A Study on Social Support and ART Adherence at Carletonville Hospital and Zola Clinic in Gauteng Province

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Declaration

I hereby declare that this research report has not been submitted for a degree or diploma in any university. All the work contained is original unless otherwise acknowledged.

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Abstract

The challenges facing the health system in South Africa are likely to impact on life-long adherence for patients in the context of the rollout of ART. Smaller ART programs have been able to demonstrate good adherence rates, but the question remains if this can be achieved by large public sector ART programs. Most adherence researchers share the basic understanding that patients are adherent when they take their medications as prescribed by the health provider. An approach to adherence that combines both clinical and social knowledge—a biosocial approach—is likely to move us to a better understanding of adherence and how to improve adherence to ART. This study on social support and ART adherence aims to gather and document information that could be used to improve services and program strategies for strengthening and maintaining adherence at ART rollout sites in Gauteng. The two study sites Carletonville Hospital and Zola Clinic were chosen randomly from all second-generation rollout sites in the Province. Data were collected from a total of 359 respondents, 164 in Carletonville and 195 in Zola. The response rate was 98.3%.

The results showed that the majority of the respondents were female (72.1%) and about 44.9% were within the age group 30-39 years. In terms of educational attainment, most respondents (70.1%) had received secondary education and 2.5% had not attended school. Based on assets quintiles scores of 1-5, with 5 being the highest score, about one-third of the respondents scored 1, and only 7% scored 5. Compared with Carletonville, respondents from Zola were more educated and better resourced. At the facilities, treatment preparation and support and adherence assessment procedures are routine features of the ART program and entail pre and post test counseling, group education and adherence counseling and serve as mechanisms for adherence support. This is enhanced by routine follow-up appointments where ART patients are provided information on side effects of ARVs, effectiveness of treatment, CD4 cell and viral load counts and

referral to services not provided at the facility. Additionally, support groups accessed by patients undertake a range of educational activities on staying healthy, viral load and CD4 cell counts and ARVs. Although respondents were largely positive about their interactions with health providers and the support they provided, some expressed concern about health workers being too busy to address their problems, not treating patients with enough respect and sometimes patients leaving without receiving treatment because staff were either absent or late or queues were too long.

The HIV disclosure rate was high (95.5%). However, respondents were more likely to disclosure to a family member, but less likely to a friend, neighbor or religious leader. Self-reported adherence and viral load adherence rates were high (97.6% and 76.6% respectively) but CD4 adherence was lower at 51.0%. The study did not document a convincing association between social support and ART adherence. Only two variables (receiving food supplements and age groups) were significantly associated with CD4 and viral load adherence.

Given the limitations of the study, a longitudinal study is needed in these sites to better understand the predictors of short and long-term adherence and to explore ways to better measure the relevance, content and quality of the social support services being utilized by ART patients at facility and community levels. Interventions and policies are needed to respond to the concerns identified from the study regarding inadequate attention and respect by health providers, absence or lateness of doctors and pharmacists and challenges pertaining to access to food, income and disability grants.

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CHAPTER ONE

1.0: BACKGROUND

The study on social support and antiretroviral therapy (ART) adherence is part of a larger study coordinated and supervised by the Centre for Health Policy (CHP), University of Witswatersrand to investigate and understand the factors affecting adherence to anti-retroviral therapy (ART) in poor urban communities in South Africa. The study was conducted in Carletonville Hospital and Zola Clinic and complements the other arms of the CHP study, which examined: (i) the quality of patient and client interactions and loss to follow-up; (ii) organizational capacity to deliver ART services; and (iii) organizational factors affecting adherence. The four study sites were Carletonville and Natalspruit Hospitals and Zola and Empilisweni Clinics in Gauteng Province.

1.1: THE SOUTH AFRICA ART PROGRAM

The South African Cabinet approved a plan for a national HIV/AIDS treatment rollout program in 2003 (1). The goal of the plan was for at least one service delivery point in each district to be able to provide treatment in the first year, followed by the development of more treatment points. To meet requirements to provide ART, in addition to medical services, sites would have a 'full range of community support services' including counseling, adherence support, community mobilization, home and community based care and palliative care. The Department of Health identified key challenges to implementing the treatment Operational Plan to include: strengthening existing programs that provide entry points to treatment (VCT, PMTCT, TB programs); building strong partnerships between health facilities and community support structures; and obtaining good patient information.

Approximately 175, 000 of the 983,000 estimated by UNAIDS to be in need of treatment in South Africa were receiving ARVs by July 2006 through the public sector. It is estimated that another 100,000-110,000 people are on ARVs through the private sector and so far ART services have been rolled-out in 273 sites, with an estimated 68.8% coverage. (2). The number of ART accredited sites in Gauteng Province stands at 27, and rollout of treatment began in 2004. According to the National Department of Health, 55,580 adults and 6,301 children had accessed ART at the end of October, 2006.

In order to improve coverage and strengthen the ART program, the treatment care and support priorities of the recently approved South Africa Strategic Plan (2007-11) include the following: a) ensuring uninterrupted supply of appropriate drugs; b) building the capacity of health professionals to provide comprehensive HIV and AIDS, STI and TB treatment and other related conditions and c) establishing a strong link between health facilities and community-based support programs.

1.2: LITERATURE REVIEW

1.2.1: Definition of social support and measurement of adherence

Social support is defined in many ways, but the core principle relates to the ways and sources of support people going through difficult situations can access in order to cope. One definition describes three components of social support: emotional support which has to do with comforting through physical affection or expressing concern for wellbeing; guidance support which has to do with giving knowledge on how to do something or suggesting some helpful action; and tangible support which includes provision of material assistance such as housing, money, transportation and others. (3). Another definition focuses on the sources of social support, describing it as the physical and emotional comfort given by family, friends and co-workers and

others as well as knowing that one is part of a community of people who love and care, and value and think well of others (4). Family practitioners for example, see social support as a significant resource for individuals and family members encountering stress. There has, however, not been an adequate way to assess an individual's or a family's perception of the social support they are receiving. Definitions of social support should include two dimensions of social support: (a) the kinds of support available, such as emotional support; and (b) the sources of support, such as friends (5)

The survival of people diagnosed with HIV dramatically improves with access to ARVs. ARVs suppress viral replication and prevent further destruction of the cellular immune system thereby allowing increase in CD4+ cells, which improves immunological response to opportunistic infections. Adherence is usually described in terms of the proportion of doses of prescribed ARVs taken. Cut-off points often used are: 80-90% of all doses taken (adherence) and 60-70% (poor adherence) and under 60% (non-adherence) (6). But, the consensus is that in order to achieve undetectable viral load, and prevent the development of drug resistance, a person needs to take at least 95% of the prescribed drug doses. However, across a number of studies, results show that high rates of adherence do not always correlate with undetectable viral load (7, 8). This is partly a reflection of the way adherence is measured. There is no gold standard as to how adherence should be measured. Often patients are asked to report how many doses they have missed in last day, or two days or two weeks. Patient feedback may be influenced by poor recall, interest in providing a socially acceptable answer, or the quality of the interview. Alternatively CD4 counts and viral load measures may be used as a proxy measure of adherence.

In clinical trial conditions data from the USA suggest that 70-80% of patients are fully adherent to ART (9). In the African context, a case study from the Khayelitsha *Medecins sans*

*Frontieres (*MSF) project reported high levels of adherence resulting from combining simplified regimens with low pill burden and a comprehensive patient support program. A total of 89% of 73 respondents in 2003 reported adherence greater than 95% at three months on treatment. (10). In Uganda, self-reported adherence among 304 ART patients in Kampala was assessed to be comparable to levels in resource-rich settings (11). High adherence levels were also observed in a recent study from Uganda (12) in which participants received individual and group sessions on HIV prevention, care and treatment, family members received education, clients had support from a "medicine companion" and health workers delivered medications at home. The proportion of pills used and daily doses taken was 98-99%. A quarterly follow-up showed that less than 0.7-2.6% of clients took less than 95% of their pills, and 3.3 to 11.1% took less than 95% of daily doses. In the fourth follow-up quarter, 96% of participants had a viral load of <1000copies/μl. Independent predictors of high viral load (>1000 copies/μl) were pill use less than 95%, and taking less than 95% of the daily dose of medications. Research indicates that missing more than 5-10% of doses leads to incomplete suppression of viral replication and declining CD4 cell count (13, 14).

Despite challenges in measuring adherence, studies have shown a significant association between high levels of self-reported adherence and viral load count. For example, a South African study showed that among 700 patients investigated, over 95% of all doses had been taken on pill count returns, and 94% of the patients had viral suppression rates of less than 400 copies/ml (15).

Loss to follow-up is another factor that impacts on the success of ART adherence. A study conducted at the Helen Joseph Hospital analyzed data on 74 patients who had stopped attending the clinic. The results showed that 35% had died, 30% were still alive and the status of others was unknown. Of the patients who were living, the reasons for non-return to the clinic were: had moved

(43%), had side effects (19%), transport/financial problems (14%), employment factors (5%) and unknown reasons (19%) (16).

1.2.2: Factors affecting adherence

Currently, very different approaches and models are being adopted to promote ART adherence, but it is not clear if and how effective these are. A study in the USA, which examined barriers to positive adherence, showed that forgetfulness, social and physical environment, drug side effects and patient knowledge played a role. Factors associated with good adherence included use of mechanical devices, commitment, social and professional support and health beliefs (17). In comparison, recently reported results of a workplace ART program in South Africa (18) showed that being away from home, forgetfulness and feeling worse were commonly cited reasons for missing tablets. The study also examined reasons patients declined to initiate ARVs. The most common reasons for refusal were not being convinced of the benefits of treatment, and inability to accept HIV diagnosis.

In general, it is commonly acknowledged that multi-faceted interventions, including social support are needed for good chronic disease care outcomes, yet research on ART adherence has tended to focus on micro factors limiting themselves to experimental control such as educational strategies, scheduling accommodations to the regimen, and various forms of reminders, which achieve only modest results (19, 20).

Adequate attention has not been paid to research required to understand how social factors influence adherence. It is however, known that several sociological and psychological factors influence adherence of patients to treatment (21), and these have been summarized to include:

- *Scheduling demands and accommodations*. Scheduling demands are challenges which relate to work, daily routine and mealtime dosing, and scheduling accommodations are the steps taken to deal with these challenges e.g. pill-boxes, use of a timer, fitting work routine to fit daily medication schedule.

- *Cognitive demands/accommodations*: Cognitive demands refer to patient difficulties in concentrating, forgetfulness and inadequate information. Cognitive accommodations refer to accurate understanding of purpose of ART, feedback on adherence achieved, and patient education.

- *Mental health:* Refers to depression, hopelessness, anxiety, psychiatric morbidity, and avoidance of positive attitudes about the future, long term plans and goals, active-behavioral coping, and stable mental health all demonstrated consistent relationships with adherence.

- *Treatment and medication attitudes:* Fear and skepticism of the drug regimen, mistrust and myths regarding treatment, trust in drug efficacy and positive expectations of their effect are consistently associated with adherence.

- *Social climate:* Social support, confidentiality fears and fear of public exposure are either positively or negatively associated with adherence.

- *Provider support:* This includes the extent of support from the care provider, and the patient's perception of the provider's degree of caring.

1.3: STUDY JUSTIFICATION

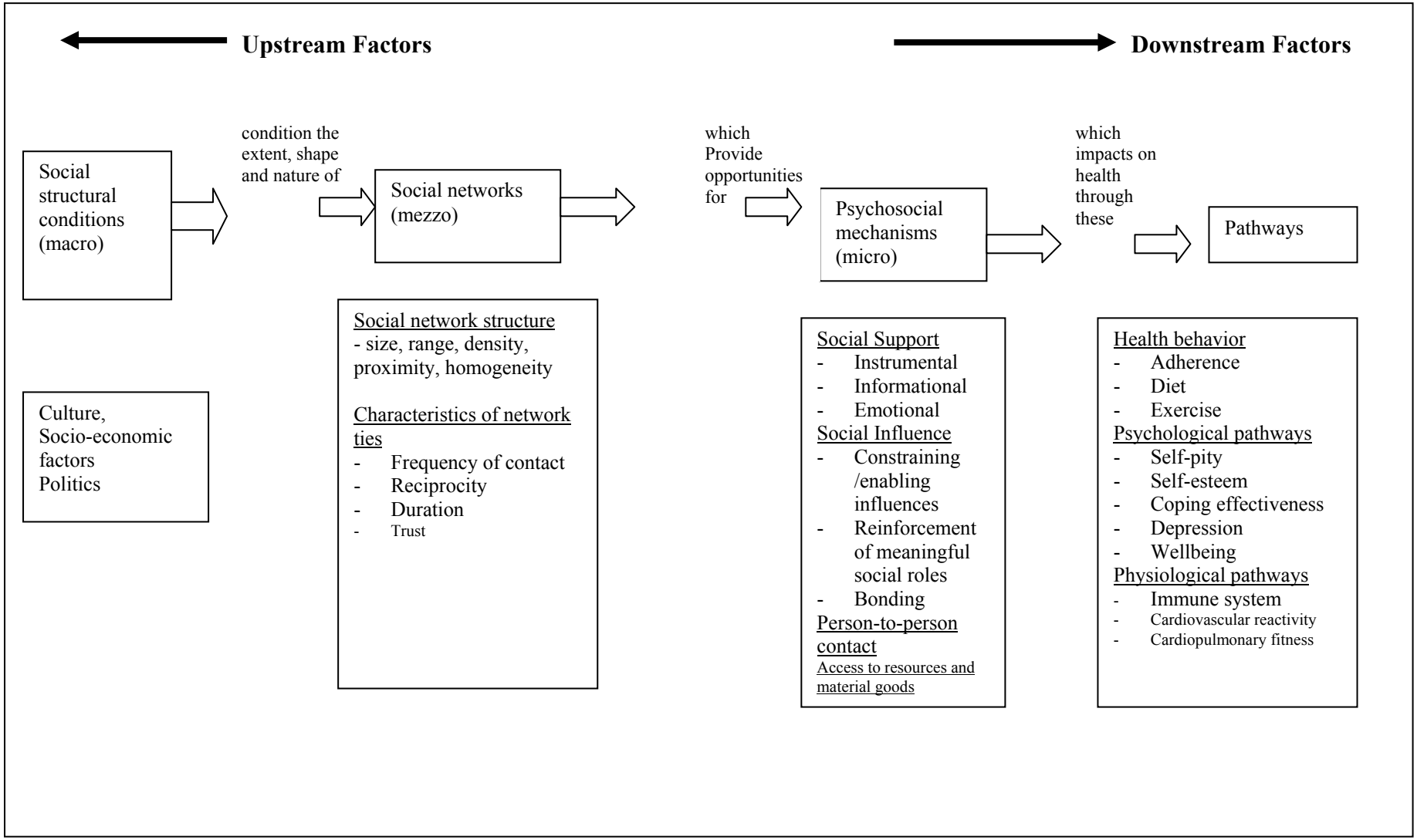
The challenges facing the health system in South Africa are likely to impact on life-long adherence for patients in the context of the rollout of ART. Smaller treatment programs have been able to demonstrate good adherence rates, but the question remains if this can be achieved outside carefully monitored sites such as the well-resourced MSF program in Khayelitsha, which has placed 2,000 people on ART since inception in 2001. By the end of 2004, 225 patients had been on treatment for more than two years. A study examining adherence in this group showed high

