AIDS in a Nigerian teaching Hospital: Staff Attitudes and Knowledge. ***AIDS Care****,* 7 Suppl 1: 63-72.

Baleta, A. (1998) South Africa Holds Crisis Summit on HIV. ***Lancet***, 352 (9132): 968.

Bellani, M.L., Furlani, F., Gnecchi, M, Pezzotta, P., Trotti, E.M., Bellotti, GG. (1996) Burnout and Related Factors among HIV/AIDS Health Care Workers. ***AIDS Care****,* 8 (2): 207-221.

Bradshaw, D., Johnson, L., Schneider, H., Bourne., D and Dorrington, R. (2002) Orphans of the HIV/AIDS Epidemic: The Time to Act is Now. MRC Policy Brief No 2, May 2002.

Broomberg, J., Malcolm, S., Mosobe, P. and Behr, G. (1991) ***Aids in South Africa: The Demographic and Economic Implications. Part II The Economic Impact of AIDS in SA***. Johannesburg: Centre for Health Policy.

Colvin, M., Dawood, S., Kleinschmidt, I., Mullick, S. and Lalloo, U. (2001) Prevalence of HIV and HIV-related Diseases in the Adult Medical Wards of a Tertiary Hospital in Durban, South Africa. ***International Journal of STD and AIDS****,* 12(6):386-9.

Department of Health (2000) ***National Antenatal HIV sero-prevalence survey***. Pretoria: South Africa National Department of Health.

Fawcett, D.(1993) Attitudes Toward Patients with AIDS: A Comparison Between Urban and Rural Perioperative Nurses. ***AORN Journal***, 57(2): 489-492.

Firth-Cozens, J. (2001) Interventions to Improve Physicians' Well-being and Patient Care. ***Social Science and Medicine****,* 52 (2): 215-222.

Floyd, L. and Molekwa, S. (2000). ***Gauteng "The Partnership Against AIDS in Action***" ***Annual Report of the Gauteng AIDS Programme 1999/2000.*** Johannesburg: Gauteng AIDS Directorate.

Floyd, L. and Simon, J. (1999) ***The Partnership Against AIDS in Action, How Can I Make A Difference? Local Inter-Sectoral Aids Programme. A Consultative Document for the Gauteng Inter-Governmental Forum on Social Services.*** Johannesburg: Gauteng Aids Directorate.

Fransman, D., McCulloch, M., Lavies, D. and Hussey, G. (2000) Doctors Attitudes to the Care of Children with HIV in South Africa. ***AIDS Care***, 12 (1): 89-96.

Fusilier, M., Manning, M., Santini Villar, A. and Torres R, D. (1998). AIDS knowledge and attitudes of health-care workers in Mexico. ***Journal of Social Psychology***, 138 (2): 208-210.

Gilson, L. (1997) Lessons of User fee experience in Africa. ***Health Policy and Planning,*** 12 (4): 273-285.

Hiscox, C. (1991) Stress and its Management. ***Nursing Stand***, 5 (21): 36-40.

Love Life and Abt Associates. (2000) ***The Impending Catastrophe: A Resource Book on the Emerging HIV/AIDS Epidemic in South Africa.*** Johannesburg: Love Life and Abt Associates.

Makella, M. and Thorsen, T. (1999) A Framework for Guidelines Implementation studies, in Thorsen, T. and Makella, M. (Editors) ***Changing Professional Practice: Theory and Practice of Clinical Guidelines Implementation***. Denmark: Danish Institute for Health Service Research and Development.

Maslach, C. (1982) ***Burnout, The Cost of Caring***. Englewood Cliffs: Prentice-Hall.

Miller, D. (1992) Staff Stress in HIV Health Care Workers. ***AIDS Care,*** 4: 429-432.

Nesbitt, W.H., Ross, M.W., Sunderland, R.H. and Shelp, E. (1996) Prediction of Grief and HIV/AIDS Related Burnout in Voluteers. ***AIDS Care***, 8 (2): 137-143.

Prince, N.A., Beard, B.J. and Ivey, S.L. (1989) Perinatal Nurses Knowledge and Attitudes About AIDS. ***Journal of Obstretrics and Gynaecological Neonatal Nursing***, 18: 365-368.

Rispel, L., Price, M. and Cabral, J. (1996) ***Confronting Need and Affordability: Guidelines for Primary Health Care Services in South Africa***. Johannesburg: Centre for Health Policy, University of Witwatersrand.

Statistics SA. (2000) ***Census in Brief: The People of South Africa: Population Census 1996***. Pretoria: Statistics South Africa. Report No.03-01-11 [1996]

Steinberg, M., Kinghorn, A., Soderlund, N., Schierhout, G. and Conway S. 2000. HIV/AIDS – Facts, Figures and the Future. Chapter 15 in Ntuli A et al (eds). South African Health Review 2000. Durban: Health Systems Trust.

UNAIDS. (2000) ***Report on the Global HIV/AIDS Epidemic***. Geneva: UNAIDS.

Whiteside, A. and Sunter, C. (2000) ***AIDS: The Challenge for South Africa***. Cape Town: Human & Rousseau Tafelberg.

William, B and Campbell, C. (1998) Understanding the Epidemic of HIV in South Africa: Analysis of the Ante-Natal Clinic Survey Data. ***South African Medical Journal***, 88 (3): 247- 51.

Zwi, K., Soderlund, N. and Schneider, H. (2000) Cheaper Antiretrovirals to Treat AIDS in South Africa (Editorial). ***British Medical Journal****,* 320: 1551-1552.

Zwi, K.J., Pettifor, J.M. and Sonderlund, R.N. (1999) Paeditric Admissions at a South African Urban Regional Hospital: The Impact of HIV 1992-1997. ***Annals of Tropical Paediatrics****,* 19: 135-142.