

Thesis for the degree *Cand.Pharm*

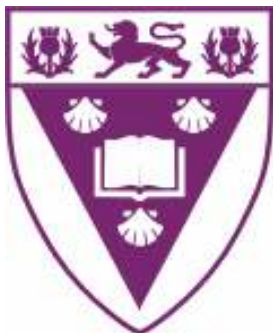
Karine Wabø Ruud

**The role of the different health care professionals
in the antiretroviral therapy and follow up of
HIV patients in Grahamstown's public sector**



University of Oslo

Faculty of Mathematics and Natural
Sciences
School of Pharmacy
Department of Social Pharmacy



Rhodes University

Faculty of Pharmacy

Supervisors: Prof. Else-Lydia Toverud, Prof. Sunitha C. Srinivas

November 2006

Acknowledgements

The study presented in this thesis is in social pharmacy, and is part of my degree cand.pharm from School of Pharmacy, University of Oslo. The work for this study was done between December 2005 and November 2006. During the time January - February I visited Princess Marina Hospital Pharmacy in Botswana, and February - November was spent in Grahamstown, South Africa, where this study was conducted and where I was hosted at Rhodes University as a visiting researcher.

I would like to thank my two supervisors Prof. Else-Lydia Toverud, University of Oslo, and Prof. Sunitha C. Srinivas, Rhodes University. Your supervising, involvement, interest and help in my work during the whole year have been of immense value. Thank you for guiding me as a beginner in the world of research, and for giving me the opportunity to have this great experience!

Thanks to all interviewees from the health care facilities in Grahamstown's public sector, and to participants in group discussions. This study could not have been carried out without your help and contribution. Special thanks to Mr M. Docrat, Mr D. Scott, Mr H. Hutchinson, Mrs L. Somyalo, Mrs J. Dredge and Mrs S. Whiteley for facilitating my observational studies.

Thanks to Rhodes University, Faculty of Pharmacy for accepting me as a visiting researcher, and thereby giving me the opportunity to conduct this study.

Special thanks to Prof. Sarah Radloff, Rhodes University, for great help with statistics!

I would also like to thank all staff at Princess Marina Hospital Pharmacy for letting me visit and learn from you during my preparations for this study. During this stay I learned so much of great importance to myself and my research. I truly appreciate your kindness and all your help!

Thanks to *Norsk Farmaceutisk Selskap* for funding.

Finally I wish to thank my mother, Inger Wabø, for all your support and technical help!

Abstract

South Africa is greatly affected by the Human Immunodeficiency Virus (HIV), and the prevalence rate was estimated to be 29.5% by testing of pregnant women in December 2005. “Roll out”¹ of the HIV treatment programme started in 2004. By the end of 2005 there were between 980 000 and 985 000 people estimated in need of Antiretroviral Therapy (ART) in South Africa, while less than 235 000 people received this treatment.

By conducting observational studies in health care facilities, semi structured interviews with 55 Health Care Professionals (HCPs), and two group discussions, the present study analysed the follow up and care of HIV patients benefiting from the roll out of ART in Grahamstown’s public sector. Recruitment of respondents and data collection were carried out between February and August 2006.

Since roll out of ART in Grahamstown in May 2004 until September 2006, 687 HIV-positive patients have been enrolled on the programme. As the number of patients receiving treatment is still very low compared to the need, the programme is growing continually. Observational studies showed that though the number of patients receiving ART in local clinics was small, HIV patients required special care and attention, and therefore this required more time and focus in the clinics. This led to a great challenge for HCPs who were already coping with stretched limits with regard to workload and the opportunity to provide each individual with sufficient health care. Results from observational studies and semi structured interviews showed that there were few pharmacists and physicians involved in this work, whereas nurses and support staff² played an important role with major responsibilities in the treatment.

HIV patients represented a diverse group with different needs with regard to social and medical support. When newly diagnosed, many patients were afraid of stigmatisation from other people, and also often believed that ARVs were dangerous. This provided a challenge for HCPs involved

¹ “Roll out” is the most common used term in South Africa for the launching of the antiretroviral treatment programme.

² Support staff includes: Community health workers, community care workers, health educators and clinic assistants.

in this work, to ensure that the patients returned for follow up after being diagnosed as HIV-positive, and that they were well enough educated, especially with regard to adherence, to manage the ARV regimen. All interviewees pointed out that work with HIV patients required specific training, though sufficient training had not been provided for all HCPs. The majority of the interviewees acknowledged the need for prioritising in their work with HIV patients, with time constraints being one of the limiting factors.

Table of Contents

1 Introduction.....	1
1.1 The epidemic in numbers.....	1
1.2 About HIV/AIDS.....	2
1.3 HIV/AIDS in Africa.....	3
1.4 HIV/AIDS in South Africa.....	4
1.4.1 History of HIV in South Africa.....	4
1.4.2 South Africa's response to the HIV epidemic.....	5
1.4.3 Health care system in South Africa.....	6
1.5 Antiretroviral therapy.....	7
1.5.1 Combination therapy.....	7
1.5.2 ARVs available in South Africa's public health sector.....	7
1.5.3 Costs of antiretrovirals.....	8
1.5.4 Challenges in providing antiretroviral therapy.....	9
1.6 Impact of HIV in South Africa.....	11
1.6.1 Stigma and discrimination.....	11
1.6.2 Impact on households.....	11
1.6.3 Impact on the economy.....	12
1.6.4 Impact on the health sector.....	13
1.7 International mobilisation to fight HIV/AIDS.....	14
1.7.1 International initiatives for improvement of health.....	14
1.7.2 ARV design in resource constrained settings.....	15
1.7.3 The World Bank's Global HIV/AIDS programme: Elements of effective programmes.....	17
1.7.4 Need for health research.....	17
1.7.5 Antiretroviral therapy in Grahamstown, South Africa.....	17

2 Purpose.....	18
2.1 Objectives.....	18
3 Material and method.....	19
3.1 Setting.....	19
3.1.1 Health care services provided in Makana Local Services Area.....	19
3.1.2 Distribution of health care professionals in public sector in Grahamstown.....	20
3.1.3 The antiretroviral treatment programme at Settlers Hospital.....	20
3.2 Material.....	20
3.2.1 Observations.....	20
3.2.2 Pilot study.....	21
3.2.3 Semi structured interviews.....	21
3.2.4 Group discussions.....	21
3.3 Method.....	22
3.3.1 Observations.....	22
3.3.2 Pilot study.....	22
3.3.3 Semi structured interviews.....	22
3.3.4 Permission for research.....	23
4 Results.....	24
4.1 HIV treatment structure in Grahamstown.....	24
4.1.1 Description of the treatment structure in Grahamstown.....	24
4.1.2 Health care professionals involved at different stages in the antiretroviral treatment programme.....	25
4.2 Follow-up of HIV patients in public sector.....	28
4.2.1 HCP characteristics.....	28
4.2.2 Patients and HCP interaction.....	29
4.2.2.1 HCP involvement.....	29
4.2.2.2 Patient and HCP communication.....	30
4.2.3 HIV treatment follow up.....	35
4.2.4 HCP cooperation	39
4.2.4.1 Communication between HCPs.....	39

4.2.4.2 Referring of patients.....	40
4.3 Workload.....	41
4.4 Training of HCPs.....	44
4.5 Preparing for HIV treatment programme in Makana district.....	45
5 Discussion.....	48
5.1 Material.....	48
5.2 Method.....	48
5.2.1 Choice of method.....	48
5.2.2 The interviewing process.....	49
5.2.3 Validity and reliability.....	49
5.3 Results.....	50
5.3.1 The role of the pharmacist in ART programmes.....	50
5.3.2 Down-referral treatment structure.....	51
5.3.2.1 Facilitating and constraining factors of the system.....	52
5.3.2.2 Health Care Professional cooperation in the treatment programme.....	55
5.3.3 Patient education, care and follow up	56
5.3.3.1 Patient education.....	56
5.3.3.2 Treatment follow up.....	56
5.3.4 ARVs and adverse effects.....	61
5.3.5 Adherence.....	62
5.3.6 Excess workload for HCPs.....	66
5.3.7 Training of HCPs.....	67
5.3.8 Policy and Practice.....	69
5.4 Recommendations.....	70
6 Conclusion.....	72
Acronyms.....	73
Tables.....	75
Figures.....	76
References.....	77
Appendices.....	82

1 Introduction

1.1 The epidemic in numbers

Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (HIV/AIDS) have been described as the most devastating epidemic in human history, progressing with a catastrophic potential in the near future [1]. The challenges with regard to HIV/AIDS and the need for action are elaborated in the 2003 report from the Joint United Nations Programme on HIV/AIDS (UNAIDS), where the following statement is made: “HIV infects and kills people, it tears apart families, destabilizes communities, slows economies, disrupts social services and weakens democracies. Entire societies become vulnerable to implosion” [2]. Its destructive effects exacerbate every other challenge to human development [3] and at the same time undermine achievements as it leads to countries losing young productive people [4].

According to the UN/WHO, the AIDS epidemic has continued to grow immensely and by the end of 2006 an estimated 39.5 million people were living with HIV/AIDS. In sub-Saharan Africa the number of people living with HIV/AIDS is 24.7 million. This accounts for two-thirds of the total number of people living with HIV/AIDS in an area hosting only 10 % of the world’s population. In South Africa there were approximately 5.5 million people living with HIV/AIDS by the end of 2006 [5]. Since AIDS was first recognised in 1981 it has killed more than 25 million people of all ages, from all classes of society all over the world [6]. Total deaths in the world from AIDS in 2006 were 2.9 million people, and more than five million people will die in the next one to two years if they don’t receive ART [7].

According to the UN less than one in five people at risk of becoming infected with HIV have access to basic prevention services, and among people living with HIV only one in ten have been tested to know their HIV status. There are several factors contributing to reasons why people are not aware of their HIV status. One main reason, besides low availability of HIV testing facilities in the neighbourhood, is fear of stigma and discrimination as a result of being HIV positive. The lack of sufficient treatment for HIV patients in many countries is also seen as a factor. Treatment provides a motivation for HIV-positive people to be aware of their status. Without treatment as

an option, knowledge that one is HIV-positive can be seen as offering little more than stigmatisation [8].

It is widely agreed upon that simultaneous focus is needed on both prevention of new infections and on treatment and care for people already infected in order to address this epidemic [9]. It has also been emphasised that access to ART is both a premise for improved health for HIV-positive people and promotes prevention by motivating people to undergo HIV testing. “Access to anti-retroviral therapy is a vital and indispensable complement to both treatment of HIV disease and effective HIV prevention. It can restore hope to both health professionals and patients, and can assist us in regaining control of this epidemic” [10]. Though access to ART for a large number of people is growing steadily, it still remains a challenge in coming as close as possible to the United Nation’s (UN’s) goal of universal access to treatment for all who need it by 2010. By June 2006 there were 6.8 million people in need of ARVs in resource-poor countries, and only 1.65 million were receiving ART [11]. As a step towards this target, The World Health Organization (WHO) and UNAIDS launched the “3 by 5” initiative with the target of providing three million people living with HIV/AIDS in low and middle income countries with ART by the end of 2005 [12]. In sub-Saharan Africa numbers of people receiving treatment increased from 100 000 to 810 000 between 2003 and 2005, mostly due to increased treatment access in a few countries such as Botswana, Kenya, South Africa, Uganda and Zambia [3].

1.2 About HIV/AIDS

HIV is a retrovirus which interacts with the immune system and results in a lifelong chronic infection. After several years the infection progresses to AIDS and induces dysfunction of nearly all elements of the immune system. This is a condition which leaves the patient in a very vulnerable situation because of the weak immune system, so the patient has low chances of recovery from any kind of infection. Diseases associated with immunodeficiency are called Opportunistic Infections (OI) because they take advantage of a weakened immune system. The majority of HIV infected people will develop signs of AIDS after eight to ten years if not treated, but the rates of the disease progression can be highly variable in infected individuals. Due to long incubation period of HIV many people do not become aware of their infection until years after

exposure and HIV transmission. This makes it difficult to measure the extent of sexual transmission and the relatively higher risk of transmission for females compared to males [13].

Development of HIV antibodies usually takes place six weeks to three months after a person has become infected. This is referred to as seroconversion. At this point some people may experience a glandular fever-like disease. Any HIV test during this time, based on the presence of HIV antibodies, may fail to give correct results due to delay in development of the antibodies.

Though the most widely accepted explanation among scientist is that AIDS is caused by HIV, there is a small group of academics who do not believe in an association between HIV and AIDS, or who question the validity of evidence of the virus's existence. The Perth Group (Perth Hospital, Australia) is an example of academics of this opinion. They have questioned the existence of the virus by claiming that HIV has never been isolated. The issue of ARVs has also caused controversy as some academics have stressed the toxicity and denied the value of such medication. A professor of pharmacology has stated the following: "I think Zidovudine [AZT] was never really evaluated properly and that its efficacy has never been proved, but its toxicity certainly is important. And I think it has killed a lot of people. Especially at the high doses. I personally think it not worth using alone or in combination at all." [14]

1.3 HIV/AIDS in Africa

Africa is hard hit by HIV/AIDS and sub-Saharan Africa is the region in the world that has been most heavily affected by the HIV/AIDS pandemic. Since the beginning of the epidemic, more than 15 million Africans have died from AIDS. The majority of the people living with HIV/AIDS in Africa are in their most productive working ages, between the ages of 15 and 49 [15]. To reverse the AIDS crisis in Africa there is an urgent need for greater coordination and commitment among governments, communities, donors and international organisations to turn principle into action on the ground. This was highlighted at the 14th International Conference on AIDS, and emphasised by the UNAIDS Executive Director, Dr. Peter Piot, who stated that: "Africa is still facing an unprecedented AIDS crisis. The reality is that in sub-Saharan Africa over three million people were newly infected with HIV in 2005 – that's 64% of all new infections globally and more than in any previous year of the region. Young people are making up half of these new

infections. (...) Increased coordination and scale up of HIV prevention and treatment programmes is needed urgently to turn the tide on AIDS in Africa.” [6]

1.4 HIV/AIDS in South Africa

1.4.1 History of HIV in South Africa

South Africa has the highest number of people living with HIV/AIDS in the world, and is one of the countries with the highest prevalence of HIV infected people [15]. The AIDS epidemic is said to be one of the greatest challenges confronting South Africans [10], and HIV/AIDS accounts for 30% of all deaths in South Africa. This makes it the single largest cause of death in the country [16].

According to the available data, based on the results of HIV tests, the prevalence was low during the 1980s and increased to a very high level during the 1990s. The first case of HIV diagnosed in South Africa was in 1982. During the first few years of the epidemic, the cases were mainly among homosexual men. In 1990, the first antenatal surveys to test for HIV were carried out and 0.8% of women were found to be HIV positive. Since 1990, antenatal testing has been carried out annually. In 1991 the number of heterosexually infected people equalled the number of homosexually infected. The prevalence at this time was 1.4%. During the years from 1993 to 1999 the documented prevalence increased from 4.3% to 22.4% [17]. Numbers from UNAIDS/WHO AIDS epidemic update December 2006 reports that HIV prevalence among pregnant women has reached 30.2%, which is the highest level in South Africa to date [5]. Prevalence is highest among women aged 23-34 years. According to this update, the worst affected province in the country is KwaZulu-Natal, where the prevalence of HIV-positive pregnant women has reached 40%. Due to lack of infrastructure, it is difficult to get a clear picture of the HIV/AIDS prevalence. There is also a problem with regard to the validity of the common method of measuring HIV prevalence, since this is based on HIV test results from pregnant women who attend antenatal clinics. Therefore, prevalence estimates are based on results from sexually active women only. Some areas lack the availability of Antenatal Clinics (ANC) and not all pregnant women will be required to undergo HIV testing. The extremely rapid growth in HIV seroprevalence may result from several conditions that are all determinant for exposure to disease. Such influencing factors are social inequalities in income and employment

status, mobility such as mass resettlements of populations under apartheid, seasonal labour migrations, trade, refugees fleeing; and sexual violence [18].

1.4.2 South Africa's response to the HIV epidemic

The South African Department of Health provides ART free of charge for infected people, but the demand is still greater than the serving ability. The latest update for South Africa pointed out that the estimated number of people in need of ARVs by the end of 2005 was 983 000 people while only about 235 000 received treatment at that point [15].

The African National Congress has played a major role in the development of South Africa's national HIV/AIDS policies. The National AIDS Coordinating Committee of South Africa (NACOSA) was established in 1992 after a conference on AIDS which was brought together by the ANC and the apartheid government's National Department of Health. The progress of the NACOSA AIDS plan was assessed in 1997 by the South African National STI and HIV and AIDS Review. Built on this review, identifying strengths in the response and highlighting areas for further strengthening and improvement, the government launched its five-year Strategic Plan for HIV and AIDS in 2000. The four key areas of interventions in the Strategic Plan were: (1) prevention; (2) treatment, care, and support; (3) research, monitoring and surveillance; and (4) legal and human rights. One of the overall goals in the strategic plan was minimising the impact of HIV/AIDS on individuals and families, and improving care and treatment for infected and affected people. To achieve their goals the government outlined the following general strategies: use appropriate Information, Education and Communication (IEC), increase access to Voluntary HIV Counselling and Testing (VCT), improve Sexually Transmitted Infection (STI) management, and improve care and treatment for HIV infected and affected people. Capacity building through training was one of the key strategies for support of the National HIV/AIDS programme [19]. In 2000, the South African National AIDS Council (SANAC) was formed and brought together government and civil society. In 2003 the Cabinet instructed the South African Department of Health (DoH) to develop a detailed operational plan on an antiretroviral treatment programme [20].

HIV/AIDS has been highly politicised in South Africa. Statements and action from political leadership concerning the disease and response to it have contributed to controversies between the government, national and international scientists, and HIV activists. Controversial statements from political leadership ranges from the President publicly questioning the link between HIV and AIDS, the minister of health's declaring AIDS to be a notifiable disease, the announcement that neither AZT nor NVP would be provided to pregnant HIV-positive women, and warnings about the toxicity of ARVs [21]. The government's response to HIV/AIDS has been criticised by individuals and NGOs, like the Treatment Action Campaign (TAC) for not taking sufficient responsibility as shown by the statement: "Absence of strong committed leadership has compromised an effective response to the epidemic" [18].

1.4.3 Health care system in South Africa

Like most countries in southern Africa, South Africa has built its health care system around Primary Health Care (PHC) principles. This means that local clinics offer first-level care and refer patients to hospitals when necessary. Since the HIV/AIDS epidemic struck, many clinics have been upgraded to provide VCT. In South Africa, clinics have been upgraded as part of the prevention programme [22].

South Africa is one of the most inequitable countries in the world, which reflects the social and economic inequities that exist at global level. A large inequity in the distribution of human and financial resources exists between the public and the private health sector. There is also an inequitable distribution of resources between the rural poor provinces and urbanised provinces. The private sector serves those of the population who can afford health insurance, which is less than 20% of the population. In spite of the small part of the population who are able to benefit from this, the private sector employs more than 70% of the health care specialists and consumes more than 60% of the health care budget [23]. For the public sector there is a district-based health care system to ensure local level control of health services. Public healthcare is free to pregnant women and children under six years; others pay on a means-tested, fee-for-service basis. The public health sector includes general hospitals, specialised hospitals, PHC centres and support institutions, and serves about 80% of the population [23].

1.5 Antiretroviral therapy

1.5.1 Combination therapy

Adequate antiretroviral therapy (ART) for treatment of HIV infected patients consists of a combination of at least three different ARVs. ARV medicines are classified as Protease Inhibitors (PI), Nucleoside Analogue Reverse Transcriptase Inhibitors (NRTI), Non Nucleoside Reverse Transcriptase Inhibitors (NNRTI) or Fusion Inhibitors (FI) based on how they function. Zidovudine (AZT/ZDV) was the first ARV to be approved by the Food and Drug Administration (FDA) in 1987, and in 1996 the efficacy of combining two or more ARVs became known [24]. The need for a combination therapy is due to the high incidence of resistance development of the virus if not sufficiently suppressed, and standard treatment guidelines at present advocate the combination of at least three ARVs. Antiretroviral therapy for treatment of HIV infection has improved steadily and to date there are a total of 21 ARVs approved by FDA for use in the United States [25]. Especially in developed countries, new medicines are being approved that offer more dosing convenience and improved safety profiles, and some previously frequently used medicines are now being used less often as their disadvantages become better defined and there are more options [25].