adherence levels, with 90% of the clients reporting that they were adherent after 12 months. The study concluded that among other things, social support from family, friends, support groups, treatment literacy as well as disclosure are critical for adherence. It found that men who were likely to be non-adherent were unmarried or lived alone, had poor social support, were reluctant to disclose and consumed alcohol (22). Similarly, a smaller study conducted at a government facility, the Helen Joseph Hospital in Johannesburg to determine the factors influencing adherence showed that over 92% of 184 patients on ART interviewed were adherent (less than 2 doses missed in the prior 3 weeks). Poor patient knowledge, negative perceptions of the provider-patient relationship, socio-economic barriers such as transport and lack of family support were associated with low adherence (23). However, more information is required to understand what is going on in the public sector ART programs in terms of social support and adherence given the goal to put 1.4 million people on treatment by the end of the decade.

Most adherence researchers share the basic understanding that patients are adherent when they take their medications as prescribed by the health provider. An emphasis on this limited approach impairs our understanding of adherence as a complex process embedded in the clinical and social course of AIDS. An approach to adherence that combines both clinical and social knowledge—a biosocial approach—is likely to move us to a better understanding of adherence and how to improve adherence to ART. The biosocial approach enables an understanding of how adherence changes over time, and the reasons for non-adherence. Berkman et. al. (24) developed a conceptual model to show how social factors impact on health (See Figure 1). These include macro factors – socio- structural conditions which influence the extent, shape and nature of social networks (mezzo factors), which create the opportunity for micro factors, largely psychosocial mechanisms to operate and impact on health through different pathways. There are four primary pathways through which micro factors impact upon health. These are through: social support, social influence, social engagement and attachment, and access to resources and materials.

This study will focus on aspects of psychosocial mechanisms (downstream factors) such as social support, social influences, and access to resources and materials, which could affect adherence to ARVs. It will assess how support from health providers, family and friends as well as HIV and ARV related knowledge, educational level and HIV disclosure relate to reported adherence levels and biological outcomes such as CD4 cell and viral load counts. Aspects of the framework by Berkman et al relevant to the study are highlighted.

Figure 1: How Social Integration Affects Health (Berkman et al 2000)



1.4: RESEARCH HYPOTHESIS

ART clients who receive social support that is sensitive, relevant, sustained and reinforced at different levels will be motivated to adhere to treatment and to remain in ART programs in the long-term. For this study, it is hypothesized that patients who have access to and participate in support group activities, receive support from health providers, family and friends, disclose their status and have high HIV, AIDS and ARV knowledge are likely to achieve high adherence levels.

1.5: STUDY OBJECTIVES

The study aims to gather and document information that could be used to improve services and program strategies for strengthening and maintaining ART adherence at two rollout sites in Gauteng. The specific objectives are to:

1. Determine what types of support services are available at facility and community levels for ART adherence in the sites of the study.
2. Investigate what social support services patients are using and how these services are meeting their needs.
3. Determine adherence levels among ART patients and examine the association between social support and adherence.

1.6: ETHICAL APPROVAL

The research protocol (Protocol Number M051101, 2005), and instruments for the study were submitted to the Committee for Research on Human Subjects (Medical), University of Witwatersrand in 2005. Approval for the study was given after minor corrections were made to the protocol based on suggestions from the Committee. See Appendix 1.

CHAPTER TWO

2.0: METHODOLOGY

Chapter two describes the methodology of the study including the study design, study sites and study population. It provides a brief outline of questionnaire development and pre-testing and describes some of the steps taken to obtain administrative approval to conduct the study and to gain access to the sites. Data management procedures and methods of analysis, the scope and limitations of the study and plan for dissemination of results are also discussed.

2.1: STUDY DESIGN

This is a cross-sectional descriptive study conducted in two randomly selected health facilities, a hospital and a community clinic in Gauteng Province. The study comprised of both quantitative and qualitative components. Exit interviews were conducted with ART patients, while in-depth interviews were conducted with key respondents involved with the ART program at the two sites. The study was conducted over a two-month timeframe. Data collection was first completed at the first site (Carletonville Hospital) before the second site, Zola Clinic was embarked upon. This approach made it easier to manage the logistics given the distance between the sites, and provided the opportunity for the research team to learn from the experience of the first site.

2.2: STUDY SITES

The two study sites, Carletonville Hospital and Zola Clinic were chosen randomly from all the second-generation rollout sites in the Province, which did not have the same magnitude of time and resources as were dedicated to the pioneer or champion rollout sites.

The Carletonville Hospital is a district hospital, while Zola Clinic is a community health center. These two facilities are located in regions A and B in Gauteng Province. The Carletonville Hospital started rolling-out ART in February 2004. At the time of the study, it had 377 patients still on the program, having enrolled 540 since inception. Daily services provided at the ART clinic include HIV testing, assessment of patients for ART, counseling, referral and follow-up appointments. About 50 patients are attended to each day. The ART clinic operates on Mondays, Tuesdays and Wednesdays and the Wellness Clinic on Monday to Friday. However, rollout services are available daily to accommodate patients who cannot attend on the designated days. The ART program team is headed by a Manager, and includes 1 doctor, 1 pharmacist, 2 professional nurses, 1 nursing assistant, 5 lay counselors, 1 dietician, 1 social worker, 2 clerical and 3 support staff.

At the Zola Clinic, the "Khululeka" Wellness/ART Clinic provides rollout services Monday to Thursday and wellness and follow-up services on Tuesdays and Thursdays. Zola Clinic started rolling-out ART in October 2004 and in total enrolled 1,001 with about 885 patients still using services. The daily client load is about 200. The ART program has a multi disciplinary team comprising 1 doctor, 2 professional nurses, 2 auxiliary nurses, 2 nursing assistants, 1 dietician, 7 lay counselors, 1 social worker, 1 pharmacist, 1 clerical staff and support staff. At both sites, the Comprehensive Care Management and Treatment (CCMT) Manager, a registered nurse, heads the ART program.

2.3: STUDY POPULATIONS

The respondents for the exit interview were HIV positive men and women who had been on ARVs for at least 3 months. Other inclusion criteria were: aged 18 years and over, willing to take part in the study and available for interview. All respondents meeting the

inclusion criteria were interviewed during their routine visit to the ART/Wellness Clinic. A total of 164 and 195 patients were interviewed in Carletonville Hospital and Zola Clinic respectively. Management and health staff including the ART Program Managers, doctors, pharmacists, nurses and social workers were interviewed to collect qualitative data.

2.4: INSTRUMENT DEVELOPMENT

A draft structured exit questionnaire was developed using questionnaires previously used to collect adherence data, or determined to be relevant to the study. The questionnaire addressed some of the key domains identified for the CHP studies aimed to understand the factors affecting access to ART in poor urban communities in South Africa (See appendix 2). After a number drafts were developed, the questionnaire was pretested with 8 individuals receiving ARVs at different facilities in Gauteng. The questionnaire was modified after the pre-test, and a workshop held to train interviewers was used to further refine and finalize the questionnaire. A final pretest was conducted with ART patients at the study sites prior to data collection. Once the researchers were satisfied, an adequate number of the questionnaire was reproduced for field use (See appendix 3). The unstructured, qualitative instruments used were developed and pre-tested by two members of the research team.

2.5: DATA COLLECTION

Permission to conduct the study was requested by the CHP and provided by the Provincial HIV/AIDS/STI/TB (HAST) Manager. The Provincial HAST Technical Adviser provided a letter of introduction to the ART Managers at the sites. At each site, key documents—questionnaire, ethics approval, letters of request and introduction (See Appendix 4a and b) and the study protocol were submitted to the facility management and

the research discussed. A meeting was also held with the ART Program Manager and staff to acquaint them with the research and to streamline the process and logistics for data collection. Seven interviewers were trained during a 2-day period to administer the questionnaire. Training activities included: a review of the different sections of the questionnaire, translation of key terms, questions, information sheet and consent form into local languages, role play and other practical exercises. Five of the 7 were selected to conduct interviews at the two sites, with one taking on the role of supervisor.

In Carletonville, respondents were interviewed in June and in July 2006 in Zola. All patients attending the ART clinic during this period were provided with information about the research by interviewers and requested to take part in the study. Respondents were informed of their right to participate or not to take part in the study, including withdrawing from the interview if they chose to. Those who met the inclusion criteria and agreed to participate were requested to complete the consent form after the research study and the consent process were explained to them. Data were collected on socio-demographic background, ART and HIV/AIDS knowledge, continuity of care, ART adherence, experience with ART services and social support. A total of 359 respondents were interviewed. The response rate was very high, only 6 people declined to take part in the study, giving a response rate of 98.3%. Qualitative and quantitative data collection took place simultaneously. Ms. N. Naidoo contacted key respondents to obtain their consent to participate and make interview appointments. To record feedback from the interviews, copious notes were taken, and later analyzed thematically.

2.6: DATA ANALYSIS

A data entry screen was created on EpiInfo and data from completed questionnaires were captured individually for the two sites. The data were then combined, and exported to STATA for analysis. Statistical analysis was conducted on variables relating to respondents' socio-demographic background, use of support services, ARV, HIV and AIDS knowledge and perceptions, interaction with health providers and adherence levels. Combined frequencies were obtained for variables of interest, and comparisons between respondents from the two sites were made to determine differences. The data analysis plan is summarized in Appendix 5**.**

Chi square and p-values were used to determine the association between ART adherence and social support. Adherence was measured in three ways: using self-reported adherence, viral load and CD4 cell counts. Self-reported adherence was based on a scale measuring: 100% adherence and more than 5% missed tablets. Viral load and CD4 cell count were obtained from patients' records. CD4 cell counts were categorized in two groups: CD4≤200 cells/ml and >200 cells/ml, while viral load counts were grouped into: VL≤400 copies/ml and > 400 copies/ml to measure adherence and non-adherence respectively.

A record review form was designed to collect routine data from clients' records. This included data on: date when ART was started; total number of visits scheduled; CD4 and viral load counts and TB screening and treatment. See Appendix 6.

CHAPTER THREE

3.0: RESULTS

The results section focuses on the three objectives of the study. The results framework covers the description of the types of support services available at facility and community levels to promote ART adherence as well as institutional support to promote adherence; results on how ART clients are using available support services and their perceptions of these services, and the levels of adherence to ART using three measures—self-reported adherence, viral load and CD4 cell counts and how these relate to social support (See Annex 7). Clinic records at Zola indicated that of the 1001 patients enrolled since the program started, 885 were still in the program giving a dropout rate of 11.6%. In Carletonville, of 540 that had enrolled, 377 were still on treatment, giving a dropout rate of 30.1%. The dropout rate at Carletonville is about 2.5times higher than at Zola.

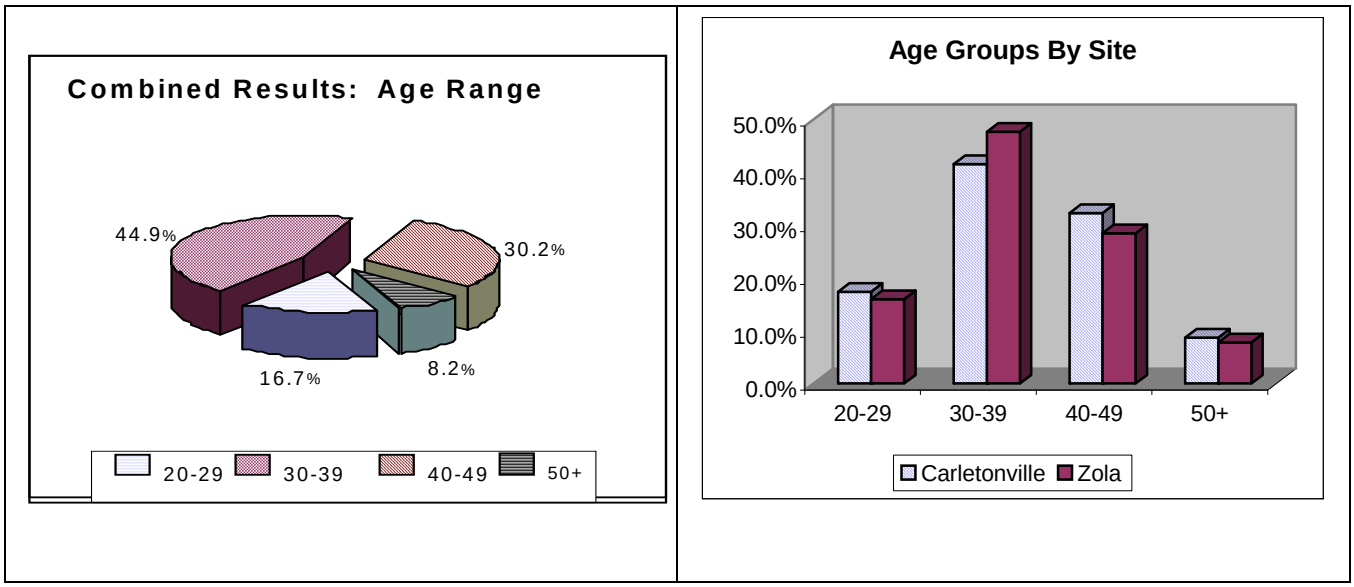
3.1: SOCIO-DEMOGRAPHIC PROFILE OF RESPONDENTS

The socio-demographic profiles of respondents are described below. These include, age, gender, educational level and economic status. The results were analyzed in two ways - aggregated for both sites, and disaggregated by site to compare differences.

3.1.1 Age distribution

Respondents' ages were categorized into 4 groups: 20-29 years; 30-39 years; 40-49 years and over 50 years. Respondents' age distribution is shown in Figure 2.

Figure 2: Age Distribution of Respondents (n=354)



Combined, the results show that most of the respondents fell within 30-39 years (44.9%), followed by 40-49 years (30.2%). Respondents from Zola were slightly younger than those in Carletonville. 47.7% of Carletonville respondents were aged 30-39 compared with 41.6% in the same age group in Zola. Slightly more respondents in Carletonville were in the age groups 40-49, and 50+ years, but these differences were not statistically significant.

3.1.2 Gender distribution

The proportions of males and females in the study are shown in Figure 3 below. Considering the combined results, the vast majority of respondents were female (71.9%). Comparing sites, the proportions of females and males were about equal: females - 72.4% and 71.3%; and males - 27.6% vs. 27.7% in Carletonville and Zola respectively. Overall, females were approximately 2.5 times more than males. Across age groups, females were 2-8 times the proportion of males, with the highest difference seen in 20-29 year olds (8 times); the magnitude of difference was least among 40-49 and 50+ (2 times). The age

group difference between females and males was significant (Chi2= 12.986, p value=0.005). See Figure 3b.

Figure 3a: Proportions of Males and Females (n=359)

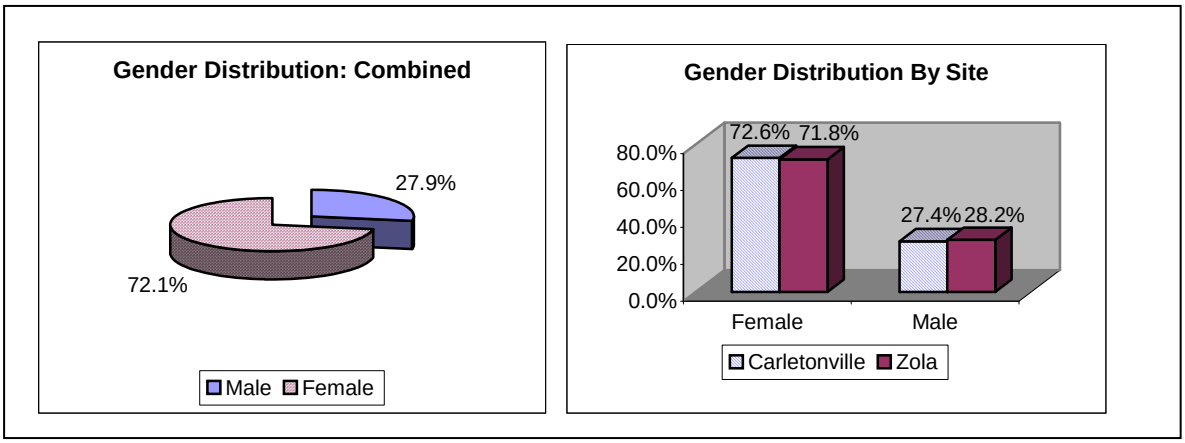
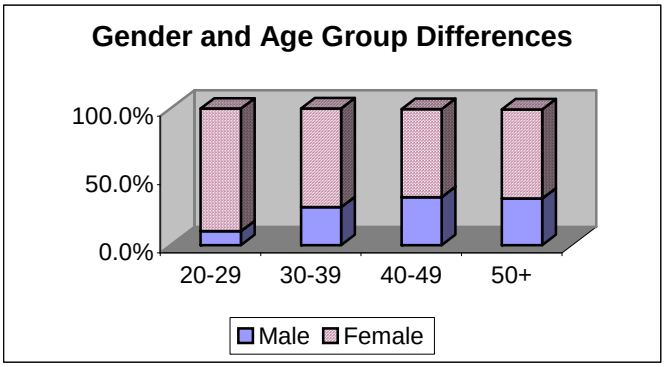


Figure 3b: Distribution of Age Across Gender

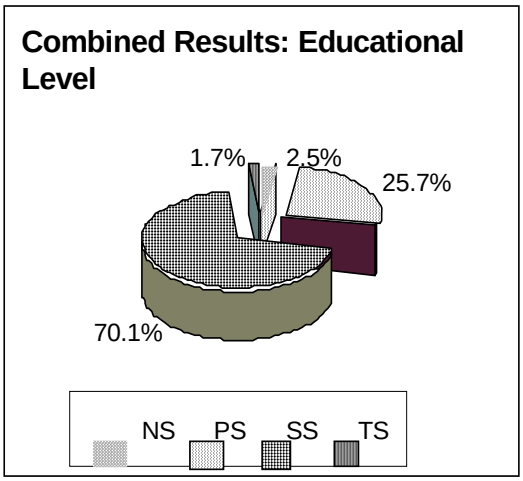


3.1.3: Educational levels

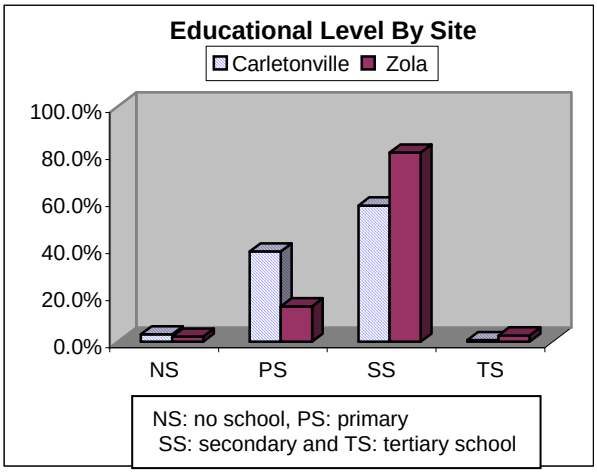
This was grouped into 5 main categories as follows: NS- no school; PS: primary school; SS: secondary school and TS: tertiary school. In total, 2.5% of respondents had no schooling at all compared with 97.5% who had had any schooling. The combined results show that most respondents (70.1%) had received secondary education while only 1.7% had received tertiary education. (See Figure 4). Examining the levels of education, respondents from Zola appeared to be more educated than those from Carletonville.

Comparing respondents who had attended only primary school at both sites, the proportions were 38.4% in Carletonville and 15.0% in Zola. The difference was more marked when secondary school attendees were compared - 57.9% in Carletonville and 80.4% in Zola. The difference in the level of education between the two sites was significant. (Chi2= 27.849; p value = 0.000).

Figure 4: Educational Levels of Respondents



(n=358)

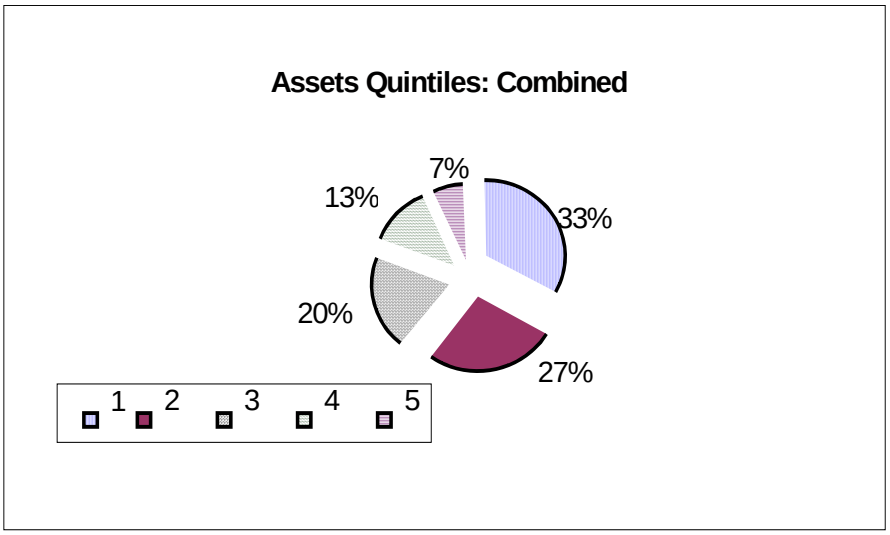


Carletonville: n=164
Zola: n=194

3.1.4 Assets quintiles

Asset scores for each household were generated using principal component analysis across all study sites. Quintiles were then used to group the households, with 5 being the highest and 1 the lowest score, ranking the economic status of respondents. This rating was based on scores derived from groupings of assets and resources accessible to or owned by respondents and their household such as TV, fridge, car, type of housing lived in and fuel used for cooking and heating. See Figure 5 for combined distribution of asset quintile scores. The combined results show that most respondents, 33% had a score of 1 and 27% had a score of 2, and only 7% had a score of 5.

Figure 5: Assets Quintile Scores of Respondents (n=359)



Site-specific results indicate that respondents from Zola had a higher ranking than their counterparts from Carletonville (See Table 1.). Approximately 10% of Carletonville respondents and 27% of Zola respondents had a ranking of 5. Slightly more than twice as many respondents in Carletonville compared with Zola have a ranking of 1. These differences are statistically significant. (Chi2=34.831; p value = 0.000). Assets scores were similar across gender.

Table 1: Assets Quintile Scores by Site (%)

	1	2	3	4	5	Total
Carletonville (n=164)	29.9	17.1	27.4	15.9	9.8	100%,
Zola (n=195)	13.3	17.4	16.4	25.6	27.2	100%

P value = 0.000

3.1.5: Access to income and grants

About three-quarters of respondents in Carletonville (78.0%) and over one-quarter in Zola (37.4 %) were receiving a disability grant at the time of the study. 57.1% of respondents in Carletonville and 46.7% in Zola who were not on a disability grant reported having applied for one. In total, only a small proportion of respondents, about 1%, were on a medical aid

scheme. The proportion of respondents receiving food supplement in Carletonville is about three times higher than in Zola. Combined, only about 15% of respondents reported earning income in the last 2 weeks. Of those who earned income in the last two weeks, Carletonville had 11.6% and Zola 18.5%. Significant differences were seen for the two sites for two variables – receiving disability grant and food supplement (See Table 2).

Table 2: Percentage of Respondents Receiving Financial and Material Resources

	Combined (n=359)	**Carletonville (n=164)**	**Zola (n=195)**	**P value**
	%	%	%	
Has disability grant	56.0	78.0	37.4	0.000
Applied for grant	49.0	57.0	46.7	0.277
Has medical aid	0.8	0.6	1.0	0.666
Gets food supplement	5.9	9.2	3.1	0.015
Earned income	15.3	11.6	18.5	0.072

Of those who worked, 52.6% in Carletonville and 57.2% in Zola described themselves as employed fulltime, while 15.8% in Carletonville and 11.1% in Zola reported being self-employed. About the same proportion from both sites said that they were part-time or causal workers (see Table 3).

Table 3: Description of Employment Status (%)

	Carletonville n= 19	**Zola n=35**
Fulltime	52.6	57.2
Self employed	15.8	11.4
Part-time	31.6	31.4
Total %	100	100

P value =0.893

Although the proportions are small, seven times as many respondents in Zola reported that people at home often go hungry compared to Carletonville and nearly twice as many respondents in Carletonville compared to Zola said that household members rarely go hungry. These differences are statistically significant – Chi2=12.88, p value 0.012. (See Table 4). These results suggest that respondents in Zola are more likely to have problems meeting their nutritional needs despite reporting earning an income and having higher assets quintile scores compared to Carletonville.

Table 4: Proportions of Hungry Household Members (n=359)

	Carletonville (n=195) %	**Zola (n=1640) %**
Often	1.2	7.7
Sometimes	46.3	50.3
Rarely	7.9	4.1
Never	44.5	37.9

Chi2 = 12.883; p value =0.012

3.2: SUPPORT SERVICES AVAILABLE AT FACILITY AND COMMUNITY LEVELS

A detailed description of the results pertaining to the types of support services at facility and community levels reported by respondents and health care providers is provided in this section. The results were derived from data collected through in-depth interviews with key respondents at the two sites, observations and exit interviews with ART patients.

3.2.1: Facility and NGO support

Using data from in-depth interviews and observations made during data collection, available facility and community-based support services were assessed. The results show that treatment preparation and support and adherence assessment procedures are routine

features of the ART program in Carletonville and Zola. However, there are some variations in their implementation. In both sites, treatment preparation entails pre and post test counseling, group education and adherence counseling, which serve as mechanisms for support. Home visits are conducted by the social worker in Zola, but not in Carletonville because it lacks the capacity to engage in this service. Home visits are used to assess patients' social background to determine if there are any barriers to adherence. Treatment support also includes follow-up appointments, supply of pill-box (Carletonville only), tick/diary sheet and facilitation to access support group services. At Zola, the Clinic is run with the participation of a Clinic Community Committee, which addresses community and social issues affecting ART services.