1.5.2 ARVs available in South Africa's public health sector

There are eight ARVs available in the public sector in South Africa, and they make up the following two treatment regimens [26]:

Treatment regimen 1:

Stavudine (D4T) + Lamivudine (3TC) + Efavirenz (EFV) or Nevirapine (NVP)

Treatment regimen 2:

Zidovudine (AZT, ZDV) + Didanosine (DDI) + Lopinavir, Ritonavir (LPV/r)

Fixed combination therapy is not used in the public sector in South Africa. The limited selection of ARVs in the public sector prevents the opportunity for individualised treatment and according to the national guidelines all HIV patients will be initiated on treatment regimen 1 when eligible

for treatment. The national guidelines also direct that patients who fail on the second line treatment continue until there is no further clinical benefit from the treatment [26].

1.5.3 Costs and availability of antiretrovirals

The costs of ARVs are of great importance for availability of ART, especially in developing countries. In developed countries, pharmaceuticals are often publicly funded through reimbursement and insurance schemes, whereas in developing countries, typically 50-95% of medicines are paid by the patients themselves. Thus prices of medicines have direct implications for access in developing countries. In 1998 the Pharmaceutical Manufacturers Association and 39 drug manufacturers brought legal action against the South African Medicines and Related Substances Control Amendment Act, regarding compulsory licenses and parallel imports, which would allow the government to procure essential drugs at cheaper prices [21]. When new medicines are protected from low-cost competition for 20 years by patent, resource-limited countries are deprived of these medicines for that period. The most important mechanism for pushing the prices down is generics competition, price negotiation, differential pricing and pool procurement [27]. Within a few years, the prices of ARVs have been reduced to a great extent, leading to increased access for ART in low- and middle-income countries. Prices of ARVs are to a great extent determined by competition between different manufacturers. In four years the price for a triple combination of ARVs has been reduced from \$10 000 per year per patient in US to \$200 per year per patient today [28].

DOHA agreement

The World Trade Organisation (WTO) adopted the DOHA agreement in 2001, which asserts that the least developed countries have the right to exclude pharmaceutical products from patenting until 2016 to address the public health crisis, including HIV/AIDS. Producers of generic drugs and major pharmaceutical companies agreed to reduce the prices. [17]. Due to falling ARV prices, new sources of international funding and growing political commitment, provision of treatment for Africa's HIV-positive people is an achievable goal [29].

1.5.4 Challenges in providing antiretroviral therapy

Immense challenges are associated with treatment and care for HIV/AIDS patients in resource-limited settings. HIV patients who present with serious AIDS defining illnesses would in developed countries be of specialist's concern, whereas in most African countries the resources available for the care of such patients are limited or frequently nonexistent. It has been claimed that money available is often not spent efficiently within expected time frames because of lack of visionary leadership, inadequate human resources, poorly developed business plans, or multi-tiered bureaucracy. Still, based on studies to date, it is suggested that with appropriate training and supervision, adherence to ART in resource limited settings will be possible [30].

Adherence challenges

In the recent years there has been an intensive discussion about the safety of providing Highly Active Antiretroviral Therapy (HAART) in resource-constrained settings and whether or not sufficient level of adherence can be achieved. One major risk associated with ART is ARV resistance, and the only way to avoid this is to adhere strictly to therapy [31]. Studies have identified drug-resistance in up to 21% of persons newly infected with HIV in Europe [32]. It is stated in an article on antiretroviral therapy in Africa that adherence to drug treatment is lower in Africa than in industrialised nations, and that there is no reason to suppose that resistance problems encountered in industrial countries will not occur in developing countries also [31]. Due to serious adverse effects, pill burden, lack of knowledge and stigma related to being HIV positive, HIV patients face other barriers than non-HIV patients, both regarding acceptance of the diagnose and adherence to treatment. The use of traditional medicine in many African countries also provides a barrier to both acceptance of, and adherence to, an ART regimen. To minimise the chance of negative effects as a result of poor adherence, a strategy involving use of supporters has been widely adopted. Use of supporters has been shown to improve adherence among HIV-positive patients, and is one of the requirements in the National Antiretroviral Treatment Guidelines for South Africa [26]. Requirement for a supporter ensures that the patients disclose their HIV-positive status to at least one person who can help them adhere to the treatment regimen.

Another approach to increase adherence is Directly Observed Treatment (DOT) strategy. DOT strategy has been studied in Haiti and the outcomes showed that a high degree of adherence was obtained [21]. Though this approach was successful in Haiti, other studies have found that DOT has been met with varying success in African countries. In Trinidad and Tobago people were not willing to let the health care worker come to their home [33]. An operational research study from Kenya studied the health care workers' and the clients' perceptions of whether a modified Directly Administered ART (DAART) approach should be conducted in the clinic or at the patient's home. More than 75% of the clients preferred to have the follow-up and observation at a health facility rather than at home due to greater confidentiality and perception of better care [34]. A study of the Senegalese government HAART initiative has looked into the feasibility, effectiveness, adherence, toxicity and viral resistance, and concludes that results are comparable to those in western countries [35]. Another study of HAART among Senegalese adults has shown that adherence can be as high in Africa as generally observed in industrialised countries, but the type of drug regimen must be taken into account [36].

Lack of health care professionals

Africa is home to 11% of the world's population and carries 24% of the global disease burden, with only 3% of global health workers. This shortage is one of the most serious problems facing antiretroviral treatment programmes [37]. Health professional resources and access to them are determinant for the development and maintenance of programmes aimed at treating and caring for patients living with HIV. Skilled health care professionals are offered better working conditions and better salary abroad, which leads to a drain of human resources from nations with declining HCPs. The WHO regional Director General for Africa, Dr Luis Sambo, says that: "Africa must reverse today's dramatic health situation by investing massively in its health workers." It is estimated that rates of health worker migration range from 8% to 60% in African countries [38].

1.6 Impact of HIV in South Africa

1.6.1 Stigma and discrimination

Social responses of fear, denial, stigma and discrimination have accompanied the epidemic since HIV and AIDS was identified. The stigma stems from fear, partly due to lack of knowledge, as well as associations of HIV/AIDS with disease and death, and with behaviours that may be illegal, forbidden or taboo. This has led to prejudice against the groups most affected, as well as those living with HIV/AIDS. Many individuals affected or believed to be infected have been rejected by their family, their loved ones and the community. The association of HIV/AIDS with stigmatised behaviours combined with lack of knowledge, can lead to people becoming fearful of undergoing an HIV test, and hence contribute to the spread of the epidemic, as many infected people are unaware of their status and do not take precautions. When blaming certain groups or individuals, the society may fail to take sufficient responsibility for the affected individuals, who are often seen as punished with the disease because of their shameful behaviour or irresponsibility [38].

A study conducted of concerns about stigma among Eskom workers in South Africa shows that workers worry more about stigma from co-workers than discrimination within the workplace. Many respondents in the study believe that HIV/AIDS is a punishment for bad behaviour [39]. Stigma and discrimination has a great impact on the lives of HIV-positive people and this is elucidated by the incident of a South African AIDS activist who was stoned to death in 1998 after announcing her HIV-positive status publicly on World AIDS Day [40].

1.6.2 Impact on households

Presence of AIDS often leads to households disintegrating, as parents die and children are sent to relatives for care. Even though no part of the population is unaffected by HIV, it is often the poorest sectors of society that are most vulnerable to the epidemic, and for whom the consequences are most severe. Individuals who would have provided the household with income are prevented from working either because they get ill themselves, or because they are caring for others. Among HIV affected households in Africa, the main coping strategies adopted are reported to be: (a) use of savings/take on debt; (b) assistance from other households and (c) changes in composition of households [15].

In a study on effects of HIV/AIDS on households in South Africa it is reported that affected households suffer from loss of income and lack of food. Approximately 22% of children under the age of 15 years have lost a parent and 12% of the households have sent children away to live with other caretakers. More than 40% of caregivers took time off from work or school to care for the ill person and only 50% of the respondents publicly acknowledged that the sick person they were caring for had HIV/AIDS. The researcher concluded that some of the long-term consequences of the HIV epidemic are: deepening poverty among the already poor; disruption and premature termination of schooling for children, especially girls; increasing childhood malnutrition and increasing strain on extended family networks. Few of the families reported that they received governmental grants. Among HIV affected households, an average of 34% of monthly income was spent on health care, compared to an average of 4% spent on health care in non-HIV households [41]. Another study from South Africa shows that households where an adult has died from AIDS are four times more likely to disintegrate than those households where no deaths have occurred [42].

1.6.3 Impact on the economy

HIV/AIDS has played a more significant role in the reversal of human development than any other single factor. One such outcome is the negative impact on economies, which also makes it more difficult for countries to respond to the crisis. In disadvantaged communities the limited access to general treatment and care exacerbates the negative effects of HIV/AIDS. Loss of human resources and the negative effect on the economic development affects Africa's ability to cope with the epidemic. Many African countries were already struggling with development challenges, debt and declining trade before HIV/AIDS worsened the economic situation. "By making labor more expensive and reducing corporate profits, AIDS limits the ability of African countries to attract industries that depend on low-cost labor and makes investments in African businesses less desirable. It therefore threatens the foundations of economic development in Africa" [29]. As labour supply and productivity decreases, the government income declines, but at the same time the government is pressurised to increase their spending on health care services as a result of rising prevalence of AIDS. In sub-Saharan Africa, the annual medical costs of AIDS is estimated to be US\$ 30 per capita [4], and cost of ART per patient in poor countries with

special agreements is estimated at a minimum of US\$148. In comparison, the overall spending on public health in most African countries is less than US\$ 10 [15].

The HIV/AIDS epidemic has threatened every economic sector in many nations. Loss of skilled workers in business and industries leads to lower profits, greater difficulty in delivering products and services, and higher costs for production, training and insurance. South African companies report that HIV/AIDS is having a significant negative effect on profits [15]. Due to these devastating consequences of the epidemic, some companies, like Eskom in South Africa, have started to implement HIV/AIDS prevention, care and treatment programmes for their workers [39]. It is estimated that without efforts to combat the HIV/AIDS epidemic in South Africa, the country will face a complete economic collapse within three generations [21].

1.6.4 Impact on health sector

In all affected countries, the HIV/AIDS epidemic brings additional pressure on the health sector. The demand for care of patients is growing steadily as HIV infection progresses to AIDS, which leads to an increase in hospitalisations. This in turn has a negative impact on the quality of care provided in hospitals, with shortage of beds, medication and trained staff. In sub-Saharan Africa more than half of all hospital beds are occupied by people with HIV-related diseases [15], and in South Africa, HIV/AIDS is a major cause of hospital admissions. Research in South Africa has estimated that patients affected by HIV/AIDS on average stay in hospital four times longer than other patients [30].

The epidemic forces governments to increase their spending on health care. However, the public health care spending in South Africa has not increased according to growth in Gross Domestic Product (GDP), but rather declined as a percentage of GDP. South Africa spends 8.7% of the GDP on health, and inequities exist. The private sector share is 5.2% while public sector share, which counts for 80% of the population is 3.5% [43]. Large inequalities in per capita expenditure on primary health care also exist between provinces. Funding of primary health care (PHC) in South Africa for 2003/04 ranges between ZAR75³ in Limpopo and ZAR246 in Northern Cape. Eastern Cape was second lowest with regard to funding of PHC, spending ZAR106 per capita.

³ ZAR100 = US\$15.5 (Cited 20.11.2006. Available from: www.dnbnor.no/person/kalkulatorer_og_verktoy/)

In Eastern Cape the total spending on ARVs for 2005 was about ZAR19 million. This places ARVs on top of the ABC analysis⁴ in the province [44].

1.7 International mobilisation to fight HIV/AIDS

1.7.1 International initiatives for improvement of health

The inequality in health was addressed in 1978 on the International Conference on Primary Health Care, Alma-Ata, with an aim for health for all by year 2000 [1]. In the Alma-Ata declaration it was stated that: “All governments should formulate national policies, strategies and plans to launch and sustain primary health care as part of a comprehensive national health system in coordination with other sectors. To this end, it will be necessary to exercise political will, to mobilise the country’s resources and to use available external resources rationally.” [45] An analysis of the complex interrelation between poverty and AIDS states that though the target of health for all was not reached, the resources to win this war are not lacking. It further states that the concept of PHC has not failed. What has failed is rather the political will of ensuring that PHC goals were achieved through a more equitable redistribution and use of the world resources [1].

A declaration of commitment on HIV/AIDS was adopted at the UN General Assembly Special Session in 2001. Leaders from 189 member states committed themselves to comprehensive, time-bound targets for the delivery of effective HIV prevention, treatment, care and support needed in order to reverse the global epidemic by 2015. The failure of delivering ART to people is a global health emergency which has been addressed by WHO’s “3 by 5” initiative. 21 countries have reached the target of providing treatment for at least 50% of those who need it by 2005. But according to the report there are still significant weaknesses in the response to HIV, especially with regard to prevention programmes that are failing to reach those at greatest risk, and failing to meet the aim for educating the majority of young people about HIV. Half of the countries submitting reports to UNAIDS acknowledged the existence of policies that interfere with the accessibility and effectiveness of HIV-related measures for prevention and care, such as laws

⁴ ABC Analysis assembles data from recent or projected procurements to determine where money is actually being spent, allowing managers to focus first on high-cost items when considering ways to reduce procurement costs.

criminalising consensual sex between males, prohibiting condom and needle access for prisoners, and using residency status to restrict access to prevention and treatment services [3].

In March 2006, with participants from 52 African countries, the Brazzaville commitment was adopted with the purpose of scaling up a comprehensive HIV response in Africa. The meeting was organised by the African Union (AU), with support from UNAIDS, Economic Commission for Africa (ECA), WHO and the Department for International Development of the UK Government. The commitment sets a concrete agenda for action to scale up comprehensive HIV responses in Africa. The agenda includes developing national account systems to monitor expenditure and resource allocation to accelerate the achievement of the target, facilitate reliable supply of ARVs, and to strengthen relevant policies [46].

1.7.2 ARV design in resource constrained settings

Optimal equitable allocation strategy

Operations Research⁵ (OR) techniques have been used to determine the optimal strategy for allocating ARVs among health care facilities (HCFs) in KwaZulu-Natal (KZN) in order to satisfy the equitable criterion that each individual infected with HIV in resource-constrained regions has an equal chance of receiving ARVs. They conclude that in order to achieve the greatest degree of equity for individuals with HIV in KZN, the HCFs should serve a region of 40 to 60km, and they suggest the use of mobile clinics. An increased number of HCFs is recommended, and all available health care facilities should be used. The Optimal Equitable Allocation Strategy (OEAS) was compared with two other ARV allocation strategies:

- a) Allocating ARVs only in the urban areas and
- b) Allocating ARVs equally to all HCFs.

The results showed that the OEAS improved equity in treatment accessibility compared to the two other ARV allocation strategies [47].

⁵ OR, also called “delivery system research”, refers to subjects and disciplines supporting the design and improvement of the systems that allow effective prevention, treatment and care reach those who need it. World Health Organization, The World Health Report 2004 – Changing History, chapter 5. Available from: <http://www.who.int/whr/2004/chapter5/en/index4.html> (Cited: 05.09.2006)

Equity challenges

When designing ART programmes where resources are scarce there are challenges concerning equity. These challenges stem from an inequitable distribution of human and financial resources and are reinforced by political inconsistency. When working towards universal access to ART in poor settings, different aspects need to be addressed. These aspects are: criteria for selection of those eligible for treatment; adherence to ARVs; monitoring ART for safety, effectiveness and acceptability; sustainable financing of ARVs and requirement for governments to commit for a long time; risks needed to be prepared for. The discussion is now shifting from ethical and philosophical concerns to practical and concrete steps to be taken and critical issues to be considered [48]. The WHO and UNAIDS have identified three core principles that should underlie every effort to fairly distribute ARVs: Urgency, equity and sustainability [12].

When only a small portion of patients eligible for treatment can access it, due to limited resources and health care in short supply, different rationing strategies are applied to decide how scarce resources can be most equitably distributed, e.g. targeting specific populations (HIV-positive mothers or new infants, health care workers, teachers, poor people), restrictions by geographical area, co-payments and “first come first serve”. Different ways of rationing ART will have different social and economic consequences for African populations. Understanding these outcomes is important for making decisions that will help combat HIV/AIDS and to sustain economic development [49]. Some prioritise the sickest to receive ARVs first. Others argue that it’s better to prioritise those who will respond better to treatment, which are generally not the sickest patients [50].

1.7.3 The World Bank's Global HIV/AIDS programme: Elements of effective programmes

A survey of experience in provision of ART in developing countries has shown that successful programs rely on [51]:

1. Simplified, standard regimens of fixed dose therapies
2. Simplified clinical monitoring
3. Provision of consumer-friendly adherence support
4. Maximum use of human resources (including non-professionals, families, and community members)
5. Active community involvement
6. Integration and phased scale-up

1.7.4 Need for health research

Health research is necessary to give evidence based recommendations on how to combat poor health and disease, and operational research (Appendix 1) carried out in the initial stages of the ART programme is crucial for the scale up of the universal access to ART and development of new treatment sites. As the scale up for universal access to ART expands, new treatment sites for ART will develop. It is important to document the work carried out to determine future requirements in effectively implementing the ART programme in resource-constrained settings.

1.7.5 Antiretroviral therapy programme in Grahamstown, South Africa

The Antiretroviral treatment programme was initiated in Makana Local Services Area (MLSA), Eastern Cape in 2004. After initiation of this programme, operational research has not been conducted to identify and document how different HCPs work together and provide treatment and follow-up for the HIV patients enrolled on this programme.

2 Purpose

2.1 Objectives of the study

The objectives of this study were to conduct operational research to:

- a) Analyse the role of the different HCPs in antiretroviral treatment and follow-up of HIV patients at Makana Local Services Area (MLSA)
- b) Based on the above findings, identify facilitating and constraining factors of the present system operating in MLSA

The aim is also to provide the different units of the health care system with information about the current work carried out in Grahamstown's public sector based on the findings of the study.

3 Material and method

3.1 Setting

This study was conducted in Grahamstown, which is part of Makana Local Services Area sub-district in Cacadu district, the Eastern Cape Province of South Africa. Figure 1 shows a map of the nine provinces of South Africa.



Figure 1: Map of South Africa

3.1.1 Health care services provided in Makana Local Services Area

The MLSA public health system consists of three hospitals and 33 clinics (including mobile clinics). Patients who are diagnosed with a chronic disease are ideally referred from the local clinic where they present with their problem, to the PHC centre or the local hospital for therapy and monitoring. When stabilised on treatment the patients are referred to the clinic closest to their home for continued treatment and follow-up monthly. This system is referred to as a referral system, which is also the structure that has been adopted for the ART programme. The health care facilities providing ART in Grahamstown's public sector are shown in table 1.

Table 1: Health care facilities providing ART for HIV-positive patients in Grahamstown

Hospital:	Settlers Hospital (down-referring site)
Primary Health Care Centre:	Settlers Day Hospital
Primary Health Care Clinics	Ragland Road Clinic Anglo African Clinic Joza Clinic V. Shumane (Tantyi Clinic) Middle Terrace Clinic N. G. Dlukulu (Extension 7)

3.1.2 Distribution of Health Care Professionals in public sector in Grahamstown

The operating referral system is organised in such a way that the majority of human resources with higher education (specifically physicians and pharmacists) are located in the hospital and the PHC centre, whereas down-referral clinics are operated by a team of registered nurses and support staff⁶. A doctor is available in the clinics on specific dates, and in case of complications there is an opportunity to either refer patients to hospital, or request patients to come back on the specific date when the doctor is available.

3.2 Material

3.2.1 Observations

One hospital and two down-referral clinics were the basis for the observational studies, as shown in table 2.

Table 2: Observational studies carried out in Grahamstown's public health sector

	Name of health care facility
Referring treatment facility:	Settlers Hospital
Down-referral clinics:	Settlers Day Hospital Raglan Road Clinic

3.2.2 Pilot study

Eleven informants were included in a pilot study of the questionnaire. To include the variety of health care professionals involved with HIV-positive patients in Grahamstown, the following professions were included in the pilot study: pharmacists, nurses, community health workers and a dietician.

⁶ Including the categories: community health worker, community care worker, clinic assistant, health educator

3.2.3 Semi structured interviews

The informants for the questionnaire consisted of 6 males and 49 females, all South African. Of these, 78.2% had been working with HIV-related work for more than one year. The working experience in the area of HIV/AIDS ranged from two months to 20 years.

The sampling frame for the structured interviews, as shown in table 3, consists of all categories of HCPs involved with HIV patients in governmental treatment facilities in Grahamstown. Fifty five HCPs from two hospitals and six primary health care clinics were identified as potential respondents. All the selected respondents agreed to participate in a one-on-one interview, giving a response rate of 100%.