In Carletonville, NGOs and home-based care organizations such as the Kokosi and Carletonville Home Based Care Organizations provide support for HIV positive people. Also, the VCT unit runs a support group on Tuesdays, but it is unclear why ART patients tend not to use this service that is located on a different floor from the ART clinic. The program manager reported that while patients are not required to nominate a treatment buddy, peer support has developed spontaneously among them. ART patients support one another, and often patients will notify the staff if a patient does not attend the clinic. Zola ART clients and affected families have access to support groups organized by the Red Cross and Hope*worldwide*. In addition, ECHO provides both clinical and support services, operating a children's VCT service once a week.

Lay counselors prepare patients for treatment, assist with on-going adherence counseling and provide support to patients who are experiencing problems with their medication. Social workers also provide support to patients by assisting them with

accessing disability grant, phoning patients who do not show up for their appointment and helping to address family problems reported to them. Nutritional support is usually in the form of the provision of E/PAP (a high protein supplement) to patients who are underweight. Advice on the right type of food to eat is given to patients by the nutritionist/dietician.

To assess adherence, patients are required to report treatment compliance. In Carletonville a 3-4 day recall period is used. Zola uses a 14-day recall period to assess self-reported adherence. A monthly follow-up visit to collect medication and to conduct pill count is required. Viral load and CD4 cell counts are carried out at both sites every six months. These measures are all used to assess adherence to medication, clinical outcomes and compliance with clinic attendance.

3.2.2: Information, education and communication

Respondents appeared to be exposed to information and education from two sources: a) from health facilities and providers and b) from support groups. In both facilities it was observed that there were several educational materials displayed in visible and accessible areas such as the laboratory, corridors, and television and consultation rooms. These materials included charts depicting different ARVs by color, size and name and samples of ARV pills. Also, written information and pamphlets translated into local languages were available in Zola. As part of the preparation for treatment and during routine visit and assessment, patients are given a wide range of information including: side effects of ARVs, effectiveness of treatment, CD4 cell count, viral load count and information on where to obtain services not provided at the facility. Support groups conduct a range of educational

activities such as: advice and information on staying healthy, viral load and CD4 cell count and ARV education.

Overall, respondents' knowledge and perceptions on HIV and ARVs are impressive. These relate to respondents' responses to questions pertaining to: transmission of HIV when on ARVs, use of ARVs when one gains weight or has no opportunistic infections and having unprotected sex while on ARVs. Compared by sites, the differences are statistically significant for all the variables examined. (See Table 5). Respondents in Zola have higher knowledge levels and better perceptions compared with those in Carletonville. Also, combined, just over half of the respondents (55.4%) said they could name the drugs they take and by site the proportions were 30.1% in Carletonville and 69.9% in Zola (Chi2=43.403, p value=0.000).

Table 5: Levels of ARV Knowledge and Perceptions

True	Combined (n=359) %	Carletonville (n=164) %	Zola (n=195) %	P value
People on ARVs can transmit HIV	89.1	79.9	96.9	0.000
Can stop ARVs after weight gain	2.0	4.3	0.0	0.003
Can stop ARVs when no longer have OIs	2.2	4.3	0.5	0.035
ARVs cure AIDS	3.1	5.5	1.0	0.017
Can stop ARVs after some years	1.7	3.1	0.5	0.008
Missing a few tabs is ok	1.7	3.1	0.5	0.051
Unprotected sex safe if on ARVs is safe	1.4	3.1	0.0	0.001

3.3: USE OF SOCIAL SUPPORT SERVICES AND ENABLING ADHERENCE FACTORS

The study examined levels and preferences around disclosure and how respondents were accessing and utilizing available support services to facilitate adherence to treatment. The results are presented below.

3.3.1: HIV and AIDS disclosure

The combined disclosure rate (to anyone other than a health worker) was high - 95.5%. Disclosure rates are significantly higher for Zola, 99.0% compared with Carletonville, 91.5% (Chi2=11.801, p value=0.001). Overall disclosure rates for males and females were similar, 94.9% and 95.6% respectively. When whom respondents had disclosed to is considered, they were less likely to have disclosed to neighbors and religious leaders, but more likely to have told a family member or friend. Comparing Carletonville and Zola, there was a significant difference between the two sites regarding disclosure to family member (85.4% vs. 96.9%, Chi2 sq= 15.536, p value= 0.000), disclosure to a friend (47.6% vs. 60.5%, Chi2=9.213, p value=0.010), disclosure to neighbor (23.8% vs. 38.0%, Chi2 sq=11.028, p value = 0.004) and disclosure to a religious leader (35.4% vs. 30.8%, Chi2=5.749, p value=0.055). (See Table-6). Of the 74% of respondents who reported having a partner, 70% of them said they had disclosed to their partner.

Table 6: HIV Disclosure

Disclosed to:	Combined (n=359)	Carletonville (n=164)	Zola (n=195)	P value
Family member	91.6	85.4	96.9	0.000
Friend	54.6	47.6	60.5	0.010
Neighbor	31.5	23.8	38.0	0.004
Religious leader	32.9	35.4	30.8	0.056

On why they would keep their status a secret, respondents gave a wide range of reasons. Combined, the most prevalent reasons were fear of violence (62.4%), lack of trust in people (78.0%), fear of being denied help (77.4%), fear of stigmatization (74.4%), fear of gossip (77.4%), and fear that the community will know (76.3%). No significant difference was observed when findings were disaggregated by gender in terms of whom they had disclosed to. However, 8.4% of males and 4.8% of females reported that they had not disclosed to a family member. A significant difference was seen between the two sites with respect to: fear of family rejection (29.9% vs. 10.8%, Chi2 20.722, p= value 0.000); fear of rejection by friends (51.8% vs. 38.5%, Chi2=6.443, p value =0.011); and fear of explaining to partner (38.1% vs. 26.2%, Chi2= 5.646; p value = 0.016). For these variables, respondents from Carletonville were more likely to have expressed fear than those from Zola. (See Table 7).

Table 7: Reasons for Non-disclosure

Reasons	**Combined (n=359) %**	**Carletonville (n=164) %**	**Zola (n=195) %**	**P Value**
Family rejection	19.5	29.9	10.8	0.000
Rejection by friends	44.6	51.8	38.5	0.011
Fear of violence	62.4	67.7	58.0	0.058
Don't trust people	78.0	79.3	76.2	0.447
Will not get help	77.4	79.2	75.9	0.593
Stigmatization fear	74.4	78.7	70.8	0.088
Fear of gossip	77.4	81.1	74.4	0.128
Fear Com. will know	76.3	79.9	73.3	0.146
Fear explaining to partner	31.6	38.1	26.2	0.016

3.3.2: Reported use of support group services

In total, only 12.6% of the respondents reported being a member of a support group. There was no significant difference between males and females and between sites in terms of support group membership. Combined, 11.8% of females and 14.3% of males belonged a support group. By site, support group membership was 12.8% in Carletonville and 12.5% in Zola. With respect to support group activities, most respondents participated on a weekly basis, 85.7% in Carletonville and 66.7% in Zola (See Table 9).

Table 8: Participation in Support Group Activities (n=45)

Sites	Weekly %	Monthly %	Occasionally %	Total %
Carletonville (n=18)	85.7	4.8	9.5	100
Zola (n=16)	66.7	8.3	25.0	100

The most frequently mentioned support group services utilized were: advice on healthy living, ARV information, treatment buddies, individual counselling and income generation activities. Facilitation in collecting medicines and food assistance were mentioned by only about half of the respondents who belonged to a support group. The results were generally comparable across the sites for most of the variables, but non-significant differences were seen for some variables e.g.: treatment buddies, home visits, food and IGA. (See Table 9).

Table 9: Use of Support Group Services (n=45)

%	Combined (n=45)	Carletonville (n=21)	Zola (n=24)	P Value
Healthy living advice	93.5	95.2	91.7	0.632
ARV Info	93.5	95.2	91.7	0.632
Treatment buddies	93.5	100.0	87.5	0.094
Help collect medicines	55.6	57.1	54.2	0.841
Home Visit	75.6	81.0	70.3	0.431
Food	60.0	47.6	70.8	0.113
IGA	82.2	76.2	87.5	0.322
Individual counselling	91.1	90.5	87.5	0.889

3.3.3: Health provider support and interactions

Respondents reported on various types of support from and interactions with health providers. These were: being able to discuss with health workers in private, receiving full information on treatment, feedback on whether or not the treatment was working and communicating on sensitive issues such as disclosing if they missed taking tablets. Respondents' perspectives on whether they were treated with respect, cared for, or referred to other facilities to receive services not provided in their own facility were also explored.

The vast majority of respondents (79.4%) reported that they were able to communicate with their health provider in private. There was a significant difference (Chi2 =19.373, p value=0.000) when both sites were compared. 89.6% of respondents in Carletonville compared with 70.8% in Zola reported ability to discuss with their provider in private. However, 55 (69.6%) of the 79 respondents who could not discuss in private said that they were not bothered by this situation, a possible reflection of the high level of trust which the patients have in the providers. 32.0% of the respondents said that health workers were too busy to discuss their problems. There was a significant difference between the two facilities; about twice the proportion of respondents in Zola reporting that health workers were too busy. (40.5% vs. 22.0%; Chi2= 15.377, p value= 0.004).

With respect to support received from health workers, only about 11.0% reported that health workers did not discuss fully with them how the treatment works and side effects. More respondents in Carletonville compared to Zola said that they did not receive adequate feedback on side effects of ARVs from health workers. (19.5% vs. 3.6%, Chi2= 25.399, p value=0.000). 96.1% agreed with the statement that their health worker provided them feedback on whether on not their drugs were working. Also, 97.5% of respondents agreed that the health worker understood the difficulty in taking ARVs and provided assistance. No significant difference was observed when results from the two sites were compared. The vast majority of respondents, 94.4% said that they were assisted to obtain care elsewhere (See Table 10).

Table 10: Level of Support Received from Health Workers (%)

Agreed	Combined n=359	Carletonville n=164	Zola n=195	P value
Able to discuss with HW in private	79.4	89.6	70.8	0.000
HW did not discuss treatment & ARV side effects fully	10.9	19.5	3.6	0.000
Difficulty telling HW if missed tablets	44.6	39.6	48.7	0.084
HW too busy to listen to problems	32.0	22.0	40.5	0.004
HW provided support to take tablets	97.5	97.6	97.4	0.666
HW provided feedback on whether drugs were working	96.1	94.5	97.4	0.438
HWs do not treat patients with sufficient respect	60.7	50.0	69.7	0.000
Given help to obtain care elsewhere	94.4	92.1	96.4	0.135
HW cares about me	95.0	97.0	93.0	0.095
Left without receiving help	17.6	3.7	29.2	0.000
Queues are too long	89.7	87.8	91.3	0.290

The majority of patients (60.7%) said that staff did not treat patients with enough respect, and a significant difference was observed between the two sites (Chi2= 24542, p=

value 0.000). 50.0% of Carletonville compared with 69.7% of Zola respondents reporting that staff did not treat patients with sufficient respect. Even though the majority of respondents reported this finding, they nonetheless felt that health staff cared for their patients. Overall, 95.0% said that the health workers they see cared for them. There was no significant difference between the two sites.

Regarding satisfaction with services obtained, altogether 17.6% reported that they had left the hospital without receiving treatment since enrolling. Comparing the two sites, 29.2% of Zola, and 3.7% of Carletonville respondents reported having left without treatment (Chi2= 40.551, p value = 0.000). The key reasons for not being attended to are listed in Table 11. They are absence or lateness of the pharmacist or doctor or long queues.

Table 11: Reasons for Not Being Treated

Reasons	**Carletonville % n=6**	**Zola % n=57**
Pharmacist absent/late	0.0	64.5
Doctor absent/late	0.0	17.0
Long queue	0.0	8.3
No ARVs	0.0	3.4
Staff were too busy	16.7	0.0
Left to see another doctor	16.7	0.0
Other reasons	66.7	7.0
Total	100%	100%

3.3.4: Support from family and friends

The types and use of support services provided by friends and family members were assessed. These included home visits, sending “sms” messages as reminder to take medication, providing food, transport money and emotional support. Combined, the majority of respondents (88.0%) reported receiving emotional support from friends and family members compared with 46.8% who received “sms” messages and 59.5% who were

visited. About three-quarters said that they receive food and transport money to attend their follow-up ART appointment. The results were similar for the two sites, except that in Carletonville a significant proportion of respondents reported receiving transport money, 77.4% vs. 67.5%, chi2=4.637, p value=0.031 compared to Zola. (See Table 12)

Table 12: Help Received from Family and Friends

%	Combined n=359	Carletonville n=164	Zola n=195	P value
Visit home	59.5	60.4	58.3	0.684
Send sms	46.8	46.3	47.2	0.874
Give food	77.9	78.1	77.8	0.889
Give transport money	72.1	77.4	67.5	0.031
Give emotional support	88.0	87.2	88.7	0.658

Respondents were asked to specify if the behavior of the people they related with was supportive, unsupportive, both supportive and unsupportive or not relevant. Pertaining to how supportive friends, family and colleagues were toward respondents, combined the results showed that supportive attitudes were more commonly expressed by family members (87.5%) than by friends (52.9%) and people they lived with (36.2%). Only 10.9% reported that their colleagues were supportive. With respect to the two sites significant differences were observed for family, friends and colleagues. See Table 13. Of respondents who reported having a partner/spouse, in total 80% described their partner/spouse as supportive; by site, 91.1% in Carletonville and 73% in Zola reported that their partner/spouse was supportive.