Table 3: Participants for structured interviews (n=55)

Profession	Number
Professional nurses	23
Community health workers	15
Pharmacists	4
Health educators	3
Community care workers	3
Clinic assistants	2
Doctors	2
Social worker	1
Dietician	1
Nursing assistant	1

3.2.4 Group discussions

Group discussions were conducted with key stakeholders at the District Health Office, including: district pharmacist; clinical sister and MLSA clinic supervisor; and at Settlers Hospital, including: hospital pharmacist, programme coordinator, three doctors and a nurse. The participants in these discussion groups had been involved in the work since the preparing of the programme, or since an early stage in the roll out of the ART programme.

3.3 Method

Three methods were used in the study: observations, semi-structured interviews and group discussions.

3.3.1 Observations

Observational studies were carried out between February and March 2006 in order to document the treatment structure and to gather background information for the preparation of a structured questionnaire. Table 4 shows what the observations included at the different health facilities.

Table 4: Observational studies conducted

Name of health care facility	Observations
1. Settlers Hospital:	Dispensing of ARVs Patient/doctor interaction Patient/pharmacist; ARV counselling Patient/support staff; patient education Review meeting/ HCP cooperation
2. Settlers Day Hospital:	Patient/pharmacist; ARV collection
3. Raglan Road Clinic:	Patient/support staff; VCT (counselling) Patient/nurse; VCT (testing), screening new patients, ARV collection

3.3.2 Pilot study

A pilot study was conducted in May 2006 and only a few improvements were made to the questionnaire.

3.3.3 Semi structured interviews

Prior to the preparation of the questionnaire the researcher was introduced to management at all clinics by the district pharmacist, to inform them about the planned work. All informants for the structured interviews were contacted by the researcher at the clinic/hospital prior to the interview to inform them about the purpose of the study and to ask for their participation. Interviews were scheduled when the consent was obtained verbally, and written informed consent (Appendix 2) was obtained from each respondent on the day of the interview. Prior to the intended interview either a phone call or a personal visit to the health care facility was made to confirm the interview. The interviews were carried out between June and August 2006. Each interview took approximately 35-45 minutes to complete and was conducted by the researcher with a tested

structured questionnaire (Appendix 3). Interpreters were not essential because all respondents could speak English.

3.3.4 Permission for research

Permission to conduct the survey was obtained from Eastern Cape Department of Health (Appendix 4), Rhodes University Ethical Committee (Appendix 5), Makana Municipality Department of Health (Appendix 6) and management at the different clinics and hospitals. Access to clinics for observational studies and for interviews was allowed by the local authorities.

4 Results

4.1 HIV treatment structure in Grahamstown

4.1.1 Description of the treatment structure in Grahamstown

The following section documents the treatment structure of the ART programme in Grahamstown's public sector. This Information was gathered from observational studies conducted from February to March 2006. Observations were done at both referring and down referral health care facilities in the ART programme in Grahamstown, and details on what the observations included is specified in the section for methods, table 4.

HIV patients living in Grahamstown who use the public health care facilities are seen either at Settlers Hospital or at one of the clinics that Settlers Hospital down refers patients to, depending on which stage of the treatment programme they are in. The HIV patients seen at Settlers Hospital are the patients who are newly on treatment and those who come for check-ups with the doctor in case of complications. Figure 2 shows the public health care facilities providing ART in Grahamstown, and the treatment sites where observations were carried out are shown in yellow.

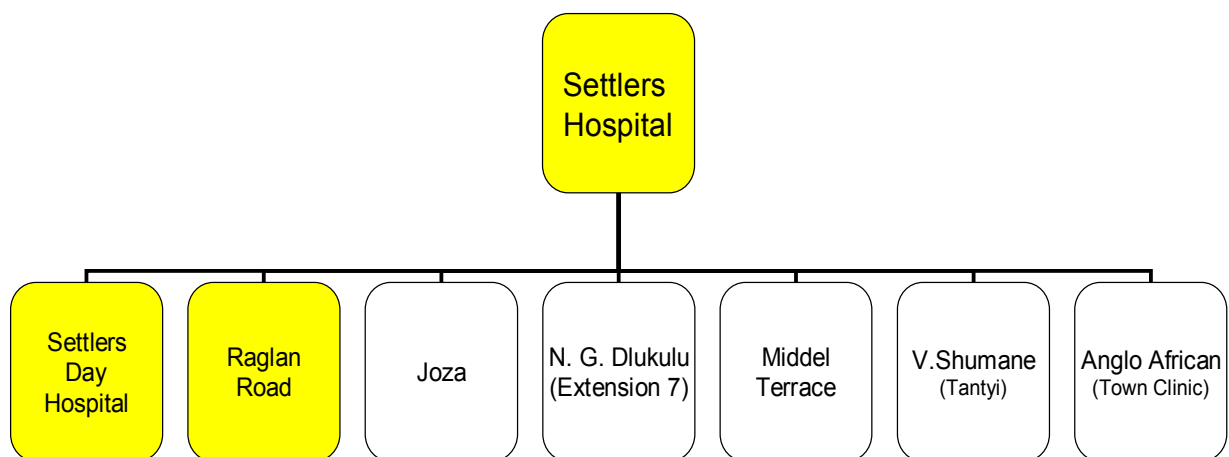


Figure 2: Public health care facilities providing antiretroviral therapy in Grahamstown

4.1.2 Health care professionals involved at different stages in the antiretroviral treatment programme

Ten categories of HCPs, as listed in table 3, are involved in the work with HIV patients in the public treatment facilities. They contribute to the patients' health care at different stages and have different responsibilities in this work. Figure 3 shows the process from the patients' point of entry to the HIV treatment programme, and at which stages the different HCPs are involved.

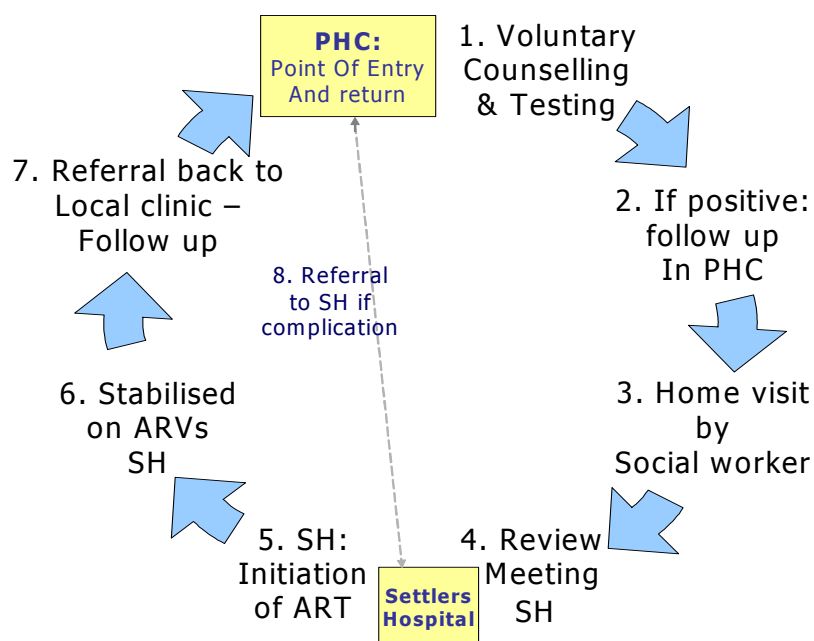


Figure 3: Structure of antiretroviral therapy programme in Grahamstown's public sector

Step 1

The patients come to their local clinic for Voluntary Counselling and Testing (VCT). Normally VCT is done on specific dates, and will be carried out the same day as the patients request it. First a pre-test counselling is done by a CHW to ensure that the patients know the consequences of the test results. The CHW discusses with the patients whether they are ready to undergo HIV testing. The tests are done by a registered nurse, and with the tests⁷ currently being used, results are available after 5-10 minutes. After HIV testing, a routine post-test counselling is done by a CHW

⁷ Pareekshak® HIV-1/2 Triline Card Test, FIRST RESPONSE HIV CARD TEST 1-2.0

who discloses the test results to the patients. During this first visit to the clinic, the patients are seen by a registered nurse and a CHW.

Step 2

The patients come back to the clinic for follow up if testing is HIV-positive. Blood sample for CD4 counts are taken every six months during the time between a positive HIV test and initiation of antiretroviral therapy. Blood samples are sent to Settlers Hospital and results are disclosed to the patients during their next visit. When the patients are in the WHO stage two (Appendix 7), they are started on antibiotic prophylaxis and trained in adherence. This is part of a patient readiness programme, which implies that the patient is not initiated on ART without being prepared for taking medication regularly.

Step 3

Before patients are started on ART, either a social worker or a CHW who has gone through specific training visits the patients at home. This is to gather information about the patients' family and economic situations, and to identify factors influencing the patients' ability to cope with the treatment and the disease. A standardised scheme is used to gather this information.

Step 4

When the home-visits are completed and patients are trained sufficiently in adherence, one of the nurses from the clinic presents the patients' cases at the weekly review meeting at Settlers Hospital. During the review meeting, doctors, nurses, the social worker and the pharmacist are present to discuss whether the patients can be initiated on ART. If a patients is ready to start treatment, the nurse is given a date for the patient to be seen by the doctor at Settlers Hospital.

Step 5

When patients have been referred to Settlers Hospital for initiation of ARV treatment, they are first seen by the doctor. While seen by the doctor they receive counselling on the disease and information about the medication and possible adverse effects. Then the medication is dispensed and the patients are provided counselling on adherence and how to use the medication, either by a pharmacist or a nurse on the same day. This counselling lasts for approximately 30-45 minutes.

The patients are given 28 tablets to last for four weeks, and are instructed to bring back any tablets left so that the pharmacist or the nurse can do a pill-count to indicate level of adherence during the patients' next visit.

Step 6

After the patients are started on ARV treatment in the hospital they are stabilised there for three to six months, based on their condition. During this time the patients return for review after two weeks, and then for check up and collection of medication monthly thereafter.

Step 7

After the stabilising period of three to six months, the patients are referred back to the local clinic for follow up and ARV collection, a procedure which is called "down-referring". There are seven down-referral clinics, which all receive ARVs pre-packed from Settlers Hospital for each patient. The district pharmacist collects the medication from the dispensary at Settlers Hospital and brings it to the different down referral clinics once a month. At the local clinic, the patients meet monthly with a registered nurses and support staff. In one of the clinics, the monthly ARV collection also includes meeting with a pharmacist. Every six months blood samples are taken to check among other among others, the patients' viral load, CD4 count, full blood count and Haemoglobin.

Step 8

Patients who receive medication at the clinic monthly are referred back to Settlers Hospital if the health worker at the clinic sees the need for an appointment with a doctor. The patients are referred to the doctor if they complain about their health and either adverse effects or poor response to medication are suspected, or if their weight drops by more than two kilograms in one month. The patients can also be referred for counselling with a dietician or a social worker if necessary.

4.2 Follow up of HIV patients in public sector

Information in chapter 4.2 through 4.4 shows the results from the semi structured interviews with HCPs at public health care facilities providing the ART programme in Grahamstown.

4.2.1 HCP characteristics

All the respondents of the questionnaire were South African. The majority of the respondents shared the same first language as the patients, either: Xhosa, Afrikaans or English. The distribution of the HCPs' first language among these three is shown in table 5. Of all respondents, 90.9% reported that they had not used a translator during the previous seven days. All respondents except three reported that they could communicate in Xhosa, and all of the respondents with English as their first language could speak either Afrikaans or Xhosa in addition.

Table 5: First languages of health care professionals interviewed (n=55)

First language	Percentage of the respondents
Xhosa	76.4%
Afrikaans	12.7%
English	10.9%

Table 3 shows the sampling frame for the study, and except for two groups this graph also represents the whole picture of HCPs involved⁸ in work with HIV-positive patients in Grahamstown's public sector at the time when data was gathered. There are only two pharmacists involved in the work with HIV patients on regular basis, while four pharmacists were interviewed. Two of the pharmacists who were interviewed were involved in this work with HIV earlier, or they contributed to the work only when it was needed. Two support staff were identified after data collection, and they were not asked to participate in the study.

⁸ Based on information from management at each health care facility and district office department of health regarding which of the HCPs are involved in the work with HIV-positive patients

4.2.2 Patient and Health Care Professional interaction

4.2.2.1 HCP involvement

Figure 4 shows how many of nurses and support staff that were involved in the different work tasks and table 6 shows the share of nurses and support staff who reported doing these different work tasks.

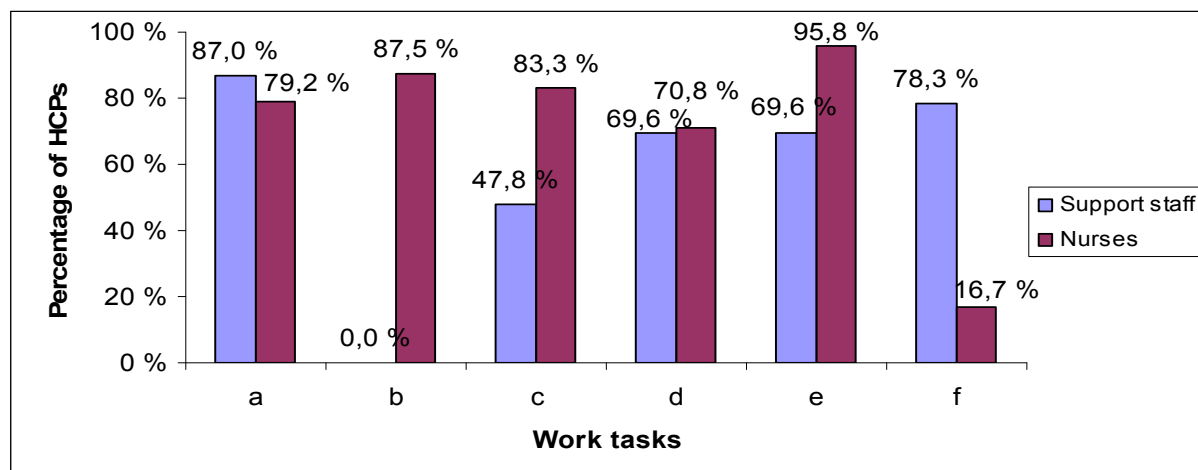


Figure 4: Nurses and support staff's different work tasks : a) Counselling in VCT, b) Testing in VCT, c) ARV collection, d) Counselling of patients starting on ARVs, e) follow-up between testing positive and initiation of treatment, f) Home visits

Table 6: Number of health care professionals involved in different work tasks (n=55)

Work task	All respondents	Nurses	Support staff
Counselling in VCT	40	19	20
Testing in VCT	22	21	0
ARV collection	36	20	11
ARV counselling	38	17	16
Follow up prior to ART initiation	43	23	16
Home visits	24	2	18

The time that HCPs spent with patients differed for first-time and follow-up visits. As shown in figure 5, more time was generally spent with the patients during their first visit than during follow up. For first time visits, time spent varied between less than ten minutes and over an hour. Within this time range, 25-40 minutes was the most frequently reported time spent for first-time visitors. Time spent for follow up visits ranged from less than ten minutes to 45-60 minutes. The most frequently reported time spent for follow up visits was 10-20 minutes.

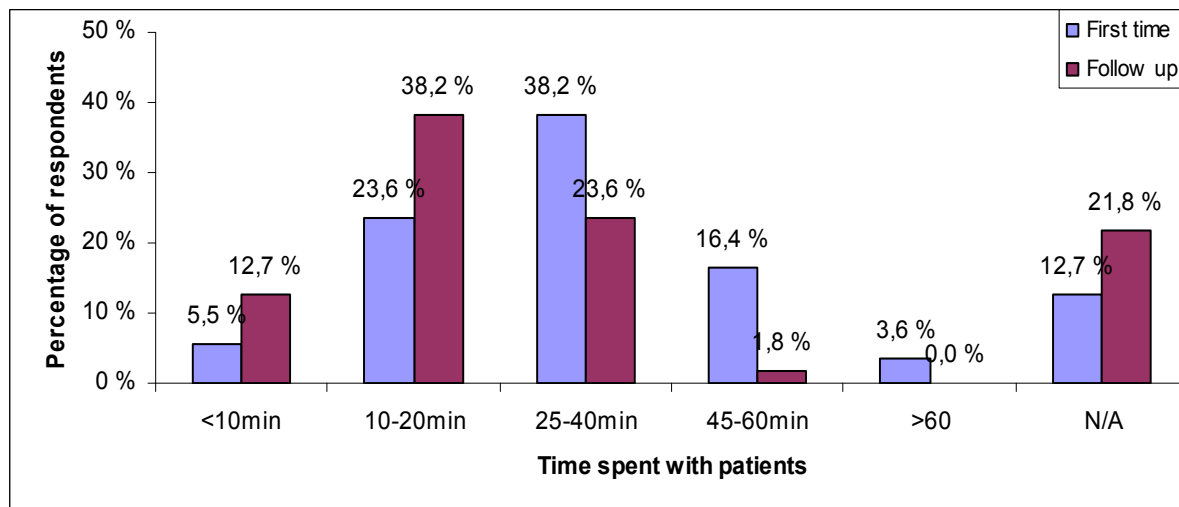


Figure 5: How much time health care professionals spent with patients during first-time and follow-up visits

The respondents reported that patients generally came to the health care facility without appointments, and only for ARV collection were patients supposed to come on specific “to come again dates”. Some of the HCPs emphasised that they encouraged patients to come back to the clinic before the scheduled date if they experienced any problems, and 96.4% of the respondents reported that the patients could meet them without an appointment. One nurse reported that she thought one of the most important issues to talk about with the patients was for them to come back if they experience problems. Many of the respondents reported familiarity with the patients on the programme, which enabled them to recognise the patients. Of all the respondents, 76.4% said that they could recognise all or most of the patients from their previous meeting.

4.2.2.2 Patient and HCP communication

Different aspects of the HCP and patient interaction were studied to identify what characterised the communication, e.g. aspects discussed with the patients, questions asked by the patients, patients’ openness towards HCPs and patients’ understanding of information given by the HCP.

Respondents identified adherence, nutrition and using condoms as the most important aspects to discuss with their patients. These three aspects were mentioned 26, 22 and 19 times respectively as shown in figure 6.

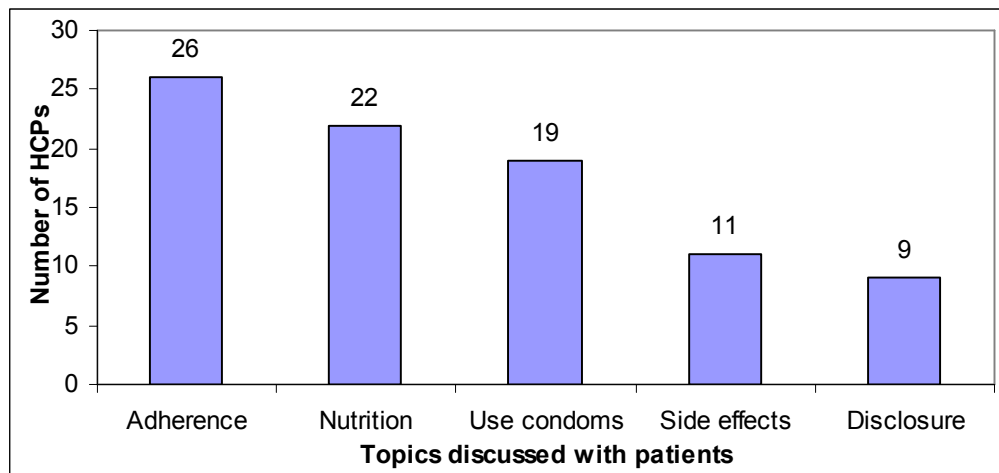


Figure 6: Health care professionals’ perception of the most important aspect to discuss with patients (n=55)

The respondents were asked which of the topics from a list (question 4.7, appendix 3) that were discussed with their previous patient. The most frequently discussed topics mentioned by nurses and support staff were diet, supporter, protection and lifestyle. The next most frequently mentioned topics after these four aspects were: adverse effects for the nurses, and grant for the support staff.

Patients and openness

Off the interviewees, 69.1% reported that none of the patients had told them about concerns with regard to treatment or the disease during the previous seven days. Further, 14.5% of the interviewees reported that one patient had told them about such concerns, and 9.1% reported that two to five patients had told them about concerns during the previous seven days. For 1.8% of the respondents it was reported that “a few” patients had told them about concerns, and for the remaining 5.5% this question was not applicable.

About half (54.5%) of the respondents reported that, during the previous seven days, patients had told them that they were more comfortable talking to one HCP than another. About half (45.5%) of the respondents also had the impression that patients were more open to one HCP than another because of the HCPs’ profession. Table 7 shows HCPs’ comments on patients’ openness, given during the interviews.