Table 13: Support from Family, Friends and Colleagues (n=359)

Supportive behaviour	Combined n=359	Carletonville n=164	Zola n=195	P value
Family's behaviour	87.5	82.3	91.8	0.017
Friends' behaviour	52.9	46.3	58.5	0.030
Behaviour of people	36.2	39.6	33.3	0.086
Colleagues behaviour	10.9	14.7	7.7	0.000

3.3.5: Disincentives to adherence

Respondents were asked to state 3 possible reasons why people would not take their medication. Some of the most common responses provided are summarized in Table 14. Although respondents were not directly asked why they would not take their own ARVs, it gives an indication of what factors could impede their ability to adhere to treatment. In Carletonville, the most common reasons cited were: drinking alcohol, being out of town or visiting, being irresponsible, being sick, having wrong information or negative attitudes towards ARVs, forgetfulness, and feeling better. The reasons were similar for respondents from Zola, except that the lack of food was cited by nearly 2 times as many people and stigma reported 2.5 times more by respondents in Zola compared with Carletonville.

Table 14: Reasons People Miss Taking ARVs

	Carletonville n=164	Zola n=195
Alcohol	35.4	30.5
Out of town, visit/late home	23.1	14.0
Don't care, irresponsible	16.5	5.2
Sick/Ill	15.9	12.2
Wrong / negative views on ARVs	14.6	17.6
Forget	13.4	6.2
Feel well/better	10.4	11.9
Lack of food	7.9	13.0
Shame/stigma	4.9	10.3
Don't believe in ARVs	4.3	4.1

With respect to monthly appointments, only 9.5% of respondents said that there was a month when they had missed their appointment. There was no significant difference between the two sites, although respondents in Zola reported a higher frequency of missed appointments compared to Carletonville (11.4% vs. 7.3%). The main reasons for missing a monthly appointment in Zola had to do with being sick and in Carletonville being away or lacking transport money. (See Table 15).

Table 15: Reasons for Skipping Monthly Appointment (%)

Reasons	**Carletonville n=164**	**Zola n=195**
Working N=34	Yes: 0. 0 No: 100	Yes: 13.6 No: 86.4
Sick N=32	Yes: 0. 0 No: 100	Yes: 50.0 No: 50.0
Forgot N=32	Yes: 25.0 No: 75.0	Yes: 10.0 No: 90.0
Was away N=32	Yes: 33.3 No: 66.7	Yes: 15.0 No: 85.0
No transport money N=32	Yes: 41.7 No: 58.3	Yes: 15.0 No: 85.0
Nobody to look after children N=32	Yes: 0. 0 No: 100	Yes 5.0; No: 95.0
Afraid of negative judgment N=32	Yes: 0. 0 No: 100	Yes: 5.0 No: 95.0
Afraid of partner N=32	No relevant: 8.3 No: 91.7	Not relevant: 0.0 No: 100.0

3.4: ADHERENCE LEVELS AND ASSOCIATION WITH SOCIAL SUPPORT

The main results under this section pertain to levels of adherence measured by self-reported, viral load and CD4 adherence. The association between ART adherence and social support indicators is analyzed and presented. To provide additional context, an analysis of when respondents were first diagnosed HIV positive and when they first started taking ARVs was also carried out and compared with adherence.

3.4.1: Length of period of HIV diagnosis

Over half (55.9%) of respondents were diagnosed 1-2 years prior to data collection. Only 2.7% had been newly diagnosed - less than 1 year. 22.2% of the respondents had been diagnosed for 3-4 years, 11.6% for 5-6 years and 7.6% for more than 6 years prior to data collection. See Table 16.

Table 16: When First Diagnosed with HIV Infection

Years	< 1 year (%)	1-2 years (%)	3-4 years (%)	5-6 years (%)	> 6 years (%)	Total (%)
Combined n=329*	9 (2.7)	184 (55.9)	73 (22.2)	38 (11.6)	25 (7.6)	100
Carletonville n=144	2 (1.3)	88 (61.2)	31 (21.5)	15 (10.4)	8 (5.6)	100
Zola n=185	7 (3.8)	96 (51.9)	42 (22.7)	23 (12.4)	17 (9.2)	100

* data missing on 30 respondents

3.4.2: Length of time on treatment

Respondents were categorized into two groups based on the number of months they had been on treatment. These groups were: a) on ARVs for 6 or less months and b) on ARVs for over 6 months. In Carletonville this was calculated by determining the number of months between when they first started ARVs and June 2006 when data was collected, and in Zola, July 2006 was used. Information on when respondents first started taking ARVs was available for 271 respondents. Combined, 65.7% of respondents had been on treatment for over 6 months. The results for the sites show that in Carletonville 73.0% of respondents had been on treatment for over 6 months and 27.0% for 6 months or less. In Zola 59.7% of respondents had been on treatment for 6 months and over, and 40.3% for less than 6 months (See Table 17). There was a significant difference between the sites when length of

time on treatment was compared (Chi2 = 5.200, p value=0.023), a higher proportion of Zola patients were on treatment for 6 or less months.

Table 17: Length of Time on Treatment (n=271)

Treatment Months	Combined (n=122)	Carletonville (n=122)	Zola (n=149)
6months	34.3	27.0	40.3
>6months	65.7	73.0	59.7
Total %	100	100	100

Chi2=5.200, p value=0.023

3.4.3: Adherence levels

The frequencies of the three measures of adherence analyzed are listed in Table 18 and described below. They are I) self-reported adherence ii) viral load adherence and iii) CD4 adherence.

i) Self-reported adherence (SRAdh): Self-reported adherence was high at 97.5% for all respondents using 100% adherence in the last 3 days. Compared by site, proportions were nearly identical with 97.6% vs. 97.4% for Carletonville and Zola respectively. Only a total of 2.5% reported that they had missed more than 5% of their tablets in the last 3 days. The proportions for both sites were also nearly the same.

ii) CD4 cell adherence (CD4Adh): CD4 adherence was determined by two values (CD4>200 cells/ml and CD4 ≤200 cells/ml. CD4>200 cells /ml indicates adherence. Combined, 51.0% of 286 respondents for which CD4 data were available achieved CD4 adherence. The level of CD4 adherence was higher in Carletonville compared to Zola (53.5% vs. 48.1%). This difference was not however significant. Combined, 49.0% did not achieve CD4 adherence.

iii) Viral load count adherence (VLAdh): This was based on two values, a VL count equal to or less than 400 copies/ml for adherence and over 400 copies/ml for non-

adherence. Viral load suppression (undetectable) was achieved by 76.1% of all respondents. The VL adherence levels for Carletonville and Zola were similar, with Carletonville slightly higher (77.6% vs. 74.4% respectively). Combined, 23.9% did not achieve VL adherence.

Table 18: Adherence Levels: SRAdh, CD4Adh and VLAdh

	100% adherence in last 3 days	**Missed more than 5% in last 3 days**
SRAdh		
Carletonville (n=164)	97.6	2.4
Zola (n=192)	97.4	2.6
Combined	97.5	2.5
	CD4 >200 cells/ml	**CD4 ≤200 cells/ml**
CD4Adh		
Carletonville (n=155)	53.5	46.5
Zola (n=131)	48.1	51.9
Combined (n=286)	51.0	49.0
	VL≤400 copies/ml	**VL>400 copies/ml**
VLAdh		
Carletonville (n=143)	77.6	22.4
Zola (n=121)	74.4	25.6
Combined (n=264)	76.1	23.9

An analysis of VLAdh against CD4Adh showed a significant association as would be expected. See Table 19. The results indicate that 90.8% of respondents who achieved CD4Adh also achieved VLAdh, while only 9.2% of those who achieved CD4Adh did not achieved VLAdh. Additionally, 63.5% of respondents whose CD4 cell count was 200 or less achieved VLAdh and 36.5% of those who did not achieve VLAdh also did not achieve CD4Adh. No significant association was seen when CD4Adh and VLAdh were tabulated against SRAdh. This result of a strong correlation between CD4Adh and VLAdh, but of no

correlation between CD4Adh, VLAdh and SRAdh is of interest, but difficult to explain. It may be related to incomplete CD4 and VL count data or the fact that about one-third of the patients had been on ARVs for six months or less.

Table 19: VL Adherence vs. CD4 Adherence (n=245)

	VL≤400 copies/ml	**VL>400 copies/ml**	**Total %**
CD4 >200 cells/ml	90.8	9.2	100
CD4 ≤200 cells/ml	63.5	36.5	100

Chi2=27.0996, P value=0.000

3.4.4: Correlation between adherence and social support

Social support and contextual variables were analyzed against adherence measures to determine correlation. Because SRAdh was very high, this measure does not constitute a suitable measure to determine association. Ideally, it would be useful to compare a number of social support indicators against those who reported 95% and over adherence and those who reported less than 95%. However, there were only 9 respondents in the latter group. Therefore, VLAdh and CD4Adh measures were used to explore associations between adherence, social support and contextual variables.

a). Length of period on treatment and adherence: Length of period on treatment was stratified into 2 groups – longer than 6 months and 6 or less months. When results were compared for adherence levels between these 2 groups for the 216 respondents for which data was available on both CD4 count and date when treatment was first started, it was found that 65.3% of those on treatment for over 6 months achieved CD4Adh . The proportion of those on treatment for 6 months or less who had achieved adherence was

lower (43.1%). More respondents (56.9%) in this group were likely to have CD4 cell count that was less than 200. As expected, CD4Adh compared with length of time on treatment showed a significant association (Chi2=9.482, p value=0.002). See Table 20.

Table 20: Months on Treatment vs. CD4Adh (n=216)

	CD4 >200(%)	**CD4≤200(%)**	**Total**
> 6 months	65.3	34.7	100
≤6 months	43.1	56.9	100

P value=0.002

In contrast, when VLAdh was compared with length of time on treatment no significant association was seen. The proportions between the two categories (6 months or less and over 6 months) were about the same - 76.6% and 75.6% respectively, See Table 21

Table 21: Months on Treatment vs. VLAdh (n=201)

	VL≤400 copies/ml	**VL>400 copies/ml**	Total %
> 6 months	77.6	22.4	100
≤ 6 months	75.4	24.6	100

Chi2=0.1232, p value=0.726

b). Adherence by socio-economic status: Three variables were used to assess correlation between adherence and socio-economic status of respondents. These were age group, educational level, and assets quintiles. Considering age group, a significant association was seen with VLAdh (Chi2=9.7696, p value=0.012), but not with CD4Adh. The proportion of respondents who achieved CD4Adh and those who did not were split nearly equally among respondents aged 20-29, 30-39 and 40-49. VLAdh on the other hand showed a different pattern of distribution when the age groups were compared. See Tables 22 and 23.

Table 22: VL Adherence vs. Age Groups (n=259)

	VL≤400 copies/ml (%)	**VL>400 copies/ml (%)**	Total %
20-29	74.5	25.3	100
30-39	69.1	30.9	100
40-49	81.0	19.1	100
50+	100	0.00	100

P value=0.012

Table 23: CD4 Adherence vs. Age Groups (n=286)

	CD4 >200 cells/ml	**CD4 ≤200 cells/ml**	Total %
20-29	50.0	50.0	100
30-39	49.4	50.6	100
40-49	51.3	48.7	100
50+	75.0	25.0	100

Chi2= 1.0165, P value=0.797

When VLAdh and CD4Adh were compared with educational levels, no significant association was observed. A similar observation was made when assets quintile scores and CD4Adh and VLAdh were compared. However, with regard to assets, although no significant association was seen, respondents with an assets quintile score of 5 were nearly two times more likely to have a CD4 cell count over 200 (60.8% vs. 39.2%). The proportions of respondents with assets quintiles 1-4 who were CD4 adherent and non adherent were fairly similar across these quintiles. See Table 24. Viral load adherence compared across assets quintile scores showed that proportions of respondents who achieved VLAdh were between 3-5 times those who did not across the 5 scores. These differences were not significant. Respondents with a score of 5 also had the highest VLAdh level. See Table 25.

Table 24: CD4 Adherence vs. Assets Quintiles Scores (n=286)

Assets Quintile Scores	CD4 >200 cells/ml	CD4 ≤200 cells/ml	Total %
1	43.3	56.7	100
2	46.9	53.1	100
3	56.1	43.9	100
4	49.1	50.9	100
5	60.8	39.2	100

P=0.327

Table 25: Viral Load Adherence vs. Assets Quintiles Scores (n=264)

Assets Quintile Scores	VL≤400 copies/ml (%)	VL>400 copies/ml (%)	Total %
1	75.0	25.0	100
2	76.2	23.8	100
3	80.6	19.4	100
4	72.6	27.5	100
5	96.1	23.9	100

P=0.885

c) Adherence and social support: This was investigated by examining the relationship between social support and CD4Adh and VLAdh, using the following variables: support group membership, HIV disclosure, emotional support from family and friends, receiving food supplements, income in last two weeks and disability grants. The results are tabulated in Table 26. The main finding of interest is the significant association between CD4Adh and receiving food supplements.

Table 26: Adherence and Social Support

	CD4 >200 cells/ml	CD4≤200 cells/ml	P value	VL≤400 copies/ml	VL>400 copies/ml	P value
Yes						
Support group member n=37	59.0	41.0	0.287	70.3	23.9	0.367
Disclosed HIV status n=251	50.0	50.0	0.118	75.7	24.3	0.462
Receive emotional support from family and friends n=235	51.8	48.2	0.494	76.1	23.9	0.337
Receive food supplement n=20	80.0	20.0	0.007	90.0	10.0	0.130
Income in last 2 weeks n=37	61.5	38.5	0.159	70.3	29.7	0.367
Receive disability grant n=162	49.7	50.3	0.580	77.8	22.2	0.430

Of those who received food supplement (n=20), 80.0% achieved CD4Adh and 20% did not (Chi2=7.212, p value=0.007). There was no significant correlation between VLAdh and receiving food supplement. Furthermore, no association was seen between CD4Adh and VLAdh and any other social support variable.

d) Adherence by ARV and HIV knowledge: Respondents' results for ARV and HIV knowledge and perceptions were tabulated against VLAdh and CD4Adh to determine correlation. No associations were observed for any of the 3 variables compared: ARVs cure AIDS; unprotected sex is safe when taking ARV; and one can stop ARVs after weight gain. See Table 27 for details of results.

Table 27: ARV/HIV Knowledge and Adherence

	CD4 >200 cells/ml	CD4≤200 cells/ml	P value	VL≤400 copies/ml	VL>400 copies/ml	P value
Agreed	%	%		%	%	
ARVs cure AIDS (n=286)	90.0	10.0	0.074	70.0	30.0	0.154
Unprotected sex safe when on ARV	40.0	60.0	0.486	60.0	40.0	0.358
Stop ARVs after weight gain	57.1	42.9	0.896	71.4	28.6	0.434

e) Adherence, interaction with and social support from health providers: Three main variables were used to assess any correlation between adherence and support provided by health workers. The variables addressed respondents' perspectives on how helpful health workers were, and how positive their interactions were with them. Correlation analysis showed no association between CD4Adh and VLAdh and health workers support for ART adherence with respect to assistance with taking ARVs, how busy they were to listen to their problems, and if respondents were referred elsewhere to seek care that could not be provided. See Table 28.

Table 28: Health Worker Support and Adherence

	CD4 >200 cells/ml	CD4 ≤200 cells/ml	P value	VL≤400 copies/ml	VL>400 copies/ml	P value
Agreed	%	%		%	%	
HW assisted with problem of taking ARVs (n=264)	50.7	49.3	0.531	76.1	23.9	0.710
HW too busy to listen (n=264)	48.4	51.7	0.299	75.3	24.7	0.952
Referred for other care services (n=264)	50.4	49.6	0.172	76.5	23.5	0.568

3.5: STUDY LIMITATIONS

The study collected information from respondents at a point in time, focusing on their current experiences with adherence and their access to and use of social support services. It is therefore difficult to establish any causal relationship between exposure and outcome variables, which would require a different study design such as a prospective, longitudinal study or one with a well-established control group of non-adherent patients or patients who have dropped out of treatment. Also, because this is not a randomly selected study population, the results would largely apply to the study population and sites. Socio-economic factors may also confound the results. Because the sample size is not large enough, it was not possible to adjust for possible confounders or to stratify respondents as much as one would like to. It was not within the scope of the study to investigate exposure to social support from the time patients were first diagnosed with HIV. This presents a problem as many patients may have received support, and were coping with their HIV status, and therefore needed little support to adhere when they started treatment.

The study did not determine the quality of social support services or the frequency of use of the different support services by respondents. Respondents reported accessing and receiving support from two levels – community and facility. The study did not investigate which support services were most beneficial to respondents, so it is difficult to draw any conclusions as to what source and type of social support services enhanced adherence among this study population. Adherence measures included self-reported adherence, which is difficult to verify, and its reliability is a subject of continuing debate. The use of the more reliable adherence measures such as VL and CD4 counts to assess the association between adherence and social support was hampered by incomplete CD4 and VL data.

CHAPTER FOUR

4.0: GENERAL DISCUSSION

In terms of socio-economic background, the study population consisted of a better resourced sub-population in Zola, with a higher level of education and economic status determined by assets quintile scores, and a poorer sub-population in Carletonville, that had lower educational levels and economic status. The study population was predominantly female and young adults mainly in the 30-39 age group. It is difficult to explain the preponderance of females accessing ART services (72.1% of the study population), except that generally women have greater access to HIV testing through routine screening services, particularly through antenatal clinics. But since there were only a few women at both sites who had accessed ART services through antenatal and the prevention of mother to child transmission (PMTCT) services, so this was unlikely to be a major source of referral for women to these ART clinics. A similar finding in terms of the preponderance of women using ART services was seen in another South African study. In a retrospective study at the Helen Joseph Hospital in Johannesburg, about twice more women than men were initiated into the ART services at the Themba Lethu Clinic (25).

4.1: DISCUSSION OF RESULTS

Although several African studies on adherence have shown encouraging results with high levels of self-reported adherence found to be the norm (26,27, 28), a recent review has shown that ART adherence and clinical outcomes vary widely across sub-Sahara Africa, suggesting a mediocre to even poor adherence (29). A study by Bekker and colleagues in South Africa (15) found a high level of self-reported adherence (95%), comparable to the results found in this study (97.6%). However, the high level of self-

reported adherence recorded for the study was not verified, additionally, incomplete adherence – not taking medication at the right time - was not investigated. Interestingly, at both sites respondents gave similar reasons as to why people miss taking ARVs- mainly due to alcohol use/being drunk and being away from home. This could be a reflection of the respondents' own experiences, suggesting that self-reported adherence levels obtained for the study might not in reality be as high. Furthermore, in Carletonville, a review of the hospital's own records on patients' self-reported adherence (3 or 4 day recall) showed that between 80-90% of respondents were adherent compared to 97.5% obtained in the study. The high self-reported adherence rate reported from this study should be viewed with caution because of the disparity with hospital records, among other considerations.

The viral load adherence was lower for this study than that reported among 700 patients in the study by Bekker and colleagues in Khayelitsha: 76.6% versus 94% respectively. From other studies, high self-reported adherence rates but low rates of viral load clearance were reported suggesting that self-reported adherence in Africa is proving to be an unreliable measure of adherence as it is elsewhere (7,8). Similarly, in this study approximately three-quarters of the respondents had undetectable viral load despite a very high level of self-reported adherence.

A study by Michaels and colleagues (22) concluded that social support from family, friends, membership of support group, treatment literacy and disclosure were critical for adherence. But, the use of social support services depends on awareness, availability, accessibility, and the level of stigma and disclosure of HIV status. Disclosure of HIV status is perceived to be an important factor in enabling HIV positive individuals to seek and utilize services and to receive necessary support. HIV disclosure rate for this

population was high (95.5%). A possible explanation could be the high level of support, especially emotional support received by respondents which could have fostered disclosure. Also, the fact that many of the respondents had been diagnosed with HIV for a long time, only a small proportion (2.7%) had been diagnosed for less than one year, may have given them ample time to come to terms with being infected, and to take the decision to disclosure. The high level of disclosure among respondents could also be an indication of their high degree of comfort and ability to cope with stigma and the trust they developed in the people they disclosed to. However, the results showed that respondents had preferences in terms of who they disclosed to, and that family members were a critical source of social support, providing particularly emotional support. Corroborating of this finding, it was observed that 87.5% of respondents also reported the behaviours of their family members to have been supportive.

The support groups used by respondents provided support through identifying a "treatment buddy", providing ARV education and counselling services, which were also offered by the facilities. It is therefore difficult to determine if the support groups provided any unique services to members. Generally, it appeared that support groups were not popular among these ART patients given that only a small proportion of them (12.6%) participated in support group activities. It is therefore unlikely that these ART patients depended much on support groups for ART adherence. However, an informal but important source of support - peer support- evolved among these patients. This informal support system developed among patients who had their monthly appointments on the same date, and it seemed to be a key adherence support feature among patients in Carletonville. This system of support requires further enhancement, documentation and evaluation.

Although the CCMT Managers reported several measures to support and assist ART patients, not all of them could be verified. For example, how well community outreach from Zola Clinic was working could not be ascertained. At Carletonville, the management staff reported that it was unable to conduct any community outreach. However, support in terms of providing educational materials, education, and counselling, routine assessment of adherence through pill count, self-reported adherence and CD4 cell and VL counts assessment appeared to be in place at the two sites. With respect to social support from health workers, respondents had very positive views about the support they received from health workers, especially assistance with taking ARVs, discussion on side effects of ARVs, feedback on whether ARVs were working and referral to obtain assistance and services that were not offered at their facility. The also perceived the providers to be very caring.

But, the effective delivery of these services could be compromised by the high workload of health workers; nearly one-third of the respondents (32%) reported that health workers were too busy to pay adequate attention to them, and 89.7% reported long queues. 17.6% of respondents reported that they had left the clinic at least once without receiving treatment. These problems were more of a concern for patients in Zola, where a higher patient flow (about 200/day) compared to Carletonville (about 50/day) seemed to be placing a lot of stress on the health workers, as well as available space and services.

There was a significant correlation between CD4Adh and VLAdh. 90.8% of respondents who were CD4Adh were also VLAdh. This association was not seen when SRAdh was analyzed against CD4Adh and VLAdh. This result suggests that both CD4Adh and VLAdh provided reliable measures for adherence, but one could not probably say the

same for SRAdh. Overall 51.0% of the respondents achieved CD4Adh and 76.1% VLAdh, a rate comparable with the 79.6% to 59.3% rate reported by Laurent and colleagues in Senegal (30), but lower than the 94% viral load clearance rate reported by Bekker and colleagues in South Africa (22).

Correlation analysis comparing CD4Adh, VLAdh and social support variables, socio-economic indicators and length of time on treatment largely showed no significant association. This may be explained by the fact that VL counts were only available for 264 (73.5%) of respondents and CD4 counts were available for 286 (79.7%) respondents. The proportions of respondents who were CD4 adherent and non-adherent were about the same (51% vs. 49% respectively). This lower level of CD4 cell increase compared with a higher viral load clearance rate may be due to the fact that ARVs more readily and directly deplete HIV when initiated, and so fewer HIV particles become detectable in blood circulation. In the case of CD4, it is plausible that CD4 reconstitution takes longer, and lags behind VL clearance, however this needs to be substantiated by studies.

Significant correlations between CD4Adh and length of period on treatment (Chi2=9.482, p value=0.002) and CD4Adh and receiving food supplement (Chi2=7.212, p value=0.007) were seen. It can be said that valuable nutrients resulting from the use of supplements may have facilitated the reconstitution of the immune system, reflected by an increase in CD4 count. Thus, the association between access to food supplement and higher CD4 cell count was seen. Regarding CD4Adh and length of period on treatment, the results showed that 65.3% of respondents who were on treatment for more than 6 months had CD4 cell count of over 200 compared with 43.1% of those who were on treatment for 6

months or less. This is to be expected given that an increase in CD4 cell count progresses with time following initiation of ARVs.

The significant correlation (Chi2=9.7696, p value= 0.012) seen between age group of respondents and VLAdh is of interest. The age groups that showed higher proportions of VLAdh were 40-49 and 50+ years. A possible explanation is that older people are more stable, less mobile, less likely to abuse alcohol, and hence more able to adhere to treatment compared with younger people. This view is supported by the reasons provided by respondents for missing ARVs, which were mainly the use of alcohol, being away from home or not caring/being irresponsible. Younger people may be more susceptible to these factors, which could affect their adherence to ARVs.

4.2: CONCLUSIONS

The study did not document a convincing association between social support and ART adherence. One likely reason is that this population of HIV positive patients on ARVs may over represent those who cope better. Also, the dropout rates for the sites were high. In Carletonville it was 30.1%, about 2.5 times that of Zola, which recorded 11.6%. It is possible that some of those who dropped out were less able to cope. It was not possible to follow-up with these patients to determine how different they were in terms of their coping ability, access to and use of social support services and their adherence rate as the facilities maintained little or no contact with, or information on drop-outs. However, it could be postulated that the majority of the respondents had accessed adequate social support and were already coping with their HIV status prior to treatment initiation. This however, could not be confirmed because it was not within the scope of the study to determine past exposure to and use of social support services.

Although CD4Adh and VLAdh were associated with some variables (access to food supplements, length of time on treatment and age groups), these could not be satisfactorily explained. The high levels of SRAdh and adequate access to and use of social support services suggest that despite this lack of demonstrable association, these respondents were doing well particularly in accessing social support and they were largely satisfied with the support they were receiving from the ART clinic providers. This finding is of importance given concern about the ability of public sector ART programs to provide and facilitate support services which promote adherence. It, thus appears, that the support provided at the facility level – information, educational materials, training prior to starting treatment and counseling and community level support from families, friends and support groups were adequately meeting the main needs of the respondents and motivating them to adhere to ART. However, given the limitations of the study, it is not clear if the services being provided and utilized are all relevant, useful, of good quality, and sustainable.

4.3: RECOMMENDATIONS

Qualitative research is required to better determine how patients in these public sector facilities understand adherence and non-adherence to treatment and what factors they take into consideration in reporting self-adherence. Additionally, it is necessary to unpack the meanings of social support in the context of ART, the key components of social support, and to understand which social support services are most beneficial for ART adherence. It is also important to explore practices pertaining to timely adherence in taking ARVs, as well as understanding of how the reasons reported for non-adherence apply to this population.

Research that would lead to a better understanding of the behavioural factors that are necessary to maintain long-term, high level adherence and reasons why more women

than men are accessing treatment is also required. Based on a review of literature on ARV adherence and intervention studies, Goudge (31) made similar recommendations, including broadening the concept of social support/integration, interventions to assess which are the most effective approaches to improving adherence and determining the local contextual factors that are important and what works within that context.

From the few African studies that reported longitudinal data on adherence, declining levels of adherence was noted over time. For example, in Senegal, Laurent et al (30) noted that over 95% of their patients had adhered, exceeding 80% after one month on therapy. However, 18 months later, only 80% remained above this level. The proportion of patients with undetectable viral load correspondingly fell from 79.6% to 59.3%. Similarly, Akam (32) in Cameroon reported a mean self-reported adherence that was initially only 68%, that declined further with time. The ART programs in Carletonville and Zola are only about two years old, and only 65% of the patients had been on treatment for more than 6 months. As seen from the studies reported from Senegal and Cameroon, adherence levels could decline with length of time on treatment resulting in a decline in VL clearance. Thus, a longitudinal study is needed to better understand the predictors of short and long-term adherence and to explore ways to better assess the relevance, content and quality of social support services being utilized by ART patients at facility and community levels.

Additionally, appropriate interventions and polices are needed to respond to the concerns identified from the study regarding inability to attend to the problems of patients because staff are too busy, and the perception that staff do not treat patients with enough respect. Other concerns requiring action include patients leaving without receiving

treatment, absence or lateness of doctors and pharmacists and challenges around access to food, income and disability grants.