Table 7: HCPs’ personal comments on patients’ openness towards different categories of health care professionals

Sometimes you can see that the patients are more likely to talk to a nurse. No patient has told that they prefer one HCP more than the other, but after they have left the doctor they might stop and ask the nurse something they didn’t understand. Maybe they are afraid of taking up too much of the doctor’s time. They know the doctors are busy and have to see many patients.
Some patients are afraid to talk to the nurses because of their high profession.
Some patients go straight to one of the CHW because they know them better. They [CHW] visit at home and feel that the CHWs are more like their friends. Then the CHW might refer them to the nurse.
Some patients are less comfortable with the CHWs because they are afraid that the confidentiality is not kept as much.
The patients are more open to CHW because they visit them at home. They are used to them and are more comfortable with them.

Also factors other than the category of profession are seen to influence the patients’ openness to the HCP. These include trust, personality, language barriers, gender, personal relevance of knowing the HCP, personal skills and attitudes of HCPs. The diversity of the presumed influencing factors is shown in table 8, by the HCPs’ personal comments on this topic during the interview:

Table 8: HCPs’ personal comments on influencing factors for patients’ openness

Patients are not open to all, but want those involved in the ARV clinic.
Ladies want to see lady HCPs, males want to see male HCPs. Think they are more open to nurses than to CHW.
Patients are more open to those who show empathy. Personality is important, how concerned the worker is and how much the patient trust the worker.
Patients can be shy in the beginning. One Afrikaans-speaking patient might have been more comfortable with an Afrikaans speaking worker.
Who the patients are more open to is depending on personal skills and attitude.

Forty percent of the interviewees reported that none of the patients had asked any questions on their own initiative during the previous seven days. The frequency of patients asking questions is summarised in figure 7. When comparing support staff and nurses, 43.5% of support staff and 42% of nursing staff reported that no patients had asked any questions. 13% of support staff and 17% of nurses reported that a few patients had asked questions. The most frequently asked questions are shown in table 9. Comments from HCPs on why patients did not ask many questions are shown in table 10.

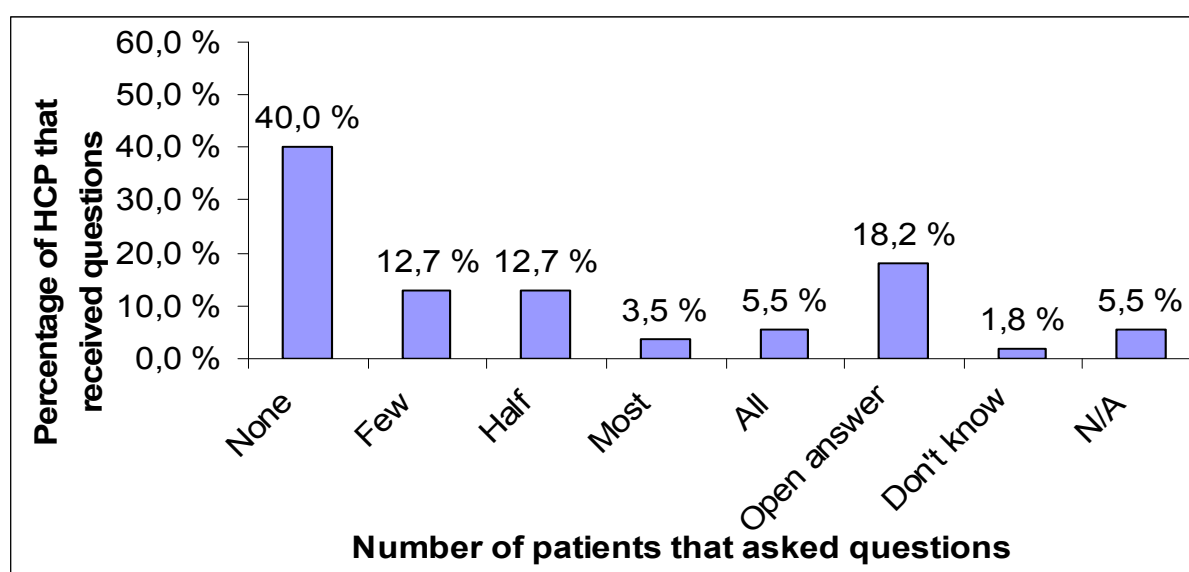


Figure 7: Frequency of patients asking questions during the previous seven days

Table 9: Health care professionals reporting on questions frequently asked by patients

Topic asked about	Frequency
Grant	63.6%
Side effects	47.3%
How to use medicines	29.1%
Other	67.3%

Topics less frequently asked about by patients, covered by “other” in table 7:

1. About the treatment, about things they’ve heard/ how they will feel.
2. Pregnancy/ breastfeeding/ PMTCT/ their children.
3. About the illness, stage of disease and CD4 count.
4. When to start treatment? How long they must take the medication?

5. Food parcels, nutrition.
6. Why they need a supporter. What to do if they don't have a supporter.
7. Why they got HIV, where it came from.
8. Blood tests.

Table 10: HCPs' personal comments on why patients do not ask many questions

Patients just accept how things are and don't ask questions.
Most aspects are covered in the counselling, so the patients don't ask about this on their own initiative, but they often ask about grants.
The patients generally don't ask on their own initiative because they we about most things. The HCPs ask questions and tell everything of importance.
Sometimes there is no time for patients to ask questions.

Feedback from patients:

When asked about the kind of feedback HCPs get from the patients to indicate if patients understand what they have been told, the most frequent responses can be classified into the following four categories, summarised in table 11.

1. The HCPs ask the patients questions or ask them to repeat. The HCP can tell by what the patients answer.
2. The HCP can tell from patients' body language and facial expression.
3. The HCPs report that they just know or can tell if patients understand.
4. The HCPs can tell by asking if patients understand, or the patients tell that they understand.

Table 11: Responses on the feedback HCPs get from patients (n=55)

Category	Frequency
1	30 of the respondents
2	19 of the respondents
3	14 of the respondents
4	6 of the respondents

Other responses on how the HCPs indicate the patients' understanding of information given can be classified into (a) initiatives from the HCPs and (b) the patients' actions. These are listed in table 12.

Table 12: Basis for HCPs perception of patients' understanding

	Action/ initiative
Initiative by the HCP	Maintain eye contact. Give room for feedback. Give space to ask. Make sure the patients understand. Talk to the patients. Some patients are crying at first. HCP checks their state when they leave. Ask someone else to translate if language barrier. The HCP knows the patients. Can see when patients appreciate something. Can see if they're anxious about something. Patients are enthusiastic when leaving. The HCP asks what she can do for the patient. Give very clear message.
Action of patients	Patients come back and say that advice was helpful. Patients express themselves well. The patients ask questions if they don't understand. Patients may come back and ask about things they didn't understand. Patients tell that they appreciated what the HCP has done. Positive response from the patients. The patients ask questions to clarify. Some patients come back and say that they are happy and have improved their health. The patients talk a lot. They respond and nod. Get feedback from most of them.

4.2.3 HIV treatment follow-up

As elaborated in section 4.1.1, the patients are introduced to the treatment programme in their local clinics before initiation of ART. After patients are stabilised on treatment, the follow up is primarily done in the local clinic where patients meet with nurses and support staff for their monthly ARV collection and check up. Figure 8 summarises nurses and support staffs involvement in the following aspects of the treatment: repeating how to take medication, handing out medication and monitoring for adverse drug reactions and adherence daily.

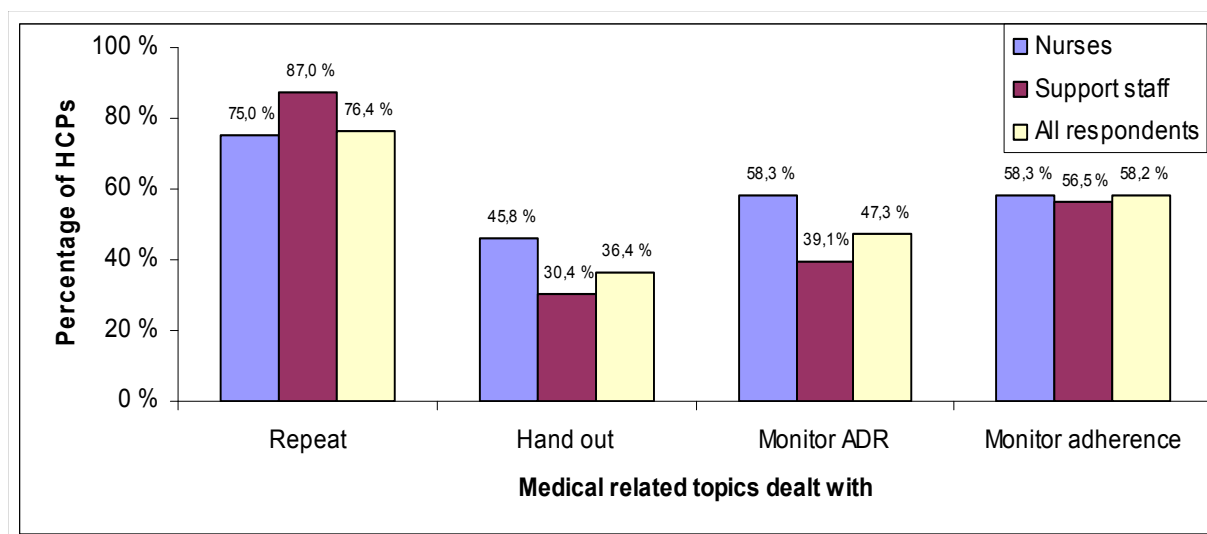


Figure 8: Nurses versus support staff in dealing with medication to HIV patients (n=55)

Graph 8 shows that 75% of the nurses and 87% of support staff responded that they repeat to the patient how to take the medication. Off all the respondents, 16.4% reported that they did not repeat how to take the medication.

About 30% of support staff handed out medication⁹ daily, while 45.8% of nurses handed out medication daily. Half (50.6%) of the support staff and 16.7% of nurses said that they never handed out medication to patients.

Adverse effects

As shown in figure 8, 58.3% of nurses and 39.1% of CHW monitored for adverse effects daily. The majority (76.4%) of all the interviewees reported that none of the patients had complained about symptoms of adverse effects during the previous seven days. Above 80% of both nurses and support staff reported that they had not received any complaints from patients during the previous seven days. Above 60% of the same groups reported that they had not met any patients during the previous seven days who received medication to treat symptoms of adverse effects. However, the pharmacist who was preparing medication for all the HIV patients collecting their medication in the different clinics estimated that about 30-40% of the patients received

⁹ either antibiotic prophylaxis or ARVs

medication to treat symptoms of adverse effects. One of the doctors estimated that 75% of the patients received medication for symptoms of adverse effects.

Adherence

As shown in figure 8, 58.3% and 56.5% of nurses and support staff monitored for adherence daily in their work with HIV patients. Table 13 shows the frequency of three different methods used to indicate adherence: pill count; asking questions and tick chart/medical diary. Pill count, which was reported most frequently, implies that the patients bring back the pill bags and the HCPs count how many tablets are left out. It was also mentioned by one of the respondents that the only way to get a more accurate indication of a patient's adherence was to do blood tests. If the patients were adherent, the viral load should be low and CD4 count should be high. Blood tests were normally done every six months and could be done more frequently if the HCP suspected poor adherence.

Table 13: Frequency of methods used to indicate patients' adherence to ART by HCPs in Grahamstown's public sector (n=55)

Method for adherence indication	Frequency %
Pill count	69.1
Ask questions	56.4
Tick chart/ medical diary	43,6
Other	9.1
No method reported used	10.9

Of all the respondents, 70.9% reported that none of the patients they had met during the previous seven days had told them that they had forgotten to take any of their medication. Table 14 shows the reports from the interviewees on the number of patients who had forgotten to take any of their medication during the previous seven days, and table 15 shows the reports on the number of patients who had told HCPs that they didn't want to continue taking the medication. 25.5% of the respondents had the impression that some patients were unwilling to take their medication, regardless of what the patients had told them, while 72.8% of the respondents believed that none of their patients were unwilling to take their medication.

Table 14: Patients reported missed doses to HCPs during the previous seven days

Number of patients forgetting to take any medication	Frequency of response from HCP
0	70.9%
1	9.1%
2	7.3%
4	3.6%
5	1.8%
7	1.8%
N/A	5.5%

Table 15: Number of patients reported to HCPs during the previous seven days that they did not want to continue with medication (n=55)

Number of patients not wanting to take medication	Frequency or reported by HCP
0	89.1%
1	3.6%
2	1.8%
N/A	5.5%

The respondents were asked about how often they had experienced that patients had misunderstood how to take the medication, and 65.5% of the respondents reported that they had not met any patients during the previous seven days who had misunderstood how to take their medication. It was reported by 25.5% of the interviewees that they had met one to four patients during the previous seven days who had misunderstood how to take the medication.

Use of traditional medication was mentioned as a possible reason for patients not wanting to take their medication, and therefore not being adherent. Opinions from group discussions were that stigma had not been as problematic as first expected, though HCPs from down referral clinics pointed out that many patients had problems with disclosure and were afraid of being stigmatised. Respondents report that patients were generally more afraid of ARVs in the beginning because of things they had heard about the treatment.

4.2.4 Health Care Professional cooperation

4.2.4.1 Communication between HCPs

The respondents were asked who they confirmed with if the patients were complaining about symptoms of adverse effects. Of the support staff, 91.3% reported that they would confirm with a nurse, and 87.5% of the nurses reported that they would confirm with a doctor. Figure 9 shows the number of times that nurses and support staff asked other HCPs for advice during the previous seven days while a patient was waiting.

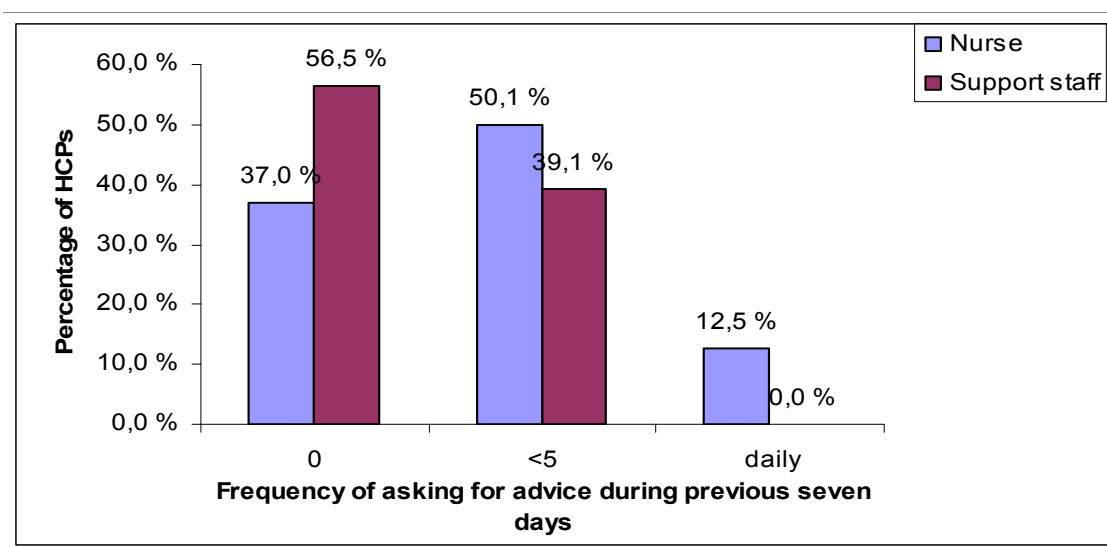


Figure 9: Nurses versus support staff in asking for advice (n=55)

Half of all the respondents (49.1%) had not asked for advice while dealing with a patient during the previous seven days, 40% of the HCPs had asked for advice one to five times and 1.8% of the respondents asked for advice daily.

Table 16 shows the frequency of the participation in HCP interactions, varying from informal discussions about the patients to scheduled weekly meetings with other HCPs. One-third of the nurses had participated in meetings during the previous seven days due to their work with HIV patients.

Table 16: Health care professionals discussing of patient cases (n=55)

Type of HCP cooperation:	Frequency
Discuss patient case while patient is waiting:	85.5
Discuss patient case after patient has left	87.3
Review meeting, Settlers Hospital	41.8
ARV clinic Friday meeting	18.2
Ward round, Settlers Hospital	10.9
ARV task team meeting	32.7
Attended scheduled meetings during previous seven days due to work with HIV patients	27.3

The respondents who reported that they sometimes discussed difficult patient cases with colleagues were asked to quantify how many times during the previous seven days they had discussed such a case. Table 17 shows the frequency of such discussions reported by the HCPs:

Table 17: Frequency of discussing difficult patient cases with colleagues during the previous seven days (n=55)

Frequency of discussions	Percentage of HCPs
0	41.8%
1-4	47.2%
Daily	5.5%
Many	1.8%
Most of them	1.8%
N/A	1.8%

4.2.4.2 Referring of patients:

It was reported by 33 of the 55 HCPs that they had done one or more referrals due to problems of a kind that was beyond the HCPs' competence during the previous seven days. Of these respondents, 25 were HCPs working in down referral clinics. Of a total number of 45 respondents from down referral clinics, 20 reported that they had not made any referrals during the previous seven days. Fourteen of the respondents who reported they had made referrals reported that they had referred patients due to medical issues. The most frequent reason for referral of patients was social problems, reported by 29.1% of the respondents. Table 18 shows the most frequent reasons for referrals done during the previous seven days for the day of the interview.

Table 18: Frequency of referrals (n=55)

	Frequency
Social issues	29.1%
Disease progress	25.5%
Adverse effects	23.6%
Poor adherence	16.4%
Diet	10.9%
Other	29.1%

Sixteen of the respondents (29.1%) were either unable to classify the reason for the referral, or they had referred patients due to problems not covered by the five categories listed in table 18. Of the 16 open-ended responses obtained, two respondents highlighted weight changes and two referred to shingles as the reason for referrals. Patients were also referred to the antenatal clinic if found pregnant or to the gynaecologist because of lesions. Among the other reasons highlighted were: sickness, co-existing HIV and tuberculosis, septic leg, bleeding when urinating and dehydration. One of the important aspects highlighted by a respondent was that patients were referred to Raphael Centre for VCT because public sector clinics at times were too busy. Raphael Centre is a Non-Governmental Organisation (NGO) providing VCT for free to people in Grahamstown.

4.3 Workload

The HCPs were asked how many patients they had met for VCT and follow-up during the previous seven days. Table 19 shows the results.

Table 19: Number of patients seen during the previous seven days (n=55)

Number of patients seen	VCT	Follow up
0-10	69.1%	65.5%
11-20	18.2%	12.7%
30	0	3.6%
65-120	0	11%
N/A	9.1%	1.8%
O/A	1.8%	3.6%
Missing answer	1.8%	1.8%

All six HCPs who reported meeting 65 patients or more during the previous seven days were from the referring site where they normally have 25-30 HIV patients coming daily. Thirteen

(23.6%) of all the interviewees were occupied with HIV-related work full time. Time pressure as a limitation in the work was acknowledged by 75% of the nurses and by 62.5% of support staff. Most of the nurses (91.7%) and more than half (65.2%) of support staff reported that they made priorities in their work with HIV patients due to time shortage. Comments on workload given by the HCPs during the interview are shown in table 20.

Table 20: Personal comments on workload

Because of other duties that have to be done, less time is spent with HIV patients. Someone else must do more of the work with HIV patient. If someone else did some of the work with HIV patients they will be asked later if there were any problems.
There are too many patients, and patients have too little knowledge. There is too much to talk about for one meeting.
Because of too many formal things I can't participate in meetings anymore. They will call for me if they need me.
The work is not limited because of time shortage, but I am tired because of the workload.
If time is too short, home-visits are done after work or during weekends.
There is not enough time for counselling. I'm rushing the administration stuff.
Time shortage limits the work with other patients who must wait.
HIV related problems take time and lower the pace of patient intake.
I was supposed to attend a patient review meeting but had to ask someone from a different clinic to present because of staff shortage.

Waiting time

Waiting time for HIV patients depended on factors like the patient's reason for the visit, the treatment facility's queuing system, time of the day, and unpredictable variables like patient load and the clinic's capacity each day. In some treatment facilities, the HIV patients were separated from other patients and did not wait in line. In some clinics the HIV patients were categorised as "first line" or "priority" patients, or were separated from other patients only for particular purposes, e.g. VCT and ARV collection. In other clinics the staff reported that HIV patients queued with all other patients. Some of the treatment facilities had a special nurse for HIV patients. Table 21 summarises the HCPs' responses to HIV patients' waiting time in their clinic. Observations showed that waiting time was sometimes used to educate patients either by use of

video or a health educator talking to the patients. Personal comments from HCPs on waiting time are listed in table 22.

Table 21: HIV patients' waiting time in Grahamstown's public health care facilities (n=55)

Waiting time	Frequency
Minimal	45.5%
10-30 min	20%
35-60 min	5.5%
> 60 min	3.6%
Open-ended answers	20%
Difficult to quantify	3.6%
Response missing	1.8%

Table 22: Personal comment on waiting time given during interview

HIV patients don't wait. We have a sister for only HIV patients
Waiting time depends on the day. Sometimes it is 5-10 minutes until the sister finishes with the other client. ARV patients go straight because they are first line patients if they have come for ARV collection. Collection can be very quick so we don't want them to wait with the others patients.
Patients don't wait for the doctor, only if there is another client. They wait long for medication. If they don't get the medication before lunch time they might not be ready to leave the clinic until 4-5 hours after they arrived
Don't know the average waiting time. Sometimes it's short. It depends on the day and how many staff and patients. HIV patients queue with all the other patients. We don't separate the lines because then others can see that there is something special with these patients.

Problems not dealt with in the health facility

More than 60% of the respondents reported that there sometimes were important issues that could not dealt with before the patients left the health facility. This was due to either time constraints or problems that could not be dealt with by HCPs in the clinic. Some of the issues that could not be dealt with straight away were: social problems, delay of treatment initiation due to problems with disclosure and patients having problems with their economy. Sometimes the HCPs had to ask patients to return later for the blood test if there was a staff shortage or if the blood samples had already been collected for the day. HCPs personal comments on problems not dealt with are shown in table 23.

Table 23: Personal comments from HCPs on problems not dealt with in the health care facility

A problem if patient has not disclosed but wants to be put on treatment programme. Need to counsel. The procedure followed for treatment initiation says that the patient must have supporter.
If a patient has financial problems but can't get grant because CD4 count is too high. Can organise clothes for the patient, but not food. Only patients who have CD4 count less than 200 and disease stage 3 or 4 can get grant. The grant takes long to organise.

Patients with special needs

When the HCPs were asked if they had met HIV-positive patients in need of special help, 83.6% of the respondents could specify such situations. Frequently mentioned problems were regarding money, food and support from family. Comments from the HCPs are shown in table 24.

Table 24: Personal comments from HCPs on patients' problems

Most common problems are food and money
Most of the patients have financial problems and suffer from lack of support. E.g. the wife doesn't want the husband to know about the HIV status, so we must do the visits other places than at home.
Problems at home with no support from family

4.4 Training of HCPs

All the respondents reported that they thought specific training was required for their work with HIV patients, and 81.1% had received some kind of training. However, the training they had undergone varied to a great extent from work shops and training by colleagues in the clinic for some HCPs to a semester or a one year's course for other HCPs. Twelve respondents reported that they had participated in workshops, and for six of these this was the only training they had been provided. Table 25 shows the number of respondents who reported that they had received training in any of the following topics: ARVs, counselling, testing or training on HIV. Table 26 shows how many days of training the HCPs had been provided with in the different topics.

Table 25: Training of health care professionals in Grahamstown's public sector (n=55)

Topic:	Percentage of HCPs
ARV training	36,4
Counselling	70,9
Testing	27,3
HIV/AIDS	12,7

Table 26: Amount and kind of training provided for HCPs working with HIV patients in public sector in Grahamstown (n=55)

Topic	Number of respondents with training	How many who could quantify amount of training in days	Training two weeks or more	Training less than two weeks	In-services training
Counselling	39	13/39	9/39	4/39	0
ARV	20	10/20	3/30	7/30	0
VCT	9	9/9	6/9	2/9	1/9
HIV/AIDS	7	3/7	1/7	2/7	0
PMTCT	6	5/6	1/6	4/6	0
Testing	2	2/2	0	1/2	1/2

Other topics of training that were mentioned included: home base, palliative care for people living with HIV/AIDS, nutrition, couple counselling and sexually transmitted diseases.

4.5 Preparing for and launching the HIV treatment programme in Makana district

The information in this section was gathered from the two group discussions conducted.

The process of planning the treatment programme in Makana district started in December 2003, five months prior to the rollout in Grahamstown. Site accreditation was based on the hospital's capacity, population estimates and needs in the community. Grahamstown fulfilled the criteria and Settlers Hospital applied for accreditation when they were informed about the national programme. When Settlers Hospital became accredited they were directed to initiate the programme without further recruitment of staff. At the time of preparation any reference point regarding initiation of the treatment programme and maximum enrolment of patients annually did not exist. A multidisciplinary team was set up for Makana district and weekly meetings were held to prepare for the roll out. The Makana task team included doctors, nurses, Settlers Hospital

management, Settlers Hospital dispensary, representatives from Makana Municipality, PHC clinical nurses, representatives from non-governmental and community based organisations. Cooperation with the private sector was not established at this stage.

Initially the idea was to initiate the treatment for the patients in the local clinics, but this was changed to preparing the patients in the clinics and initiate treatment at Settlers Hospital. Ensuring sufficient space in the health care facilities for patient counselling and check-ups were important aspects of the preparations. The national guidelines were adapted, and some cumbersome forms were simplified by one of the doctors in the task team.

Three days of training in comprehensive HIV management was provided by the Regional Training Centre, and it was reported that training had mainly consisted of self-training after this. There was a frequent need for training, due to the constant turn over in staff. CHWs were trained by a doctor and a social worker to do home visits for HIV patients on the. One of the participants pointed out that Grahamstown was one of the few treatment sites where the social assessment was still done. In order to optimise the relationship between patient and HCP, home visits were done by both a social worker and CHWs.

Six months after the initiation of the rollout, Settlers Hospital was provided with a doctor, programme manager and social worker. Extra staff had been provided to the down referral clinics. The HIV specialist clinic, Masunwabe Clinic, was established at Settlers Hospital in May 2005. To facilitate the work a paediatric clinic that operated once a week had been started.

According to participants in the group discussions, communication between referring hospital and the clinics was good, and every Wednesday there was a review meeting with staff from Masunwabe clinic from the down referral clinics to select new patients. One of the participants commented that the HCPs' teamwork had been a great advantage for the treatment programme. Participants pointed out that the provinces set yearly targets and the target for 2006 was already met by August 2006. It was also emphasised that the launch of the programme happened without intensive preparations for the programme. The rapidity was exemplified by the fact the one of the members was not aware of which medication was to be used for treatment.

Participants also reported that some of the difficulties experienced were problems with sick patients who were started on treatment with ARVs in the hospital. The patient readiness programme for these patients has been speeded up, and when their medical condition allows them to be discharged some of these patients did not return for follow-up.

Steps taken to ease the pressure at Settlers Hospital

By September 2006, 687 patients had been enrolled on the ART programme, and the system was operating at its maximum. Since the treatment programme was initiated, 210 patients had been down referred to clinics and 52 patients had died while on treatment. The remaining patients were in their stabilising stage, receiving medication at Settlers Hospital. To distribute some of the workload of Settlers Hospital, Settlers Day Hospital managed all chronic out-patients. Settlers Day Hospital had recently been accredited as treatment site for the ART programme to allow for expanding of the programme.

5 Discussion

5.1 Material

Though the presented study was a project in social pharmacy, focus was on the role of all different HCPs providing treatment and follow-up of HIV patients in Grahamstown's public sector. Only two pharmacists were involved in this work on regular basis, and therefore it was not possible to study only the role of the pharmacist. Due to the limited number of HCPs in Grahamstown's public sector, it was desirable to include all HCPs from each category of HCPs involved in this work for structured interviews.

Three methods were used in this study: observational studies, semi-structured interviews and group discussions.

5.2 Method

5.2.1 Choice of method

Observation as a research method can have varying degrees of participation, and is a common used technique for data collection. Observation can give additional and more accurate information about people's behaviour than interviews, and is especially good for assessing the quality of care in health centres and hospitals [52]. For this study it was desirable to gather information about the overall work and roles of different HCPs before the questionnaire was constructed and the interviews were conducted.

Interviews as a method can have varying degree of flexibility, and in this study it was used semi structured interviews. Less flexible methods, like structured interviews, are useful when the researcher is relatively knowledgeable about expected answers [52]. A limitation to the questionnaire is that the design was based on information gathered from observation at health facilities in town or very close to the town centre only and the researcher did not have an overall picture of the whole span including clinics from the more extended areas of Grahamstown. However, this was presumed to not cause a major source of error, since all HCPs operated according to the same guidelines for ART, and it was already identified from weekly meetings that HCPs from the different clinics interact and cooperate frequently.

It was decided to conduct two discussion groups, since information about the preparation and launching process of the ART programme could not be gathered from the respondents for the questionnaire, nor could such information be gathered from the observational studies.

5.2.2 The interviewing process

The clinics faced unpredictable days with regard to workload and time pressure due to emergencies, bigger patient loads than expected or staff shortage, so many of the appointments had to be rescheduled when arriving for the intended interview. Some of the respondents preferred to make a specific appointment, whereas other respondents could not specify further than “morning” or “afternoon”. Due to these unpredictable occurrences the interviewing process was at times laborious and a high degree of flexibility was necessary to adjust to the respondents’ schedules.

5.2.3 Validity and reliability

“Validity refers to the degree to which scientific observations actually measure or record what they purpose to measure” and “reliability refers to the repeatability of scientific observations”. [52] A threat to the validity of this study is the possibility that respondents might have felt that they had answer, or answered what they thought the researcher wanted to hear. Another factor which may have affected the validity in this study is the language, since English was not the first language for neither the researcher, or for the majority of the respondents. The same questionnaire was used for all HCPs and despite effort to design widely understandable questions the varying educational backgrounds might have resulted in different perceptions of the questions. It increases the validity that all HCPs agreed to participate, and all interviews were conducted by one researcher.

The questionnaire was designed for the purpose of conducting operational research on the ART programme in Grahamstown, and not to study people’s opinions on a specific topic. When studying people’s opinions, the questionnaire can be tested with regard to reliability and validity by cross-checking the responses to different questions for the same respondent. The questionnaire for this study was not eligible for such tests.

The sample size cannot be greater than the total number of people who are involved in the specific area of investigation. Even if this is a necessary limitation of this study, it should not make it less important to investigate the operating system. All HCPs who were asked agreed to participate, which makes the impact of this limitation as small as possible.

5.3 Results

5.3.1 Role of pharmacists in ART programmes

The focus of this study was the role of different health care professionals in treatment and follow up of HIV patients in the public sector in a setting where resources are limited. Results of this study showed that there were few pharmacists involved in the ART programme, and they interacted with patients only to a limited extent. Nurses and support staff were carrying out work tasks that, according to WHO's descriptions of the roles of the pharmacist, ideally should be the responsibility of pharmacists. Therefore, the ideal responsibilities of the pharmacists will be discussed briefly before the discussion of the roles of other HCPs in this treatment programme. This is to point out clearly some of the consequences of a system with constrained resources regarding economy and HCPs with a high educational background.

The roles of a pharmacist in health care are summarised in the "seven star pharmacist" by WHO consultative group 1997. The seven roles include: care giver; decision maker; communicator; leader; manager; life-long learner and teacher [53]. According to the WHO consultative group, the pharmacist should provide caring services and be comfortable with interacting both with other HCPs and the public. The pharmacist should assume a leadership role and be responsible for cost-effective use of resources and for sharing information about medicines. With regard to work with an HIV treatment programme, these roles would naturally imply dispensing medicines and sharing information about ARVs to patients and HCPs and patients' adherence monitoring and training. The presented study showed that dispensing ARVs was the responsibility of the pharmacist, but in all clinics except one, ARVs were handed out to the patients by nurses. Nurses were also responsible for training and monitoring of adherence, monitoring of adverse effects and educating the patient about the ARVs.

5.3.2 Down referral treatment structure

The ART programme in Grahamstown was based on follow up at PHC level. This is according to directions in the Operational Plan that PHC clinics and community health centres are primary sites for diagnosis, staging and routine follow-up of HIV-positive patients. It says further that these sites will provide the majority of ARV adherence monitoring and support, and only when appropriate expertise exists can ART be initiated at primary and community level.

Research has shown that PHC-based systems, where PHC clinics offer first-level care, only work effectively if the clinics can deal with 80% of health care problems in the population and therefore reduce the pressure on hospitals [22]. The treatment programme in Grahamstown was still in an early stage, after implementation in May 2004 and results from the study showed that the major patient load was in the stabilising stage, receiving medication at Settlers Hospital. To what extent the health care-related problems among HIV patients were truly dealt with within the PHC clinics was not studied sufficiently to say whether or not they were dealing with the 80% of the problems that the above-mentioned research says is necessary for the system to work effectively. However, only approximately half of the respondents from down referral clinics reported that they had made referrals during the previous seven days, and about half of these respondents reported referrals related to disease progress, poor adherence, or adverse effects. This indicates that the clinics could deal with the majority of health-related problems that HIV patients presented with.

It has been stated that primary health care services are generally associated with improved health status, and that increased focus on this is required [54]. In order to deal with the majority of health care problems at PHC level, competent and skilled HCPs are required. The challenge in this work was acknowledged by the HCPs involved, who called for more training. By directing much of the time-consuming work to the PHC clinics, the burden on the local hospital was decreased, but this had put a pressure on the PHC clinics. The results of this study showed that support staff played a major role in treatment and follow up of HIV patients. This structure is in line with recommendations from Médecins Sans Frontières (MSF), to involve a broad spectre of contributors in treatment and healthcare. The recommendations are based on MSF's work in, among other countries, South Africa [29].

Studies by WHO in other countries in Africa show that different approaches have been adopted when initiating an ART programme. Botswana was the first country in Africa to provide a public ART clinic in 2001, and the country has often been referred to as an example to others [55]. PHC clinics in Botswana that provide preventive therapy, treatment for tuberculosis, social services and routine medical care were initially not used for provision of ART. The aim is now to decentralise the ART so that patients can receive comprehensive care at one clinic. It is also suggested in an article on lessons learned from the establishment of the ART programme in Botswana that experienced nurses should play a key role in caring for stable patients receiving ART [56].

In Chiradzulu, Malawi, the initial design of the ART programme in 2001 also required all patients to begin therapy at hospital-based HIV clinics, and some patients were referred to clinics closer to their homes. This structure changed in 2002 to HIV clinics run at health facilities instead of exclusively at hospitals, and the intention is to transform the hospital into a referral centre in order to increase patient numbers [33].

The above-mentioned studies show that other treatment programmes that initially started with centralised hospital-based HIV clinics for follow up of HIV patients are adopting the structure that exists in Grahamstown's public sector. This implies that the benefits in including PHC clinics in this work have been acknowledged by decision makers in these countries. An article on access to ART in Africa also highlights that providing treatment in central hospitals without strong links to community outreach or PHC services weakens the link between prevention and care [57].

5.3.2.1 Facilitating and constraining factors in the treatment structure in Grahamstown

VCT done at the local clinic is convenient for the patients, and it is advantageous that results from the test were given on the same day as the counselling and testing took place, as the patient would get the results immediately. The same HCP did both pre- and post-test counselling which is good for the patient/HCP relationship. This way of organising the work is potentially resource efficient since all the preparing work was done by CHW, CCW and registered nurses. Ideally only HCPs who had gone through training would do the specific tasks, this would ensure a

certain level of competence among the HCPs involved. However, the results from the study showed that the amount and kind of training received varied a lot, therefore it was difficult to generalise the level of competence for the HCPs involved.

It was a facilitating factor in this system that HCPs could visit patients at home to identify factors influencing the patient's ability to cope with the treatment and the disease. Patients with special needs could be identified during the home visit. The HCP who did home visits had gone through specific training and also used a standardised scheme to document the findings. Using a standardised scheme increases the reliability of the information gathered, as all HCPs then would ideally collect the same information about the patient's social and economical situation.

The first stage when the doctor was involved in discussion about the patient case was when the patient was eligible and ready for treatment, and the nurse presented the case at the review meeting at Settlers Hospital. A team of different HCPs met weekly to discuss whether patients were to be enrolled on the programme. Though respondents reported that they did not always have time for the review meeting, results showed that this meeting served as a regularly gathering point for HCPs from different clinics. A report on the treatment programme run by MSF in Chiradzulu, Malawi, shows that that this programme initially had a similar committee for selection of patients. However, this arrangement was disbanded as a step to increase patient numbers a year after the programme was initiated [58].

That patients in Grahamstown were stabilised on treatment before down referral to the PHC clinics ensures that prospective complications occurring at an early stage would be identified by HCPs with the highest competence available in the system. At Settlers Hospital only one pharmacist was available to prepare medication for all the patients, and the workload was heavy. Due to the workload the pharmacist's work tasks were limited to mainly dispensing and recording, without direct patient contact. There were only two doctors who worked specifically with the ART programme.

One of the strengths of the system was that patients did not use the doctors time unless it was necessary. Stable patients came to their local clinic for all issues and sicker patients were

prioritised for doctor appointments. A potentially weak point is that patients had to go via the clinic if they were very ill.

It is the intention of the Operational Plan that integration of HIV- and AIDS-related services into existing systems at the primary care level reinforces the national strategy for primary health care [20]. According to the Operational Plan, the patients should receive counselling, nutritional assistance, psychosocial support and appropriate social welfare evaluation where necessary. Results from the study showed that patients were provided with counselling. Counselling was the most frequent topic of training received, reported by 70% of the respondents. Nutrition was one of the issues that HCPs thought were the most important to discuss, mentioned by 22 of 55 respondents. Social support was the most frequent reason for referring of patients to other HCPs. This shows that the ART programme operated according to aims in the Operational Plan. Results also showed that patients on the ART programme in Grahamstown are provided with a drug readiness programme, according to requirements in the Operations Plan.

The structure of the treatment programme in Grahamstown and use of HCPs corresponded to a recommendations in a WHO report on overcoming constraints in a public approach to ART. The report emphasises the importance of making optimal use of human resources and highlights the need for delegating routine aspects of managing treatment and care to other health care workers as one such strategy. WHO reports that physicians should play a lead role in assessing people living with HIV/AIDS, initiating or switching therapy, managing serious conditions and supervising staff. Clinical officers, nurses and counsellors will routinely follow up ART [33].

Equity in access to ART was ensured by a “first come, first serve” structure. Equity challenges and how resources should be allocated are elaborated in an article on access to ART in Africa. It is stated that in a health sector that suffers from lack of resources and underdevelopment, providing treatment on a “first come, first served” system favours urban, higher educated people who are not poor, and that it unfairly leaves decisions about who will receive treatment on the health care workers [57]. It is also emphasised in the article that CHWs have had an important role in Africa in many health-enhancing interventions, and that developing their role in access to treatment could strengthen primary health care and should be further explored. The results from

this study showed that in general all patients who approached for testing and follow up were dealt with at the clinic. However, in times of understaffing and heavy workloads, patients were referred to other facilities. According to respondents from the discussion groups, the system was operating at its maximum, and initiative was taken to facilitate expansion of the treatment programme by accreditation of Settlers Day Hospital as a new treatment initiating facility in the ART programme in Grahamstown.

5.3.2.2 HCP cooperation in the treatment programme

According to the Operation Plan, there should be ongoing communication between the primary health care facility and district hospital HIV/AIDS specialty clinic to ensure that patients are seen and monitored according to national treatment guidelines [20]. It has been stated that “a functional referral system involve communication between providers and agencies involved in patient care to maximise the quality and effectiveness of those services” [59]. The opinions of the discussion groups were that communication between the local clinics and the hospital was good, and teamwork had been an advantage. Many of the HCPs met weekly to discuss patient cases. 60% of the HCPs had referred patients to other HCPs during the previous week, and HCPs interacted and communicated actively with each other for the patients’ benefit.

Clinic meetings were generally held weekly at the health care facilities. In the PHC clinics there was no separate time for HIV cases, so time available for discussions was divided between all issues dealt with in the clinic. CHW and CCW reported back to nurses after home visits, but further studies are needed to identify the information reported back to the nurses. Over 85% of the HCPs reported that they had discussed patient cases among them, but only about half of the respondents reported that they had asked colleagues for advice during the previous seven days. Communication within the health care facilities was facilitated by HCPs working in close proximity to each other. The results showed that HCPs had intern training with HCPs who have not received training. This indicates that there was cooperation among the HCPs, and motivation to learn from each other.

5.3.3 Patient education, care and follow-up

Since time available with a patient is limited, the way this time is spent is crucial for the quality of health care provided. The time available needs to cover monitoring of adverse effects, adherence monitoring, health-check, social aspects of the patient's life, and regular blood tests.