Finally, it is important that funding agencies and government at all levels support the implementation of comprehensive social support services, that are capable of promoting adherence, and facilitate research activities to study adherence, qualitatively and quantitatively over time, rather than the current focus on supplying basic kits, materials, training and medications for ART rollout in South Africa.

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DISSEMINATION

The results of the study were dissemination at the Centre for Health Policy to members of the research team and representatives of the donor agency supporting the study. A poster on the organizational aspects of this study presented at the 2nd Priorities in AIDS Care and Treatment (PACT) Conference held in Cape Town in November 1-4, 2006, included aspects of the results from this research. More recently, two presentations relating to the study were made at the School of Public Health Research Day (May 10, 2007). This provided the opportunity for the results to be shared with a wide audience of researchers, policy makers, program managers and academic staff of the university. Plans are underway to present the results of the study to staff and managers of the two facilities where the study was conducted and to the Provincial Department of Health.

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APPENDICES

Appendix 1. Ethics Committee Letter

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Academic & Research)

MEMORANDUM

TO: Dr EE Williams
School of Public Health
Sent by e-mail ewilliams@pcjoburg.org.za

FROM: Ms Anisa Keshav
Secretary: Human Research Ethics Committee (Medical)
Tel 717-1234 fax 339-5708 e-mail keshava@research.wits.ac.za

DATE: 2 December 2005

REF: ***R14/49***

Protocol M051101: A Study of Social Support an Art Adherence at Two Sites in Gauteng Province

The above protocol was considered at a meeting of the Human Research Ethics Committee(Medical) on Friday 25 November 2005. The Committee requires the following amendments/corrections/information from you before your application can be approved.

-The consent form must be revised to be more user friendly and include a greeting, an invitation to participate etc
-Separate consent signatures needed for tape recording and the fate of the tapes must be stated
-Please clarify- how will individuals be contacted?
-Remove DOB as this is loss of confidentiality

Please let me have the amendments as soon as possible as protocols on which no action has been taken will be removed from the agenda without approval after two months.

Cc

NB: please highlight the changes you submit

Appendix 2: Data Collection Domains

Domain	Indicator(s)	Method
Background information	• Demographic profile age, sex, • Socio-econ profile e.g. Location, medical aid, assets owned, grants, employment, education level	• Review of ART register • Exit interview
Continuity of care	Pathways of care e.g. • Entry • Referrals • Preparation • Aids and reminders (locus of ctrl ->self Mx)	• Review of TB register • Presence of networking and referral relationships • Exit interview
Social support	• Links to NGO's • Needs? • Disclosure and acceptance • Family support • Alternative therapy e.g. trad. Healing • Counseling	• Semi-Structured interview schedule • Presence of networking relationships
Knowledge and treatment literacy	• Identification of medicines • Number of regimens • Definition of HIV/AIDS and transmission • Definitions of anti retro-virals and dosages and side effects	• Semi-Structured interview schedule • Exit interview
Patient provider relation ship-Quality of relationship	• Type of staff attending to patient e.g. nurse doctor • Language barriers • Perception of attitude of staff e.g. rude, courteous etc • Advice about regimens • Type of information provided e.g. leaflets, posters •	• Semi-Structured interview schedule • Exit interview

Adherence	• Patient self reported adherence rates, • Viral load suppression, • Patient follow-up rates	• Review of patient clinical records, • Review of information systems for monitoring of patients
and Physical barriers to adherence	• Costs –indirect (transport and food, accommodation) • Direct (Rx related)-cost of regimens etc • Proportion of doses missed in last 2days, 1 week and 2weeks • Side effects • Clinic visits per capita and missed visits	• Exit interview

Appendix 3: Exit Interview Questionnaire

ARV Adherence Questionnaire

CONSENT			
INTERVIEWER INTRODUCES HIM/HERSELF, AND THE STUDY, AND THEN…. **I would like to ask you questions to ensure that the information I have provided so far is clear, and give you the opportunity ask any question(s) you have.**			
NO	QUESTION	RESPONSE	CODES
1.	**Do you understand the purpose of the study, and what will be required of you if you agree to take part?**		Yes=1 No=0
2.	**If no, what further questions what further questions do you wish?**		
3.	**Do you understand that any time you may withdraw from this study without giving a reason?**		
4.	**Do you understand that this study is in no way linked to the organizations that provide care, and withdrawing or participating will not affect the care that you receive?**		
5.	**Do you agree to take part in this study?**		
Written consent I agree to participate in this study, having understood and answered yes to all of the above questions. **Initials of respondent:** ……..			
Verbal consent As the respondent is illiterate, or is happy to provide verbal but not written consent, I, the field worker, confirm that the respondent gave verbal consent to be interviewed. **Signature of interviewer**: …….			

INTERVIEW DETAILS											
NO	**QUESTION**	**RESPONSE**								**CODES**	**SKIP**
6.	**Clinic patient number** (8 digits + 2 letters)										
7.	**Facility name**									Carltonville = 1 Zola = 2 Empilisweni = 3 Natalspruit = 4	
8.	**Date of interview**	D	D	M	M	Y	Y	Y	Y		
9.	**Name of interviewer**									*Interviewer names* =1 =2 =3 =4	
Signature of researcher that has checked questionnaire											
10.	**Questionnaire number** ONLY TO BE COMPLETED ONCE QUESTIONNAIRE HAS BEEN CHECKED, AND IS COMPLETE										

SECTION 1: SOCIO-DEMOGRAPHIC BACKGROUND				
I would like to ask you a few questions about yourself. We are asking these questions of everybody participating in this study. Feel free to stop me if you have any questions.				
No.	QUESTIONS	RESPONSES	CODES	SKIP
11.	GENDER		Male =01; Female=02	
12.	**What is your date of birth?** WRITE AGE IF DATE NOT KNOWN	D D M M Y Y Y Y		
13.	*What is the highest educational level that you have COMPLETED?*		No formal education =0 Grade 1/SubA=1 Grade 2/Sub B=2 Grade 3/Standard 1 =3 Grade 4/Standard 2/ABET L1 =4 Grade 5/Standard 3=5 Grade 6/Standard 4/ABET L2=6 Grade 7/Standard 5 =7 Grade 8/Standard 6/ABET L3 = 8 Grade 9/Standard 7 = 9 Grade 10/Standard 8/ABET L4 = 10 Grade 11/Standard 9 = 11 Grade 12/Standard 10/ABET L5 = 12 Diploma = 13 Degree = 14 Other: Specify---------- 99	
14.	**Have you done any activity to earn money in the past two weeks?**			**IF NO, >Q17**
15.	IF YES: **Can you describe the type of work you have been doing, including how often you do this work?** PLEASE WRITE EXPLANATION			
16.	IF WORKING**: How would you best describe the work that you do?**		Full time =1 Self-employed = 2 Casual or part-time work = 3	
17.	**Do you currently receive a disability grant?**		Yes=1 No=0	**IF YES >Q19**
18.	IF NO: **Have you applied for one?**		Yes=1 No=0	

I'd like to now ask you about your costs coming here today	

	ITEM	COST PER VISIT	**Codes** Don't know = -1 PUT ZERO IF SPENT NO MONEY ON ITEM	
19.	**How much did it cost you to travel to and from the hospital/clinic (the return trip)?**	**R**		
20.	**Subsistence (food) during visit?**	**R**		
21.	**Medication received at hospital/clinic?**	**R**		
22.	**Consultation at hospital/clinic?**	**R**		
23.	**Accommodation (if needed to stay over) during visit?**	**R**		
24.	**Are there any other COSTS that I have not mentioned?**		Yes =1 No = 0	
25.	IF YES: **What else did you spend money on, and how much?**			

26.	**At present, do you have a medical aid?**		Yes =1 No=0	
27.	DID THE PERSON SAY THEY HAVE BEEN WORKING IN THE PAST TWO WEEKS? CHECK Q15		Yes =1 No = 0	**IF NO, > Q31**
28.	IF YES, **Did you miss work by coming here?**		Yes =1 No = 0	**IF NO, > Q31**
29.	IF YES: **Did you loose salary or income by coming here?**		Yes =1 No = 0	**IF NO, > Q31**
30.	IF YES, **How much income do you lose per visit?**	R_____per visit		

31.	**What is the main source of drinking water for members of your household?** READ OUT EACH OPTION Other: Specify……		Rain water /tank = 1 Borehole/well = 2 Water carrier/tanker = 3 Public tap = 4 Piped water (tap) in site, yard = 5 Piped water (tap) in dwelling = 6 Bottled water = 7 Other = 99	
32.	**What kind of toilet facility does your household have?** READ OUT EACH OPTION Other: Specify…….		Flush toilet (own)=5 Flush toilet (shared) = 4 Bucket latrine = 3 Pit latrine=2 No facility/bush or veld = 1 Other=99	

33.	**What type of home do you live in?** READ OUT EACH OPTION Other: Specify…….		Shack / informal dwelling in back yard=1 Shack / informal dwelling =2 Hostel =3	

			House/flat/Room in back yard=4 Room/flatlet not in back yard but on shared property=5 Flat in a block of flats = 6 Formal house = 7 Other = 99	
34.	**What is the main material of your house's floor?** READ OUT EACH OPTION Other: Specify…….		Earth / sand / dung = 1 Bare wood planks = 2 Cement = 3 Vinyl or plastic = 4 Carpet/ tiles/ polished wood = 5 Other = 99	
35.	**What is the main material of your house's wall?** READ OUT EACH OPTION Other: Specify…….		Plastic / cardboard = 1 Mud = 2 Mud and cement = 3 Corrugated iron / zinc = 4 Bare brick / cement blocks = 5 Plaster / finished = 7 Other = 99	
36.	**Do you have electricity in your household?**		Yes=1 No = 0	
Can you tell me if you household has any of the following appliances, that are working?				
37.	**Television**		Yes=1 No = 0	
38.	**Telephone (land line)**			
39.	**Fridge**			
40.	**Personal computer**			
41.	**Washing machine**			
42.	**Radio**			
43.	**Cell-phone**			
44.	**What does your household use <u>mainly</u> for cooking?** READ OUT EACH OPTION If other, specify……		Electricity =6 Gas = 5 Paraffin = 4 Wood = 3 Coal = 2 Animal dung=1 Other = 99	
45.	**What does your household use <u>mainly</u> for heating?** READ OUT EACH OPTION If other, specify……		Electricity =6 Gas = 5 Paraffin = 4 Wood = 3 Coal = 2 Animal dung=1 Nothing=7 Other = 99	
46.	**What does your household use <u>mainly</u> for lighting?** READ OUT EACH OPTION If other, specify……		Electricity =6 Gas = 5 Paraffin = Coal = 2 Animal dung=1 Other = 99	

			4 Wood = 3	
Does any member of your household own any of the following?				
47.	**A bicycle**		Yes=1 No = 0	
48.	**A motorbike**			
49.	**A car**			
50.	**A donkey or horse**			
51.	**Sheep or cattle**			
52.	**Would you say that the people at home often, sometimes, seldom or never go hungry?**		Often = 1 Sometimes = 2 Seldom = 3 Never = 4	
53.	**Do you receive food supplement/food parcel from any source?**		Yes = 1, No =0	

SECTION 2: KNOWLEDGE OF HIV/AIDS AND ARVs				
I would now like to ask you some questions about AIDS and ARVS				
NO	QUESTION	RESPONSE	CODES	SKIP
54.	**Can you tell me about ARVs, what do they do?** WRITE RESPONSE		Correct response=1 Incorrect response =0 Don't know = -1	
I am going to read you some statements. I would like you to tell me, for each one, whether you think the statement is True or False, or you don't know				
55.	**People receiving ARVs can still transmit HIV to other people through unprotected sex.**		True = 1 False = 0 Don't know = -1	
56.	**It is acceptable to stop ARVs after gaining weight**			
57.	**It is acceptable to stop ARVs when one no longer suffers from opportunistic infections**			
58.	**ARVs cure HIV/AIDS.**			
59.	**After a couple of years one can stop taking ARVs.**			
60.	**Missing a few tablets of ARVs is acceptable.**			
61.	**Unprotected sex is safe when one is taking ARVs**			

SECTION 3: CONTINUITY OF CARE				
I will like to obtain some information from you about when you were diagnosed with HIV or AIDS and where and how you have received treatment and care.				
NO	QUESTION	RESPONSE	CODES	SKIP
62.	**When did you first test positive for HIV?**	D D M M Y Y Y Y	Don't know = -1	
At which health care facility (clinic or hospital) did you FIRST test HIV positive?				
63.	Name of clinic or hospital:…….			

64.	FILL IN IF YOU KNOW Town / City:……..					
65.	Province:		Gauteng = 1 Mpumalanga = 2 Limpopo = 3	North West = 4 Free state = 5 E. Cape = 6	W. Cape = 7 N. Cape = 8 KZN=9	
Where did you FIRST seek treatment after you were FIRST diagnosed with AIDS?						
66.	Name of clinic or hospital:…….					
67.	Town / City:……..					
68.	Province:		Gauteng = 1 Mpumalanga = 2 Limpopo = 3	North West = 4 Free state = 5 E. Cape = 6	W. Cape = 7 N. Cape = 8 KZN=9	
69.	**When did you FIRST begin taking ARVs?**	D D M M Y Y Y Y	Don't know = -1			
70.	**Have you received ARVs from a clinic / service other than this one?**		Yes = 1; No = 0			**IF NO, >Q74**
Can you tell me the name of the clinic / hospital, which town/city AND province?						
71.	Facility name:……					
72.	Town / city: …….					
73.	Province		Gauteng = 1 Mpumalanga = 2 Limpopo = 3	North West = 4 Free state = 5 E. Cape = 6	W. Cape = 7 N. Cape = 8 KZN=9	

SECTION 4: ADHERENCE

I would like to ask you some questions about how you are coping with taking the ARVs regularly. We want to understand better the real life challenges that people on ARVs face in taking their pills.