5.3.3.1 Patient education

In this study it was found that the responses to the question about counselling of patients starting on ARVs were not uniform. A standard answer was expected, but the respondents had different perceptions of what "counselling of patients starting on ARVs" meant. Some respondents said that they didn't counsel patients starting on ARVs because this was done at the referring site when patients were initiated on treatment, while their colleagues said that they did such counselling and referred to their preparing of patients in the clinic before they were sent to Settlers Hospital. The observational studies showed that patients were prepared in general for the medication in the clinic, but not until the patients came to Settlers Hospital for treatment initiation did they receive counselling based on the exact treatment and dosage prescribed. Different HCPs were involved at different stages with regard to patient education. This can have different outcomes, for example patients might receive a lot of information repeatedly and so understand it thoroughly. It was acknowledged by respondents that it was a lot of new information for the patient in the beginning, so repetition might be necessary. Another outcome is that HCPs might feel less responsible for the patient education since information will be repeated by other HCPs later. Combined with the existing time pressure at all levels in the system it can be argued that this could lead to patients receiving insufficient information. The results showed that some HCPs did not talk to the patients about the treatment because other HCPs would talk to the patient about this later.

5.3.3.2 Treatment follow-up

Follow up includes counselling, screening after testing HIV-positive, home visits, adherence training with antibiotic prophylaxis, CD4 and viral load monitoring, examination, ARV initiation and ARV collection monthly. Except for the period when patients were stabilised on treatment at Settlers Hospital, follow up was mainly done by nurses and support staff in the local primary health care clinics. The findings show that patients generally did not have appointments. Patients

were given appointments for ARV collection, but were encouraged to come back to the clinic if they experienced any problems. Though such degree of flexibility might make it difficult to plan the days in the clinics, this was accounted for by providing different programmes on fixed days, and thereby maintaining a structure. On the other hand, the results showed that it was a necessity for patients to come on certain days for ARV collection in order to always have sufficient medication, and to facilitate adherence monitoring.

The results showed that it had been a problem that some patients did not come for follow up after testing HIV positive. HCPs' views on why patients failed to come back for follow up were among others poor disclosure, use of traditional medication, or that the urgent need to start treatment had not allowed for a sufficient patient readiness programme.

Individualised care

Results of the study showed that patients had different needs and problems. These were among others lack of support and care from family, inability to take care of themselves, difficulties with cleaning and cooking, alcohol abuse problems, and lack of food and money. HCPs did a variety of different tasks and prioritised what they included in their work. A study on health literacy and health-related knowledge among people living with HIV/AIDS highlights that patients are a diverse group with varying skills and knowledge, regardless of race or country. It was emphasised in the study that this is a challenge for the HCPs and is also relevant and important to consider when determining follow up procedures and implementing a treatment programme in a health care unit. Previous research has shown that patients of lower health literacy are less likely to have an undetectable viral load, and are less likely to know their CD4 count and viral load. Lower health literacy is also related to misperceptions that anti-HIV treatments reduce the risk for sexually transmitting HIV, and beliefs that anti-HIV treatment can relax safer-sex practices [60]. Considering these findings from other research on health literacy, it is likely that making assumptions about patients' knowledge, understanding and commitment can lead to incorrect generalisations about patients and in turn insufficient follow-up of patients. Although results showed that many of the HCPs in Grahamstown had good knowledge about their patients, as previous research has shown, HIV patients make a diverse group and therefore have different needs with regard to follow up and education. One of the actions taken that served to minimise

false conclusions about the patients in this system was the social assessment done prior to ART initiation. This contributed to achieving an understanding of each individual's situation and the patients' different needs. Another facilitating factor in this treatment system for individualised care was that almost 80% of the respondents reported that they recognised all or most of the patients. It was reported that patients with special problems could be referred to social worker or hospice.

HCPs involved in the work

Results showed that all HCPs were South African, and most of them could communicate in the patient's first language. Many of the respondents reported that they saw the patients around in the area where they lived, which gave a more complete picture of the patients' lives and situation. Knowing the culture and the language is a facilitating factor for good communication between patient and HCP, and for the patients to be as open as possible.

Results showed that nurses and support staff counted for almost 90% of HCPs involved in the work with HIV patients. As highlighted earlier there is a high degree of HCP migration from South Africa, lack of educated HCPs and lack of economic resources. It has been emphasised several times in literature that CHWs play an important role in provision of health care, and results from this study support these statements. CHWs, especially, met patients in their home sphere, and could therefore gain an overall picture of the patient's situation. WHO has defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [61]. This means that patients are not only in need for HCPs with competence on their medical condition, but also need someone to know their social condition. If trained well, the CHWs can fill a dual role by caring for the patients' medical problems and by doing social assessment.

Only five men were directly involved in the work with HIV patients in Grahamstown's public sector, and not all the down referral clinics had male HCPs. This is a possible constraint in the system since one of the factors reported necessary for patients' openness was that patients might wish to be seen by a HCP of same gender, and 30% of the patients enrolled on the programme are males. This may put a lot of pressure on the few male HCPs, and if capacity is too low it may

result in some patients not being seen by their preferred HCP. To what extent the communication and follow up was constrained by the factor that patients were not seen by the HCP they were most comfortable with, needs to be investigated further.

Time spent with patients

Time spent by HCPs with the patient varies among different professions and is different for first-time visits and follow-up visits. The higher the level of education, the fewer health care professionals are involved in the treatment programme, and the less time is spent with the patients. This shows that it is important to train all HCPs well, especially those who have less health-related educational background, since they are the ones who in general spend the most time with patients. More time is spent during the first visit, when the patients receive a lot of new information. In this situation it is possible that the patients initially do not have so many questions, but are more concerned about listening to information given.

Communication with the patients

The HCPs reported that the most important issues to talk about were adherence, nutrition and protection. At the same time it was reported that what patients asked about most frequently was the disability grant. Results showed that the HIV patients often had special needs, and often required special help both with regard to medical and social issues. Patients using public treatment facilities are those who cannot afford medical scheme and these patients often have problems with food and money. This could explain why the most frequently asked question by patients is about the disability grant.

There was a split opinion on how much the patients ask questions. Some report that patients ask questions daily, while others report that patients generally don't ask questions. At the same time most of the HCPs had the opinion that the patients were open to them and they based their assumptions on the patients' trust. Results showed that some HCPs had the impression that the patient counselling was so thorough that patients did not ask on their own initiative. Such statements do not acknowledge the possibility that there may be things of importance to the patient that were not covered by what the HCPs saw as important.

In the study a general opinion was not found on which category of HCPs the patients were more open to. The general pattern that was found was that most of the HCPs thought patients were open to them and their group of HCPs. However, it was also mentioned by both some CHWs and some of the nurses that some patients were afraid of talking to the CHWs because they were worried that confidentiality was not kept. Another respondent commented further that this had been a problem earlier, but that it was better at the moment. It is very important that the patients can trust the HCPs they are interacting with so that they are open about problems and in turn receive the health care that they need. Other factors that were seen to influence the patients' openness were HCPs' personal skills, who the patient had disclosed to in the clinic, gender, and how much the patient trusted the HCPs.

HCPs working on this treatment programme generally knew their patients well. This is to both the patients' and HCPs' benefit and facilitates good health care and follow-up as many decisions made were based on trusting the patient. The results also showed that because they knew their patients well the HCPs noticed that patients were not always honest. However, results show that not all HCPs knew the patient as well, and therefore not all HCPs involved would notice if the patients lied.

Feedback from patients

The information from patients that HCPs based their assumption and decisions about the patients on included both passive and active feedback from the patient. Some report that the patients asked questions if they did not understand; some HCPs asked patients to repeat. Some HCPs report that they could tell if patients understood or not, without specifying how, and some said that patients just told that they understood. There were large differences in the reliability of the information that decisions were based on, as this included assumptions and answers to closed and open-ended questions. If the HCPs ask open-ended questions instead of closed questions, there is a greater opportunity to pick up issues that patients have not understood.

5.3.4 ARVs and adverse effects

Pharmacists have specialised knowledge on the use of medication, and therefore have a great potential for contributing to provide better health care. Their involvement in medical treatment of HIV patients is not only of benefit, but also a requirement, as described in the treatment guidelines. As highlighted in the guidelines, “mounting an effective ART programme requires more than just the drugs. Establishing an adequate cadre of well-trained health care professionals, laboratory technicians, pharmacists and community workers is critical for the success of this programme” [26]. Despite this, the pharmacists involved in the programme are few and therefore overworked. ARV counselling was delegated to the nurse in charge in the ARV clinic because too large a workload with dispensing medication for patients only. The pharmacist in charge of ARV provision was normally prevented from interacting with patients directly, due to the workload. Nurses are not educated on the same level as pharmacists to deal with drug-related issues, and results showed that only approximately half of the nurses involved with the treatment programme had received training on ARVs. However, this solution is not uncommon when human resources are scarce, and has also been adopted by other African countries, such as Ghana, Kenya and Rwanda, where ARV adherence counselling is done by nurses who have received specific training for this [59]. When the situation is such that major responsibility is left to nurses and support staff, they should be provided with extensive training in those aspects that are not their major competence field.

Reports on percentages of patients with adverse reactions were not consistent among different HCPs in the system. A reason for this might be that the HCPs had not been trained in what to look for. Only about 20% of the respondents reported events of adverse effects during the previous seven days and less than half of nurses and support staff reported that they had met any patients during the previous seven days that received medication for symptoms of adverse effects. Some nurses reported that there were no side-effects among patient in their clinic. It was expected that the pharmacist who was preparing medication for all of the patients, and the doctors who were prescribing the medication would report to each other with regard to adverse effects, but this was not noted in this study. These interviews were conducted at different times. However, no factors or special events believed to influence the number of patients with adverse effects were identified during the period when the interviews were conducted. This inconsistency

might be due to miscalculations from both sides, and shows the disadvantage of a system operating with computers only to a limited extent.

It is well known that ARVs lead to a great deal of adverse effects. Though individual differences exist it is most unlikely there will be any patients who do not present with adverse effects if they take the treatment as prescribed. Therefore, compared to what was expected, very few HCPs reported that they had met patients with adverse effects during the previous seven days. However, this is not to say that few patients truly experience adverse effects from the treatment. There could be many reasons why some HCPs reported that there were no patients with side-effects in their clinics or that they did not meet any patients with adverse effects. One aspect is that it may be difficult to differentiate between adverse effects and symptoms caused by HIV/AIDS, or the patients may have other diseases that make it difficult to know the true cause of the symptoms. The HCPs might expect many adverse effects and side-effects, and therefore not thought of when asked about adverse effects among patients. It was reported by HCPs that many patients suffer from alcohol abuse. This could cause both symptoms i.e. dizziness and nauseous, and therefore neither the patients nor the HCPs would know the true cause of the symptoms. It is a possibility that patients, for unknown reasons, do not always tell the HCPs about experienced adverse effects. This however, should not indicate that none of these patients experienced adverse effects. Patients may be afraid of telling, or not know the difference between symptoms they experience and might therefore not know if they do experience side effects. Due to the high probability for adverse effects, the HCPs should expect that their patients experienced these, even if they did not mention any symptoms. It is also possible that if the respondents did not remember or did not know, they reported that there were none. Further studies need to be done to study and document the true occurrence of adverse effects among the HIV-positive patients on ARVs.

5.3.5 Adherence

Experiences from MSF in South Africa show that the following factors are important for long-term adherence to ART: easy to take regimen, dispensing health facilities within easy reach of the patients, individual support and educational material. Standard treatment in the public sector in South Africa consists of three different ARVs, of which each has to be taken once or twice daily. In some treatment programmes patients receive combination packages with two ARVs in one

tablet to reduce the amount of tablets administered daily. Fixed combination tablets were not used in the ART programme in Grahamstown's public facilities. One of the problems with combination packages is that one depends solely on one manufacturer for the supply of ARV, as compared to when each component of the combination therapy can be ordered separately from different manufacturers, depending on what is more convenient with regard to availability and costs. However, there is a disadvantage in using generic drugs, because the patient may be confused or uncertain about the treatment when colour and shape of the tablets change. Collection points for ARV were at the health care facilities within easiest reach of the patients and patients were provided with individual support and had access to educational material. This included leaflets and posters on different aspects of the treatment and disease, written in the three commonly spoken languages in the area. However, especially for the patients who cannot read, such written educational material will not be of great value without human resources to explain the meaning of these.

Results showed that the most frequent methods for adherence measuring were pill count, medical diary/tick chart and asking questions. All these methods were based on trust in the patient, and are therefore of little value unless the patients tell the truth. Pill count adherence was calculated by counting the remaining doses of medication brought back by the patient, and then assuming that remaining pills in excess represented missed doses. This gives a picture of the patients' adherence that is very unreliable as the sensitivity of pill counts for detecting non-adherence is compromised when patients remove pills without taking them, and leads to overestimation of adherence [62]. This was shown in the results of this study since HCPs identified that some patients lied to them. At the same time the HCPs had few opportunities to measure adherence in ways that were not based on trust.

Although it is argued and seen in several research projects that sufficient level of adherence can be achieved in resource-limited settings, it is still a very doubtful basis for the measurement of adherence to only trust the patient. It was mentioned by one of the HCPs that the only way to get a more accurate picture of a patient's adherence was to do blood tests. If the patients were adherent, the viral load would be low and CD4 count would be high. Due to a time consuming procedure and extra costs it is not likely that this method would be recommended as the standard

method for adherence monitoring in a context where both human and economic resources are limited.

It was the opinion of HCPs that traditional medication was an important aspect to talk about with the patients, and respondents emphasised that traditional medication should not be used together with ARVs. Results showed that use of traditional medication was seen as a possible reason for patients not wanting to take their medication, and therefore not being adherent. A study on barriers to ART adherence in Botswana, conducted in private clinics, shows that the most common barrier to adherence reported was finances, followed by forgetting to take medication, running out of medications, travelling, side-effects, and patients being too busy [55]. The above-mentioned study also showed that there was an inconsistency in patients' self-reporting of adherence, and patient adherence reported by the HCPs.

The importance of patient adherence is addressed by training the patients in adherence and by the requirement for a supporter before treatment initiation. Patients who do not show the ability to adhere to the treatment risk being taken off the treatment in order to give space for new patients. This is a consequence of a situation where resources are not sufficient to provide treatment for all who need it. This threat is a possible barrier for patients to be open in case of non-adherence. Adherence is always a challenge and there are many factors influencing adherence that are not related to the patients' contexts. Such universal factors are, among others, that patients forget to take their medication, or that they are scared of or experience adverse effects. Some obstructions to adherence that the researcher became aware of by personal notifications during the time of the study were that some patients share their medication with others who do not receive treatment, patients selling their medication, patients wishing to be sick enough to be eligible for disability grant and beliefs that ARVs are dangerous or kill them. Other obstructions to adherence, for patients who wish to be adherent, are among others alcohol abuse, unpredictable events like funerals resulting in patients going away for longer periods than they have medication for and patients hiding their medication from friends and family.

Though stable and reliable access to medicines is a necessity for patients' adherence, this is not the only determinant. This is due to many factors influencing both the patient's own decision on

how to take the medication, and the patient's ability to take medication according to these decisions.

Further studies need to be done to identify the adherence level among patients on ARVs. Based on the findings that patients do not always tell the truth and finding from the above-mentioned study that there is an inconsistency in patients' and HCPs' reporting of adherence, a study on adherence should include both patients and HCPs. Such a study should not rely solely on pill count, as this will not provide valid results.

The majority of the respondents reported that they had not met any patients within the previous week who had told them they had forgotten to take any of the medication. The majority of the respondents from the questionnaire also reported that they had not met any patients during the previous week who they thought were unwilling to take their medication, regardless of what the patients had told them. It was very seldom that patients told HCPs that they didn't want to continue taking their medication. There were also very few reports of patients who had misunderstood how to take their medication. The methods that were used to gather this information was mainly by communicating with the patient, and trusting them.

Opinions from group discussions were that stigmas related to HIV/AIDS had not been as problematic as first expected, though HCPs from down referral clinics reported that many patients had problems with disclosure and were afraid of being stigmatised. These are not necessarily contradictory opinions that do not reflect the truth. It is possible that clinical nurses from down referral clinics were exposed to more fear or stigma from disclosure since these clinics were the sites where patients were diagnosed and came back regularly as part of the readiness programme. By the time a patient was initiated on treatment, it is clear that this patient disclosed their HIV-positive status to at least one person, preferably in the same household. Group discussions involved mainly HCPs working in either the district health office or at Settlers Hospital, and therefore it is less likely that they met patients in the initial stage after being diagnosed. As mentioned earlier, one nurse noted that many patients failed to come for follow up, which she thought was mainly due to poor disclosure. Even when patients have disclosed to one person, which is the requirement for initiating treatment [26], it is possible that the patients still

wish to hide their HIV status from the majority of their acquaintances, which in turn can lead to difficulties with adherence. According to the treatment guidelines, the preferred level of adherence is above 95%¹⁰. With this level of adherence 78% of the patients will achieve undetectable viral load.

5.3.6 Excess workload for HCPs

Working with HIV patients is challenging and time consuming, and the majority of respondents reported that they had to make priorities in their work with HIV patients. The work with HIV patients also affected and limited the work with non-HIV patients, reported by about 90% of the nurses and 65% of the support staff. This situation is not unique for this context, and it is reported from a study on experiences of PHC facility health workers in South Africa that pressure caused by HIV-related illnesses leads to health care workers becoming overburdened combined with morbidity and mortality among health workers themselves. The report further states that absence of complementary resource and inputs has led to HCPs providing HIV/AIDS services in addition to other services in overloaded facilities, in a health care system that is already inequitable in resources and delivery [63]. It was found in the public treatment facilities in Grahamstown that work with HIV patients takes more time and effort than work with other patients, and it was reported that even if there were fewer HIV patients they took up more time than non-HIV patients.

Public hospitals often experience shortage of doctors, and the Eastern Cape is the province in the country with the most patients per doctor [64]. At the same time there is a high migration rate of South African health care professionals to other countries, which contributes to limited human resources. This is demonstrated by a report on global migration of pharmacists. According to the report 1000 pharmacists graduated in South Africa in year 2001. The same year 600 pharmacists emigrated from South Africa to other countries [65].

¹⁰ With a treatment regimen of two tablets in the morning and three tablets in the evening the total number of tablets to be taken during the 28 days is 140 tablets. To achieve 95% adherence the patient can only miss 7 tablets during this period. If the patient during a period of 28 days misses the morning dosage twice and misses the evening dosage once this is already 7 tablets missed.

The majority of HCPs reported that they had met 1-10 patients for each of the categories VCT and follow-up during the previous seven days. This shows that the number of patients is still small. Results showed that the clinics had adopted different strategies for queuing patients. Some HCPs report that their clinic had separate queues for HIV patients whereas HCPs in other clinics reported that they did not want to discriminate among the patients, and therefore they all patients queued together. Waiting time was shown to be difficult to quantify in many cases since it depended on many different factors. Observations showed that the waiting time was sometimes used to educate patients while they were waiting, but the information provided could not be evaluated in this study due to the language barrier.

It was identified in the study that HCPs feel that the work with HIV patients was challenging. Many reported that they had met patients with special needs presenting problems that could not be dealt with at the health care facility before the patients left.

5.3.7 Training of HCPs

A report from 2002 highlights that resources spent on training of people to implement prevention, care and treatment is the most essential need when expanding the capacity of health systems to address HIV/AIDS [66].

It was found in the study that training was not compulsory, but all of the respondents reported that training was a necessity for the work they were doing. About 80% of the respondents had received some kind of training, but the amount and kind of training varied greatly. The reason for this may be that it becomes harder to prioritise for both the HCP and the management at the clinic to take initiative for the HCP to go through training when it is not compulsory. Training might not be provided in the same town so the HCPs must leave their home, which can be very inconvenient. Going for training also implies that the HCP must take time off from work, and must either be replaced or the clinic will be understaffed during this period. Research from other treatment facilities in South Africa has shown that the additional time required for staff to attend advanced training courses is not always permitted by managers because of nursing shortages [63]. Though long-term effects of trained staff could possibly serve more benefits for the clinic, it might not be prioritised enough to be put in practise. If the HCPs are not trained sufficiently to be

able to provide the patient with sufficient health care themselves they might either rely on colleagues for assistance or the patient might leave the treatment facility without appropriate follow up. This can lead to great discrepancy in care provided from time to time, based on how much training the specific HCP counselling the patient has undergone. This in turn could create a higher burden on the treatment facility than necessary. EQUINET Africa¹¹ also states that ART programmes in public sector have been constrained by poor infrastructure and poorly trained health care professionals [23].

The results showed that all of the CHWs reported that they had received training. This, however, was not the general picture for the categories of HCP with higher education. Most of the nurses and none of the pharmacists acknowledged that they had received training, even though their responsibility implied that they had more knowledge of HIV treatment than was average for HCPs who were not working with HIV patients. This may be due to lack of standardised training. Continued Professional Development (CPD) is not a requirement for the HCP to keep their position. Many of the respondents commented spontaneously that they wanted more training. This indicates that they acknowledge the challenges in this work and are motivated to learn more. It's a great facilitating factor that workers are motivated to learn more, and should not be overlooked. The most frequently reported training was counselling, which the majority of the respondents had received training in. This is one of the main responsibilities for community health workers and the majority of support staff had received training in counselling.

Training varied greatly and there were few standard responses with regard to what kind of training that has been provided, by whom, and how many days it lasted. Results show that some HCPs did not see in-service-training as specific training, whereas other respondents reported the same kind of training as the only training they had been provided with and acknowledged this as specific training. This indicates that HCPs from different professions did not necessarily acknowledge the same initiatives as specific training. It is important to keep in mind that the variety of the different professions involved in the work with HIV-positive patients represents a huge span of educational background, from no prior experience with health care by some of the support staff, to nurses, doctors and pharmacists, educated specifically for working with health

¹¹ Regional Network on Equity in Health in Southern Africa

care. The study also showed that the group with the least education reported that they have received more training.

Support staff plays a major role both with regard to health-related issues, and with regard to social aspects, and hence may be exposed to a wide spectre of problems. One social worker was appointed for the work, and major assistance in social assessment is provided by support staff. With appropriate training HCPs can manage a greater variety of work tasks, and the system becomes more flexible and less dependent on individuals. Investment in training is therefore of great importance for development of the system.

Lack of training is not a necessary outcome of limited resources, as other countries have proved ability to provide health care workers with standardised training. In Botswana, all staff involved in care of patients receiving ART, including doctors, nurses, counsellors and pharmacy staff, are required to receive standardised training [56]. The training programme, called KITSO, consists of workshops, seminars, participant presentations, group learning, instructional videos and CD ROMs. All participants in the training programme must successfully complete four core modules of training and one elective module, which are based on the participant's field of expertise [67].

5.3.8 Policy and practice

A report by the Treatment Action Campaign (TAC) and AIDS law project, from 2004, claims that the degree of prioritisation and political commitment to services has not been matched with the substantial effort directed at implementing the Operational Plan at district and provincial level [68]. It is highlighted in this report that hospitals and clinics are under pressure to start providing treatment service while they are not getting the additional capital or human resources that the plan promises. In Grahamstown it is only Settlers Hospital that has been provided with extra staff, while the down referral clinics were operating with same capacity as prior to ART programme initiation. This affects the work and care provided for both HIV patients and non-HIV patients. The Operational Plan also highlights the need for private partnership. According to the group discussions, the cooperation with the private sector was very limited from the beginning, and private practitioners did not follow the same guidelines as those in the public sector. However, this situation was reported to be improving, as private doctors were starting to pay attention to the governmental guidelines for ART.

The financial resources needed to scale up the treatment programme provide a challenge in a resource-limited country. Money is not only needed for the medication, but treatment facilities need upgrading and HCPs need to be trained. But money can be saved by investing in ART programmes. A study on cost-effectiveness of ART in South Africa, conducted by the University of Cape Town, shows that the benefits of a public sector rollout of ART outweigh the costs of not providing this treatment [69].

5.4 Recommendations

Need for training

All health care professionals working with HIV patients should receive specific training in the field of HIV/AIDS. Training should be made a requirement for HCPs working with HIV patients, and that each HCP must show a certain level of knowledge after the course to receive a certificate of approved training. How the training should be organised for different categories of HCPs must be thought through carefully, to decide what level of training that should be standard for each group of HCPs. Based on their responsibility in the treatment HCPs should be trained on HIV/AIDS, adherence, patient counselling, adverse drug reactions, HIV testing, ARV counselling and communication.

While expanding of the treatment programme to Settlers Day Hospital is still in the planning stage, it is important to address the need for training of new recruited HCPs prior to roll-out.

Programme structure

It should be determined what works better: a structure with one specific nurse for the HIV patients, or if all nurses should do follow up of HIV patients. At present the organisation of the treatment structure is not the same in all clinics. It is possibly time efficient to have one special nurse dealing with all patients, because this nurse will know the situation for all of the HIV patients in the clinic and can work independently so that less time is spent asking for advice or about patient history. A constraint with having a limited number of nurses working with the HIV programme is that everything depends on very few people, who sometimes will be unavailable. For other HCPs to be able to fill someone's place it is necessary that there are routines and

procedures to follow. Such systems are not in place in this particular context. Another concern with regard to keeping a special nurse for HIV patients is confidentiality, since the HIV patients will be separated and treated differently from the rest of the patients.

Recruitment of health care professionals

There is a need for recruitment of more staff. Solutions for the shortage of staff can be to recruit nurses and doctors from abroad, but this will raise a problem if the workers are unable to speak local languages. Another possible solution to the problem of lack of HCPs is to train more CHWs and other less specialised staff to carry out many of the routine tasks, and to ease the workload of doctors [70]. Due to the high migration rate, it should be made more attractive for HCPs to stay in South Africa.

Most of the work with dispensing and recording was done manually. The potential for facilitated work tasks by a more extensive use of computer systems should be evaluated.

6 Conclusion

Many different categories of health care professionals are working together to provide treatment and follow-up for HIV-positive patients enrolled in the ART programme in Grahamstown's public sector. Patients meet with HCPs who are South African, and who most often can communicate in the patients' mother tongue.

After diagnosed as HIV-positive, the patients require special help both with regard to their medical condition, to handle daily life activities and to handle the mental pressure that accompanies this disease. The counselling in VCT and the following "patient readiness programme" ensure that patients are not started on ART without first being prepared for difficulties they might meet. In this work, major responsibility is given to HCPs with lack of sufficient training. There is a need for training and updates due to challenges in the work with HIV-positive patients. The educational level among HCPs involved ranges from support staff without prior experience with health care, to HCPs like nurses, pharmacists and doctors with years of health care education. No extra staff have been provided to the down referral clinics after implementation of the ART programme, and due to time pressure the HCPs have to make priorities in what they include in their work with HIV patients. Therefore it is not possible to always deal with all problems patients may present with right away. Time pressure also leads to situations with no time to for patients to ask questions, or not enough time for counselling. However, HCPs try their best to deal with all problems while the patients are present, since they can not be sure that these patients will come back later.

In this treatment programme, adherence is seen as the most important aspect to discuss with the patients. Measuring of adherence is based on trust in patients, although in many cases it is difficult to know what really happens. The HCPs are motivated to learn more, and do a great job to minimise the negative outcomes for patients in a setting where resources are scarce.

Acronyms

3TC: Lamivudine

AE: Adverse Effects

ADR: Adverse Drug Reactions

AIDS: Acquired Immunodeficiency Syndrome

ANC: Antenatal Clinic

ARV: Antiretroviral

ART: Antiretroviral Therapy

AU: African Union

CHW: Community Health Worker

CCW: Community Care Worker

CPD: Continued Professional Development

D4T: Stavudine

DAART: Directly Administered Antiretroviral Therapy

DDI: Didanosine

DOT: Directly Observed Treatment

ECA: Economic Commission for Africa

EFV: Efavirenz

FDA: Food and Drug Administration

FI: Fusion Inhibitors

HAART: Highly Active Antiretroviral Therapy

Hb: Haemoglobin

HCF: Health Care Facility

HCP: Health Care Professional

HIV: Human Immunodeficiency Virus

IEC: Information, Education and Communication

KZN: KwaZulu-Natal

MLSA: Makana Local Services Area

MSF: Medicines Sans Frontiers

NGO: Non Governmental Organisation

NNRTI: Non Nucleoside Reverse Transcriptase Inhibitors
NRTI: Nucleoside Analogue Reverse Transcriptase Inhibitors
NVP: Nevirapine
OEAS: Optimal Equitable Allocation Strategy
OR: Operational Research
PMTCT: Prevention of Mother To Child Transmission
SANAC: South African AIDS Council
SDH: Settlers Day Hospital
SH: Settlers Hospital
STD: Sexually Transmitted Diseases
STI: Sexually Transmitted Infections
VCT: Voluntary HIV Counselling and Testing
ZDV/ AZT: Zidovudine
Lop/r: Lopinavir/Ritonavir
PHC: Primary Health Care
TB: Tuberculosis
UN: United Nations
UNAIDS: Joint United Nations Programme on HIV/AIDS
WHO: World Health Organization
WTO: World Trade Organization
ZAR: South African Rand

Tables

Table 1: Health care facilities providing ART for HIV positive patients in Grahamstown

Table 2: Observational studies carried out in Grahamstown's public health sector

Table 3: Participants for structured interviews

Table 4: Observational studies conducted

Table 5: First language of health care professionals interviewed

Table 6: Number of health care professionals involved in different work tasks

Table 7: HCPs' personal comments on patients' openness towards different categories of health care professionals

Table 8: HCPs' personal comments on influencing factors for patients' openness

Table 9: HCPs' reporting on questions frequently asked by patients

Table 10: Personal comments on why patients do not ask many questions

Table 11: Responses on feedback from patients

Table 12: Basis for health care professionals' perception of patients' understanding

Table 13: Frequency of methods used to indicate patients' adherence to ART by HCPs in Grahamstown's public sector

Table 14: Patients reporting of missed doses to health care professionals during the previous seven days

Table 15: Number of patients reported to HCPs during the previous seven days that they did not want to continue taking medication

Table 16: HCPs' discussing patients' cases

Table 17: Frequency of discussing difficult patient cases with colleagues during the previous seven days

Table 18: Frequency of referrals

Table 19: Number of patients seen during the previous seven days

Table 20: HCPs' personal comments on workload

Table 21: HIV patients' waiting time in Grahamstown's public health care facilities

Table 22: Personal comments on waiting time, given during interview

Table 23: Personal comments from HCPs on problems not dealt with in the health care facility

Table 24: Personal comments from HCPs on patients' problems

Table 25: Training of health care professionals in Grahamstown's public sector

Table 26: Amount and kind of training provided for HCPs working with HIV patients in public sector in Grahamstown

Figures

Figure 1: Map of South Africa

Figure 2: Public health care facilities providing antiretroviral therapy in Grahamstown

Figure 3: Structure of antiretroviral therapy programme in Grahamstown's public sector

Figure 4: Nurses and support staff's different work tasks

Figure 5: How much time health care professionals spent with patients for first time visits and for follow-up visits

Figure 6: Health care professionals' perception of the most important aspects to discuss with patients

Figure 7: Frequency of patients asking questions during previous seven days

Figure 8: Nurses versus support staff in dealing with medication to HIV patients

Figure 9: Nurses versus support staff in asking for advice

References

1. Murru M. AIDS, Primary Health Care and Poverty. Bioline International, Health Policy and Development Vol. 2, **2004**.
2. UNAIDS. Accelerating Action against AIDS in Africa, **2003**.
3. 2006 Report on the global AIDS epidemic: Executive summary. A UNAIDS 10th anniversary special edition, **2006**.
4. UNAIDS. Report on the global HIV/AIDS epidemic 2002. The mounting impact, **2002**.
5. UNAIDS. AIDS epidemic update: special report on HIV/AIDS: December 2006. **2006**.
6. Press release 4 December 2005. Africa still facing unprecedented AIDS crisis. UNAIDS, **2005**.
7. UNAIDS, WHO. AIDS epidemic update, **2005**.
8. WHO, MSF. Antiretroviral Therapy in Primary Health Care: Experiences of The Khayelitsha Programme in South Africa, **2003**.
9. WHO News releases 2006. XVI International AIDS Conference. Toronto Canada, **2006**.
10. [e-drug] access to anti-retrovirals in South Africa. 2001 [cited 2006 16.10]; Available from: <http://www.essentialdrugs.org/edrug/archive/200111/msg00048.php>
11. Providing drug treatment for millions. [cited 2005 17.12.2005]; Available from: <http://www.avert.org/drugtreatment.htm>
12. Treating 3 million by 2005. Making it happen. The WHO strategy: WHO UNAIDS, **2003**.
13. Mandell GL, Bennett J, Dolin R. Mandell, Douglas, and Bennett's Principles and Practice of Infectious Diseases: Elsevier Health Sciences, **2005**.
14. Virusmyth. A rethinking AIDS website. [cited 2005 21.09]; Available from: <http://www.virusmyth.net/aids/controversy.htm>
15. AIDS Treatment: Target & Results. [cited 2006 06.04]; Available from: <http://www.avert.org/aidstarget.htm>
16. Bradshaw D, Groenewald P, Laubsher R, Nannan N. Initial Burden of Disease Estimates for South Africa, 2000: Burden of Disease Research Unit, **2003**.

17. DOHA DEFRAILED: A progress report on TRIPS and access to Medicines. MSF briefing for the 5th WTO Ministerial Conference, Cancun 2003. Campaign for access to essential medicines 2003 [cited 2006 21.11.2006]; Available from: <http://www.accessmed-msf.org/documents/cancunbriefing.pdf>
18. Fassin D, Schneider H. The politics in South Africa: beyond the controversies. **2003**;326:495-7.
19. National Drug Policy for South Africa. **1996**.
20. Operational plan for comprehensive HIV and AIDS care and management for South Africa. **2003**.
21. Garbus L. Country AIDS Policy Analysis Project. HIV/AIDS in South Africa. **2003**.
22. Uys LR. HIV/AIDS nursing research in the African context. *J Assoc Nurses AIDS Care* **2005**;16(3):1-2.
23. Ntuli A, Ljumba P, McCoy D, Padarath A, Berthiaume L. HIV/AIDS and Health Sector Responses in South Africa. *Treatment Access and Equity: Balancing the Act. Equitnet*, **2003**.
24. 25 years with HIV. *TheScientist* [cited 2006 24.08]; Available from: <http://images.the-scientist.com/supplementary/flash/23586/1.swf>
25. Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents: DHHS Panel - A Working Group of the Office of AIDS Research Advisory Council, **2006**.
26. National Antiretroviral Treatment Guidelines. National Department of Health South Africa. **2004**.
27. Leach B, Paluzzi JE, Munderi P. Prescription for healthy development: increasing access to medicines. Chapter 2 Overcoming barriers to access. UN Millennium Project. London: EARTHSCAN **2005**.
28. TRIPS, Intellectual Property Rights and Access to Medicines. *HIV/AIDS Antiretroviral Newsletter-Update WHO Regional Office for the Western Pacific*, **2002**.
29. Rosen S, Vincent J, MacLeod W, Fox M, Thea DM, Simon JL. The cost of HIV/AIDS to businesses in southern Africa. *AIDS* **2004**;18(2):317-24.
30. Ronald AR, Sande MA. HIV/AIDS Care in Africa Today. *Clinical Infectious Diseases* **2005**;40:1045-8.

31. Stevens W, Kaye S, Corrah T. Antiretroviral therapy in Africa. *BMJ* **2004**;328:280-2.
32. Little SJ, Holte S, Routy J-P, Daar ES, Markowitz M. Antiretroviral-Drug Resistance among Patients Recently Infected with HIV. *N Engl J Med* **2002**;347(6):385-94.
33. Grubb I. WHO Perspectives and practice in antiretroviral treatment. A public health approach to antiretroviral treatment: overcoming constraints. **2003**.
34. Horizons Report. Operations Research in HIV/AIDS. Introducing HAART in Africa. **2004**.
35. Laurent C, Diakhated N, Gueye NF, Toure M. The Senegalese government's highly active ART initiative: an 18-month follow-up study. *AIDS* **2002**;16(10):1363-70.
36. Laniece I, Ciss M, Desclaux A, et al. Adherence to HAART and its principal determinants in a cohorts of senegalese adults. *AIDS* **2003**;3:103-8.
37. The global shortage of health workers and its impact. [cited 2006 18.07]; Available from: <http://www.who.int/mediacentre/factsheets/fs302/en/index.html>
38. Press release: WHO calls for better deal for african health workers. **2006**.
39. Horizons Report. HIV/AIDS Workplace Programs. Mobilizing Managers, Crafting Policies, Educating Workers, **2003**.
40. Horner H. HIV/AIDS Feminisation: A new wine in an old bottle. [cited 2006 08.12]; Available from: <http://www.plusnews.org/HDiaryEntry.asp?ReportID=41>
41. Steinberg M, Johnsons S, Schierhout S, Ndegwa G. Hitting Home. How Households Cope With the Impact of The HIV/AIDS Epidemic. A Survey Of Households Affected by HIV/AIDS in South Africa. **2002**.
42. Urassa M, Boerma JT, Isingo R, et al. The impact of HIV/AIDS on mortality and household mobility in rural Tanzania. *AIDS* **2001**;15(15):2017-23.
43. Report ion Inter-Provincial Inequity Health financial Planning & Economics directorate, **2005**.
44. ABC Analysis, Eastern Cape. **2005**.
45. Declaration of Alma-Ata. **1978**.
46. Press release: Africa adopts *Brazzaville Commitment* on scaling op towards universal access to HIV and AIDS prevention, treatment, care and support. WHO, UNAIDS AFRICAN, UNION.

47. Wilson DP, Blower SM. Designing Equitable Antiretroviral Allocation Strategies in Resource-Constrained Countries. *Plos Medicine* **2005**.
48. Ciccio L. ARV treatment in poor settings: The state of the ART. *Health policy and development* **2004**;2(1):52-61.
49. Rosen S, Sanne I, Collier A, Simon JL. Hard choices: rationing antiretroviral therapy for HIV/AIDS in Africa. *The Lancet* **2005**;365(9456):354-6.
50. Smart T, Alcorn K. Treatment equity in practice: how scarce resources for treatment are being used, and the ethical dilemmas that need to be debated. 2005 [cited 2006 17.03]; Available from: <http://hivinsite.ucsf.edu/InSite?page=pa-hatip-46>
51. Provision of ARV therapy in resource-limited settings: the challenges of drug resistance and adherence. Global HIV/AIDS Program of the World Bank 17-18 June 2003. 2003 [cited 2006 20.09.2006]; Available from: http://www1.worldbank.org/hiv_aids/WHOIATCMeeting.asp
52. Hardon A, Boonmongkon P. *Applied Health Research - Anthropology of Health and Health Care*. Amsterdam, **2001**.
53. The role of the pharmacist in the health care system. Preparing the future pharmacist: curricular development. Third WHO consultative group on the role of the pharmacist. Vancouver, **1997**.
54. Primary Health Care Progress Report: Department of Health, Republic of South Africa, **2000**.
55. Weiser S, Wolfe W, Bangsberg D, Thior I. Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *J Acquir Immune Defic Syndr* **2003**;34(3):281-8.
56. Wester CW, Bussmann H. Establishment of a Public Antiretroviral Treatment Clinic for Adults in Urban Botswana: Lessons Learned. *Clinical Infectious Diseases* **2005**;40:1041-4.
57. Loewenson R, McCoy D. Access to antiretroviral treatment in Africa. *BMJ* **2004**;328:241-2.
58. Antiretroviral Therapy in Primary Health Care: Experiences of the Chiradzulu Programme in Malawi. *Perspectives and Practice in Antiretroviral Treatment* WHO, MSF, **2004**.
59. Ritzenhaler R. Delivering Antiretroviral Therapy in Resource-Constrained Settings. Lessons from Ghana, Kenya and Rwanda. **2005**.

60. Kalichman SC, Benotsch E, Suarez T, Catz S, Miller J, Rompa D. Health literacy and health-related knowledge among persons living with HIV/AIDS. *American Journal of Preventive Medicine* **2000**;18(4):325-31.
61. WHO. [cited 2006 07.11]; Available from: <http://www.who.int/about/en/index.html>
62. Machtinger EL, Bangsberg DR. Adherence to HIV Antiretroviral Therapy. **2006**.
63. Ljumba P. 'Voices' of Primary Health Care Facility Workers. Health Systems Trust, **2002**.
64. Bassett H. Healthcare in South Africa. MedHunterscom 2004 [cited 2006 26.10]; Available from: <http://www.medhunters.com/articles/healthcareInSouthAfrica.html>
65. Felling B, Amenyah J, Sam-Abbenyi A, et al. Ghana. Preparing for the Management of Antiretroviral Drugs. Findings and Recommendations of the ARV Assessment Team: Ministry of Health/Ghana Health Service, **2003**.
66. Morison JS. Expanding Antiretroviral Treatment in Developing Countries Creates Critical New Challenges, **2002**.
67. KITSO AIDS Training Program. 2006 [cited 23.10.2006]; Available from: http://www.aids.harvard.edu/kitso/program_description.html
68. Bekwa A, Hassan F. Updated ARV rollout: AIDS law project TAC, **2004**.
69. South Africa: Antiretriviral therapy is cost-effective. IRINnews 2004 [cited 2006 15.11]; Available from: www.IRINnews.org
70. Darkoh-Ampem E, Sargent J, Butler J. Logistics and models of implementing large-scale HIV treatment, care and support in Africa. *Journal of HIV Therapy* **2006**;11(1).
71. WHO. [cited 2006 03.04]; Available from: http://www.who.int/3by5/publications/briefs/en/Op_research.pdf
72. The 10/90 Report on Health Research 2001-2002: Global Health Forum for Health Research, **2002**.

Appendices

- 1. Operational Research and The 10/90 Gap**
- 2. Consent form**
- 3. Questionnaire**
- 4. Research permission by Department of Health, Eastern Cape**
- 5. Research permission by Rhodes University Ethical Committee**
- 6. Research permission by Department of Health, Makana Municipality**

Appendix 1

Operational Research

There is an urgent need for operational research to aid in the direction of care programmes that can not be overemphasised. In the process of creating and scaling up programmes for prevention and care it is essential to monitor and evaluate the effectiveness of these programs [30]. The WHO Operational Research Agenda for “3 by 5” initiatives [71] describes ways to gather strategic information that will indicate how ART delivery systems in resource-limited settings work. Activities of priority according to the agenda are among others “to identify ways to define the externalities of ART scale-up on health systems’ performance”, and “to incorporate new knowledge rapidly back into ART programme policy and practice”. As treatment programmes proceed it is important to provide clear evidence that this is strengthening health systems, and it is important to identify constraints and facilitating factors of the system. When this information is gathered it is necessary to feed back information for decision making to where operational research is to be carried out and in settings facing a similar situation.

The 10/90 Gap

The principles of universal comprehensive health care, by combining medical and social interventions, were emphasised by the 1978 Alma Ata Declaration. This is far from being implemented at present, and even in countries considered to have good functioning systems, some people are not satisfied by the countries’ ability to care for the poor. While poor health has the tendency to increase poverty, “good health is central for (a) the promotion of development; (b) the fight against poverty; and (c) global security” [72]. In order to improve the design of health interventions, policies and service delivery, it is important to conduct health research. This is to make sure that decisions made are built on recommendations that are evidence based, so that resources available are spent in the most effective way to combat poor health and disease. The current situation is such that only 10% of health research funds from public and private sector are devoted to 90% of the world’s health problems, referred to as the “10/90 Gap”, and funds are not always used as effectively as possible. Better health for anyone, anywhere on earth, is a global good that would benefit everybody else. Therefore health research, which is a key determinant of health improvements, is also to be seen as a public good [72].

**Patient and Health Care Personnel interaction study
Consent Form**

Title of Research Project: The role of the different health care personnel in the work with HIV patients in the public sector in Grahamstown

Principal Investigator: Karine Wabø Ruud

Introduction: I am a student from Rhodes and am conducting research on the interaction between health care personnel and HIV patients in Grahamstown. It would be highly appreciated if you as health care professional participated in my research. Please ask any questions about this study before you agree to join in. You may also ask questions at any time after joining the study.

Purpose: To find out how the health care professionals work with regard to HIV patients in the public sector.

Procedure: Questionnaire

Risk/ Discomfort: None

Confidentiality: You will remain anonymous in this study. The details of your name and profession will only be available to Karine Wabø Ruud

Compensation: You will not be paid any money to participate in this study.

Consent:

I have read/ or understood the conditions about and I consent to voluntarily participate in this research study. I realize I am free to withdraw my consent without any explaining reason and to withdraw from this study at any time without negative consequences. I hereby consent to the use of visual images (photos etc) involving my participation in this research.

Name of subject (Please print).....

Signature or thumbprint of subject.....

Address.....

Date.....

Name of witness to consent.....

Signature of witness.....

Name of person obtaining consent.....

Signature of person obtaining consent.....

Date.....

Name of clinic.....

Appendix 3

The role of health care personnel (HCP) in work with HIV patients

1 Demographics

1.1	Age							
1.2	Gender	Male ¹	Female ²					
1.3	Nationality	SA ¹	Other ²					
1.4	First language	Xhosa ¹	Afrikaans ²	English ³				
1.5	What different languages do you speak?							
	a) Xhosa		Yes ¹	No ²				
	b) Afrikaans		Yes ¹	No ²				
	c) English		Yes ¹	No ²				
	d) Other		Yes ¹	No ²				
1.6	What is your profession?	Reg. nurse ¹	CHW ²	Pharm ³	Doctor ⁴			
		Social worker ⁵	Nursing assistant ⁶	Dietitian ⁷	CCW ⁸			
		Clinic ass ⁹	Health educator ¹⁰					
1.7.1	How long have you been working in this clinic (months)?	0-3 ¹	4-6 ²	7-12 ³	13-18 ⁴	19-36 ⁵	>3yrs ⁶	
1.7.2	How long have you been working with HIV (months)?	0-3 ¹	4-6 ²	7-12 ³	13-18 ⁴	19-36 ⁵	>3yrs ⁶	
1.7.3	For how long have you been in this profession (months)?	0-3 ¹	4-6 ²	7-12 ³	13-18 ⁴	19-36 ⁵	>3yrs ⁶	
1.8	Which of the following patient / HCP interactions do you take part in?							
1.8.a	Pre-testing counselling in VCT	Yes ¹	No ²					
1.8.b	Testing in VCT	Yes ¹	No ²					
1.8.c	Post-testing counselling in VCT	Yes ¹	No ²					
1.8.d	Patients' monthly ARV collection	Yes ¹	No ²					
1.8.e	Counselling of patients who start ARV	Yes ¹	No ²					
1.8.f	Follow up of patients between testing positive and initiation of ARV	Yes ¹	No ²					
1.8.g	Home visits	Yes ¹	No ²					

2 General aspects in follow-up

2.1.1	Did you see HIV patients today?	Yes ¹	No ²		
2.1.2	If no, when was the previous day you saw HIV patients?				
2.1.3	How many patients did you see during the last 7 days for VCT?				
2.1.4	How many patients did you see during the last 7 days for follow-up?				

2.2	How many patients during the last 7 days did you talk to in:						
2.2.a	Xhosa	All ¹	Most ²	Half ³	Few ⁴	None ⁵	
2.2.b	English	All ¹	Most ²	Half ³	Few ⁴	None ⁵	
2.2.c	Afrikaans	All ¹	Most ²	Half ³	Few ⁴	None ⁵	
2.3	How many times during last week did you have someone translate to the patients?						
2.4.1	Are there sometimes important issues that for any reason are not being dealt with before the patient leave the health facility?	Yes ¹	No ²				
2.4.2	Can you list any of the reasons?						

2.5.1	Do you know the average interaction time between you and the patients?	Yes ¹	No ²				
	If yes, please specify in minutes;						
2.5.2	First time (minutes)	<10 ¹	10-20 ²	25-40 ³	45-60 ⁴	>60 ⁵	
a							
2.5.2	Follow up (minutes)	<10 ¹	10-20 ²	25-40 ³	45-60 ⁴	>60 ⁵	
b							
2.6.1	Do the patients complain about anything? A)	Very ¹ often	Often ²	Not often ³			
	B)	Daily ¹	Once ²	Twice ³	Trice ⁴	<weekly ⁵	

2.6.2	If yes, please specify;					
2.7	How long is the average waiting time for patients at this unit (minutes)	Minimal ¹	10-30 ²	35-60 ³	>60 ⁴	
		Open answer ⁵	Don't know ⁵			

3 Training of involved Health Care Personnel

3.1	Do you think your work with HIV patients require any specific training?	Yes ¹	No ²	
3.2	Have you been sent to do any specific training to be able to do this work with HIV patients?	Yes ¹	No ²	

3.3	If yes, can you specify the contents of the training?					
	a) ARVs	Yes ¹	No ²			
	b) Counselling	Yes ¹	No ²			
	c) Testing	Yes ¹	No ²			
	d) HIV	Yes ¹	No ²			
	other:					

3.4	How many days did the training last?	a)	b)	c)	d)	
3.5	Are you aware of any documents explaining your job description?	Yes ¹	No ²			

4 Patient / Health Care Personnel Interaction

4.1	Does your work involve direct patient contact? If yes, proceed;	Yes ¹	No ²			
-----	---	------------------	-----------------	--	--	--

4.2	Which of the following subjects do you deal with:					
4.2.a	Adherence monitoring	Daily ¹	Weekly ²	Monthly ³	Never ⁴	
4.2.b	Explaining how to use medication	Daily ¹	Weekly ²	Monthly ³	Never ⁴	
4.2.c	Handing out medication	Daily ¹	Weekly ²	Monthly ³	Never ⁴	
4.2.d	Monitor adverse effects	Daily ¹	Weekly ²	Monthly ³	Never ⁴	
4.3	Are the patients allowed to meet you before their scheduled date? If yes proceed;	Yes ¹	No ²			

4.4	What are the reasons for which a patient comes to see you without an appointment?					
4.4.a	Patient is going away and need a new appointment	Yes ¹	No ²			
4.4.b	Run short of tablets	Yes ¹	No ²			
4.4.c	Patient comes late for the appointment	Yes ¹	No ²			
4.4.d	Side effects	Yes ¹	No ²			
4.4.e	Family or friends were worried	Yes ¹	No ²			
4.4.f	Patient was worried about health	Yes ¹	No ²			

4.4.g	Other:					
4.5.1	Where there any patients during last week who came to see you without an appointment?	Yes ¹	No ²			
4.5.2	If yes, how many?					

4.6 What do you think is the most important aspect to discuss with your HIV patients? ¹²

4.7 Did you discuss any of the following issues with HIV patients today/ the previous day you met patients:

4.7.a	Adverse effects	Yes ¹	No ²			
4.7.b	Money	Yes ¹	No ²			
4.7.c	Diet/ nutrition	Yes ¹	No ²			
4.7.d	Family situation	Yes ¹	No ²			
4.7.e	Disclosure about status	Yes ¹	No ²			
4.7.f	Treatment failure	Yes ¹	No ²			
4.7.g	Family planning	Yes ¹	No ²			
4.7.h	Protection of partner/ children	Yes ¹	No ²			
4.7.i	Supporter	Yes ¹	No ²			
4.7.j	Weight change	Gain ¹	Loss ²	N/A ³	General ⁴	
4.7.k	Lifestyle (smoking/ drinking)	Yes ¹	No ²			
4.7.l	Other?	Yes ¹	No ²			
4.8	During the last seven days, could you recognize any of the patients from their last meeting?	Yes ¹	No ²			
4.8.1	If yes, how many?	None ¹	Few ²	Half ³	Majority ⁴	All ⁵
4.9	How often during last seven days did you experience that patients had misunderstood from earlier visit how to take their medication?					
4.10.1	Are there some questions you always ask the patients?	Yes ¹	No ²			
4.10.2	If yes, please specify					
4.11.1	Are there other questions that you generally don't ask unless there are specific problems?	Yes ¹	No ²			
4.11.2	Can you think of any situation when the patient need special help compared to the average?	Yes ¹	No ²			
	Please specify;					
4.12	How often during the last 7 days did you talk to a patient about change dosage/ formulation?					

¹² Adherence¹ / Nutrition² / Disclosure³ / Side effects⁴ / Any problems⁵ / Keep appointment⁶ / Sex⁷ / General health⁸ / Use condom⁹ / Avoid pregnancy¹⁰ / CD4+, immunity¹¹ / HIV, Aids¹² / Treatment for life¹³ / Alcohol¹⁴ / Drugs¹⁵ / Take tablets well¹⁶

4.13	What kind of feedback do you get from the patients that tell you how well they understand what you explain to them?								
4.14	Which methods do you use to indicate patient adherence?								
	a) Tick chart	Yes ¹	No ²						
	b) Ask questions	Yes ¹	No ²						
	c) Pill count	Yes ¹	No ²						
	d) Other:								
4.15.	Do you know the exact number of patients expected to be seen for VCT every day?	Yes ¹	No ²						
1									
4.15.	Do you know the exact number of patients expected to be seen for scheduled visit every day?	Yes ¹	No ²						
2									
4.16.	How many patients during the last 7 days told you that they didn't want to continue to take their medication?								
1									
4.16.	How many times during the last 7 days did a patient tell you that they forgot to take their medication?								
2									
4.17.	How many patients during the last 7 days told you about concern with regard to treatment/ disease?								
1									
4.18.	Have any patients told you that they feel more comfortable about talking to one HCP than another?	Yes ¹	No ²						
1									
4.18.	If yes, did they give any reasons why?								
2									
4.18.	Do you have the impression that patients are more open to any HCPs than other because of their profession?	Yes ¹	No ²						
3									
4.18.	If yes, please specify:								
4									
4.19	How many of the patients you have seen during the last 7 days asked questions on their own initiative?	none ¹	few ²	half ³	most ⁴	all ⁵	Don't know ⁶		
4.20	Which questions are frequently asked by HIV patients?								
4.20.	Side effects	Yes ¹	No ²						
a									
4.20.	How to use the medicines	Yes ¹	No ²						
b									
4.20.	Money / Grant	Yes ¹	No ²						
c									
4.20.	Other:								
d									

4.21.	Have you during the last 7 days sensed that ARV patients are unwilling to take their medicines?	Yes ¹	No ²				
1							
4.22.	How many HIV patients you met during the last 7 days complained about symptoms of minor side-effects?						
2							
4.22.	How many HIV patients you met during the last 7 days complained about symptoms of major side-effects?						
3							
4.23	How many of HIV patients you met during the last 7 days receive medication to treat symptoms of A/E						
4.24	Do you know how many of the patients you met during the last 7 days switched treatment due to A/E?						
4.25	Who, if anyone, do you confer with if patients complain about adverse effects?						
	a) Doctor ¹	Yes ¹	No ²				
	b) Reg. nurse ²	Yes ¹	No ²				
	c) Pharm ³	Yes ¹	No ²				
	d) Other ⁴	Yes ¹	No ²				
4.26	Which of the adverse effects have shown to be most frequent among patients you have met?						
	a) Peripheral neuropaty ¹	Yes ¹	No ²				
	b) Lactic Acidosis ²	Yes ¹	No ²				
	c) Only side effects ³	Yes ¹	No ²				
	d) Don't know ⁴	Yes ¹	No ²				
	e) none	Yes ¹	No ²				
5 ARV related questions							
5.1	How many HIV patients have you explained to today/ the previous day you saw patients how to use their medication?						
5.2	Have you provided any patients with new instructions about their medication today or the previous day you saw patients?	Yes ¹	No ²				
5.3	When were you last time involved with an HIV patient who needed additional information because of new dosage or formulation?	This week ¹	1-2 weeks ago ²	Last month ³	>1 month ago ⁴	Don't remember ⁵	
5.4	Do you sometimes repeat to HIV patients how to use their medication?	Yes ¹	No ²				
5.4.1	If yes, for what reasons do you repeat?						

6 Health Care Personnel Cooperation

6.1 What kind of discussions about patient cases are you involved in with other HCP?

6.1.a Discuss patient case while patient is waiting

6.1.b Discuss patient case after patient has left

6.1.c Patient presentations for HCP team/ review meeting

6.1.d ARV clinic meeting at SH / Friday meeting

6.1.e Ward round SH

6.1.f ARV task team monthly meeting

Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²

6.2.1 Have you participated in any scheduled meetings during the last 7 days with other HCP because of the work with HIV patients?

6.2.2 If yes, how many?

6.3 How many times during the last 7 days did you discuss difficult patient cases with other HCP when the patients were not present?

6.4 How many times during the last 7 days did you ask someone for advice while dealing with a HIV patient?

Yes ¹	No ²
------------------	-----------------

--

6.5 Have you participated in any meetings during the last 7 days to discuss the present work being done with regard to HIV?

6.5.a Formal meetings

6.5.b Informal meetings

Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²

6.6 Did you refer patient to other HCP during the last 7 days because of problems with regard to any of the following issues;

6.6.a Adverse effects

6.6.b Poor adherence

6.6.c Disease progress

6.6.d Social issues

6.6.e Diet

6.6.f Other

Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²
Yes ¹	No ²

7 Questions about work

7.1 How big part of your work during the week consists of HIV related work?

Percentage

Minimal ¹	5-10% ²	15-25% ³	30-45% ⁴	50% ⁵	55-70% ⁶	75-85% ⁷	85-90% ⁸	100% ⁹	
					Hours/day				
					Days/week				
7.2 Does the time pressure in any way limit your work with the patients?					Yes ¹	No ²			
7.2.1 If yes, Please specify									
7.3 Do you have to make any priorities with regard to what you include in your work with HIV patients because of time shortage?					Yes ¹	No ²			
7.3.1									

ATT: PROF SRINIVAS



Eastern Cape Department of Health

Enquiries: Zonwabele Merle
Date: 01st June 2006
e-mail address: merle@ecdhpc.escpe.gov.za

Tel: 040 509 3810

Fax: 040 639 1440


Dear Miss Karine Wabonud

Re: The role of the different health care personnel in the rollout of the antiretroviral treatment programme at Settlers Hospital, Grahamstown.

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants. You will not impose or force individuals or possible research participants to participate in your study. Research participants have a right to withdraw anytime they want to. However, you shall be responsible in dealing with any adverse effects following the research treatment provided in your study.
3. The Department of Health expects you to provide a progress of your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.


DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT

Appendix 5



RHODES UNIVERSITY
Grahamstown • 6100 • South Africa

FACULTY OF PHARMACY • Tel: (046) 603 8381 • Fax: (046) 636 1205

28 April 2006

Miss Karine Waboruud
Faculty of Pharmacy
Rhodes University

Dear Miss Karine Waboruud

ETHICS APPROVAL: The role of the different health care personnel in rollout of the antiretroviral treatment programme at Settlers Hospital, Grahamstown.

I am pleased to inform you that your application for ethical approval of the above study has been considered and approval has been granted. You may proceed with your study.

Thank You

Yours Sincerely

A handwritten signature in black ink, appearing to read 'Santy Daya', written over a horizontal line.

Professor Santy Daya
Chairman: RUESC

Appendix 6

From:

Karine Wabo Ruud
Faculty of Pharmacy
Rhodes University
Grahamstown, 6140
June 2006

To:

Makana Municipality
Grahamstown

Request for permission to conduct research

I, Karine Wabo Ruud am in Grahamstown from February until November 2006 for master study in pharmacy, doing research with Professor Sunitha Srinivas. For that purpose I would kindly request for permission to interview health care personnel involved in work with HIV patients in public clinics and hospitals in Grahamstown. My master topic is in social pharmacy, on the role of the different health care personnel in the work with HIV patients. This request is for permission to do structured interviews with health care professionals only, as no patients will be involved in the study.

My proposal for carrying out the study has been approved by the ethics committee at Rhodes University (April 2006) and by Department of Health, Eastern Cape (June 2006).

With regards,

Karine Wabo Ruud

Approved by Department of Health, Makana Municipality, Grahamstown;

.....
Signature

12/06/2006
.....
Date

Appendix 7

World Health Organisation Adults HIV and AIDS Staging System

Stage I

1. Asymptomatic
2. Persistent generalised lymphadenopathy (PGL)
3. Acute retroviral infection (sero-conversion illness) and/or performance Scale 1: asymptomatic, normal activity.

Stage II

4. Unintentional weight loss <10% of body weight
5. Minor mucocutaneous (e.g. seborrhoea, prurigo, fungal nail infections, oral ulcers, angular cheilitis)
6. Herpes zoster within the last five years
7. Recurrent upper respiratory tract infection (e.g. bacterial sinusitis) (URTI) and/or performance Scale 2: symptomatic, normal activity.

Stage III

8. Unintentional weight loss >10% of body weight
9. Chronic diarrhoea >one month
10. Prolonged fever >one month
11. Oral candidiasis
12. Oral hairy leukoplakia
13. Pulmonary TB within the last year (PTB)
14. Severe bacterial infections (pneumonia, pyomyositis)
15. Vulvovaginal candidiasis >one month / poor response to therapy and/or performance Scale 3: bedridden <50% of the day during the last month.

Stage IV

16. HIV wasting (8+9 or 10)
17. *Pneumocystis carinii* pneumonia (PCP)
18. CNS toxoplasmosis (Toxo)
19. Cryptosporidiosis plus diarrhoea >one month
20. Isosporiasis plus diarrhoea
21. Cryptococcosis – non pulmonary
22. Cytomegalovirus infection other than liver, spleen or lymph node (CMV)
23. Herpes simplex infection; visceral or >one month mucocutaneous (HSV)
24. Progressive multifocal leucoencephalopathy (PML)
25. Disseminated mycosis (i.e. histoplasmosis, coccidiomycosis)
26. Candida oesophageal/tracheal/pulmonary
27. Atypical mycobacteriosis disseminated (MOTT)
28. Non-typhoidal Salmonella septicaemia
29. Extra-pulmonary tuberculosis (ETB)
30. Lymphoma
31. Kaposi's sarcoma (KS)
32. HIV encephalopathy (ADC)
33. Invasive cervical carcinoma and/or performance Scale 4: bedridden >50% of the day during the last month