NO	QUESTION	RESPONSE	CODES	SKIP
74.	**Can you tell me the name of each of your drugs?** (WITHOUT LOOKING AT THE CONTAINER)		Yes = 1 No = 0	**IF YES >Q76**
75.	IF NO**: Can you point to the pictures of each of your drugs?** OR PERSON READS THE NAMES FROM THE CONTAINERS WRITE IN ALL DRUG NAMES BELOW FIRST AND THEN GO BACK ASK QUESTIONS ABOUT EACH ONE?		Yes = 1 No = 0	
76.	**DRUG 1**: WRITE DRUG NAME GIVEN, CHECK SPELLING ON LIST			
77.	**How many times a day to do you take …….** (drug)**?**			
78.	**How many tablets of ……** (drug) **do you take in one day?**			

79.	**DRUG 2**: WRITE NAME GIVEN, CHECK SPELLING ON LIST			
80.	**How many times a day to do you take ……** (drug)**?**			
81.	**How many tablets of …….** (drug) **do you take in one day?**			
82.	**DRUG 3**; WRITE NAME GIVEN, CHECK SPELLING ON LIST			
83.	**How many times a day to do you take …..** (drug)**?**			
84.	**How many tablets of …..** (drug) **do you take in one day?**			
85.	**DRUG 4:** WRITE NAME GIVEN, CHECK SPELLING ON LIST			
86.	**How many times a day to do you take ……** (drug)**?**			
87.	**How many tablets of ….** (drug) **do you take in one day?**			

People may miss taking their ARVs for various reasons. What, in your experience, are the main reasons why people miss their tablets? WRITE RESPONSES, PROMPT FOR MORE THAN ONE REASON

88.	**Reason 1:**		
89.	**Reason 2:**		
90.	**Reason 3**		

For each of drugs, can you tell me how many tablets, if any, you missed YESTERDAY? WRITE IN DRUG NAMES FROM ABOVE

		NAME OF DRUG	**Number of tablets missed**	**Reason for missing**	
91.	Drug 1				
92.	Drug 2				
93.	Drug 3				
94.	Drug 4				

For each drug, can you tell me how many tablets, if any, you missed THE DAY BEFORE YESTERDAY (INDICATE WHICH DAY YOU ARE REFERRING TO - MON, TUE ETC.)? WRITE IN DRUG NAMES

		NAME OF DRUG	**Number of tablets missed**	**Reason for missing**	
95.	Drug 1				
96.	Drug 2				
97.	Drug 3				
98.	Drug 4				

For each drug, can you tell me how many tablets, if any, you missed 3 DAYS AGO? (INDICATE WHICH DAY YOU ARE REFERRING TO - MON, TUE ETC.)? WRITE IN DRUG NAMES

	NAME OF DRUG	**Number of tablets missed**	**Reason for missing**	

99.	Drug 1					
100.	Drug 2					
101.	Drug 3					
102.	Drug 4					
103.	**If you didn't miss any tablets in the last three days, when was the last time you missed any of your medications?**			Within the last: Week =1 2 weeks = 2 3 months = 3 More than 3 months ago = 4 Never missed = 5		
104.	IF EVER MISSED TABLETS: **What is the longest time you have ever missed your tablets?**				INDICATE DAYS OR MONTHS	

105.	**Do you belong to a support group?**		Yes=1, No= 0	**If NO, >Q115**
106.	IF YES**: How often do you attend?**		Weekly = 1 Monthly = 2 Occasionally =3	
IF YES, **What services are offered at the support group?** READ OUT EACH OPTION				
107.	**Advice and information on staying healthy e.g. nutrition, exercise and prevention**		Yes=1, No= 0	
108.	**ARV information: CD4 counts, ARVs, viral load**			
109.	**Treatment buddies**			
110.	**Help with collecting medicines from the clinic**			
111.	**Home visits**			
112.	**Food**			
113.	**Income generating activities**			
114.	**Individual counselling and emotional support**			
Do you receive any of the following help or support from your friends or family to help you take your tablets regularly? READ OUT EACH OPTION				
115.	**They visit you**		Yes=1, No= 0	
116.	**They send an sms or call you by phone**			
117.	**They give you food to take your pills with**			
118.	**They provide transport money to the clinic**			
119.	**They provide emotional support**			
120.	**Is there any other type of help that you receive?** Specify:……			
121.	**Are there people interested in buying ARVs?**		Yes =1, No=0 Don't know = -1	
122.	**Do you know of people who have sold their ARVs?**			
123.	**Has there ever been a month when you couldn't come to clinic for your monthly visit?**		Yes =1 No=0	**IF NO >135**
124.	IF YES, **how many times did you miss coming in the last 6 months, since _____** (MONTH)**?**			

IF YES, **What was the reason for skipping the appointment?** READ OUT EACH OPTION				
125.	**You were working**		Yes =1 No=0 Not relevant - 2	
126.	**You were sick**			
127.	**You forgot**			
128.	**You mixed up the dates**			
129.	**You were away out of town**			
130.	**You had no transport money**			
131.	**You had nobody to look after the children**			
132.	**You were afraid that somebody would see you and judge you negatively**			
133.	**You were afraid that your partner would find out and ask me to explain**			
134.	**Is there any other reason that made you miss your visit?** Specify reason:……..			
135.	**Can you tell me in your own words what a CD4 count is?** WRITE DOWN WORDS HERE:			
136.	**Can you tell me what your most recent CD4 count is?**		*Write in number given,* OR, Don't know = -1	
137.	***When are you due for your next CD4 count?***		MONTH AND YEAR	

SECTION 5: QUALITY OF CARE/PATIENT PROVIDER RELATIONSHIP				
I would now like to know about your experiences when at this clinic and how the health providers interact with you.				
138.	**Are you able to talk to the health workers in private?**		Yes = 1, No = 0	**If YES >Q140**
139.	IF NO, **does it bother you?**		Yes =1, No=0	
140.	**How many hours do you spend at the clinic at each visit?**		INDICATE HOURS	
I am going to read some statements about your meeting with the health workers today. Can you tell me whether you agree or disagree with these statements? IF THE PERSON CAN'T DECIDE CHOOSE NO VIEW/DON'T KNOW				
141.	**The queues to be seen by a doctor or nurse are too long at this facility**		Agree=1 Disagree=2 Agree and disagree=3 No view/don't know=4 Not relevant= -2	
142.	**The *health worker* DID'NT discuss the treatment fully with you, including how the treatment works and side effects.**			
143.	**It is a problem that the *health worker* DOESN'T speak your language**			
144.	**You find it difficult to tell the *health worker* when you have missed taking your tablets**			
145.	**You would not tell him/her because s/he would shout at you.**			
146.	**The *health worker* was too busy to listen to your problems**			
147.	**The *health worker* provided you with feedback on whether the drugs were working or not**			
148.	**The *health worker* understood the difficulty of taking the drugs and assisted you where possible**			
149.	**Some staff DO NOT treat patients with sufficient respect.**			
150.	**When I need to obtain other care that they cannot provide in this clinic, I was given enough help to get to the right place**			
151.	**The health workers I see care about me.**			
152.	**Since enrolling at this clinic/hospital, have you ever left without being helped**		Yes=1 No=0	**IF NO >Q154**
153.	IF YES, **why did you leave without being helped?** *WRITE FULL EXPLANATION*:			

SECTION 6: SOCIAL SUPPORT AND ACCEPTANCE				
I would like you to tell me about the support your receive to help you cope with your HIV status and to take your ARVs.				
154.	**Apart from the health workers, have you told anyone about your HIV status?**		Yes =1 No= 0	**If NO, > Q162**
IF YES, **whom of the following have you told about your HIV status?** READ OUT EACH OPTION				
155.	**Spouse / partner, if you have one**		Yes =1 No= 0 If no spouse = -2 Yes = 1, No = 0 Don't know =-1	
156.	**Family member**			
157.	**Friend**			
158.	**Neighbour**			
159.	**Religious leader**			
160.	**No-one**			
161.	**Is there another category of person to whom you have told your status we have not already mentioned?** Other (specify)----------			
162.	**Has your HIV status been disclosed to other people without your permission?**		Yes=1 No=0	
Do you keep your status secret for any of the following reasons: READ OUT EACH OPTION				
163.	**Fear of rejection by family**		Yes =1 No= 0	
164.	**Fear of rejection by friends**			
165.	**Fear of violence**			
166.	**I do not trust people**			
167.	**I will not get help from others if they know my status**			
168.	**Fear that I will be stigmatised**			
169.	**Fear that people will gossip about me**			
170.	**Fear that HIV my status will be known by the community**			
171.	**Fear that my partner will know and ask me to explain**			
172.	**Is there any other reason?** Specify ……			

I would like to ask you how supportive your family, friends and colleagues are towards you.				
173.	**How would you describe your partner's behaviour towards you, if you have a partner – supportive or unsupportive?**		Supportive=1 Unsupportive=2 Both supportive and unsupportive=3 Not relevant=4	
174.	**How would you describe the behaviour of your family towards you?**			
175.	**How would you describe the behaviour of your friends towards you?**			
176.	**How would you describe the behaviour of the people you live with towards you?**			
177.	**How would describe the behaviour of your work colleagues towards you?**			

SECTION 7: FOLLOW-UP			
We are planning to do a more detailed study, visiting a few patients in their homes to find out more about how they are coping the HIV and the treatment. Would you be willing to be part of that study? IF YES, WRITE NAME AND TEL NO ON SEPARATE PIECE OF PAPER		Yes=1 No = 0	

THAT IS THE END OF THE INTERVIEW DO YOU HAVE ANY QUESTIONS YOU WANT TO ASK ME?

DO YOU WANT TO ADD ANYTHING? WRITE IN SPACE BELOW OR ON BACK OF QUESTIONNAIRE

MANY THANKS FOR YOUR HELP – WE REALLY APPRECIATE IT!

INTEVIEWER: PLEASE COMPLETE THESE QUESTIONS IMMEDIATELY AFTER THE INTERVIEW.				
178.	***INTERVIEWER: How clear was the meaning of the respondent's answers***		Good = 1 Average =2 Poor = 3	
179.	***INTERVIEWER: How attentive was the respondent to the questions during the interview?***		Good = 1 Average =2 Poor = 3	
180.	***INTERVIEWER: What was your impression about this person's willingness to talk in more detail about their illness and how they are coping with it?***		Willing = 1 Doubtful = 2 Unwilling = 3	

Appendix 4a: Letter of Request from Centre for Health Policy

Centre for Health Policy, School of Public Health
UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

NHLS cor. De Korte & Hospital Streets
Braamfontein, Johannesburg

✉ PO Box 1038 Johannesburg
2000 South Africa
☎ (011) 242-9905
Fax (011) 720-0010

7 April 2006

Dr A Victor
Acting Director
West Rand District
Gauteng Department of Health
Dear Dr Victor

MPH student projects

In discussions between the SPH and Head Office, a number of projects for MPH students were identified, one of which involves a facility in your district. The project is an analysis of adherence and associated facility and patient factors in one ARV/CCMT sites. In a random selection process we identified the Carletonville Hospital site, and we would like your permission to approach the facility. Alternatively, if you are of the opinion that this site is inappropriate given its relocation to the North-West we can discuss another site in your district. The project team will involve two MPH students and staff in CHP. HAST (Head Office) gave its approval for this and notified the individual sites at the end of 2005.

Attached find the following:

1) A letter of approval from head office with a list of all the MPH students and their projects in the province as a whole (to give you a sense of the range)
2) A summary of the project
3) A copy of the letter sent by HAST

I believe Dr Mazizi has forwarded a letter of approval from his office.

The topics of the projects were identified by the Department of Health and have been approved by both the Higher Degrees and the Ethics Committees of the University.

I trust that this request is in order and we hope that these activities will provide the opportunity for identifying what are your priorities for future evaluations in your district.

Many thanks

Helen Schneider (Prof)
Cc: Ms Nomsa Makwela

Appendix 4b: Letter of Introduction

Department of Health
Lefapha la Maphelo
Departement van Gesondheid
Umnyango wezeMpilo

HAST (HIV/AIDS / STI / TB)

Enquiries: Dr R.N. Dlamini:
Technical Advisor: Tel:
011 355-3383

Fax: 011 355-3297
Date: 19 November 2005

To : Natalspruit Hospital: ART Project Manager: Sr JZ Buthelezi
Carltonville Hospital: ART Project Manager: Sr Motseko / Ms Musi
Empilisweni CHC: ART Project Manager: Sr Nthombi Mokgatla
Zola CHC: ART Project Manager: Sr P. George / Makeda

HAST Project Managers
Cc : Dr D. Moloi: Director: HAST
Dr N. Ntzebeza: PMO – Ekurhuleni
Dr M. Shisana: PMO – Joburg Metro
Dr B. Ribiero: PMO – Tswane / Metsweding
Dr F. Bosama: PMO – Central Provincial Office
Ms N. Mfecane: Project Manager: ARV (CCMT)

From : Dr R.N. Dlamini: Technical Advisor: HAST
Re : Wits School of Public Health Students Projects

HAST works in very close collaboration with the Wits School of Public Health. Their MPH students are involved in operational research that will provide useful information in the way we run and manage our Comprehensive Care Management and Treatment clinics (CCMT).
The research topics and protocols have all been submitted to HAST and to the Research Unit at Central office. HAST therefore requests that the students are given access to the CCMT clinics to conduct the various research projects.

Thank you

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Dr R.N. Dlamini: Technical Advisor: HAST

Appendix 5: Data Analysis Plan Study Objectives	**Indicators (s)**	**Source and Means of verification**	**Level of Data Collection**

1. Investigate what social support services patients are using and how these services are meeting their needs.	*Questions relating to disclosure (Q 154-172) *Questions relating to support from family etc (Q 173-177) * Questions relating to support from health workers	- Exit interview - In-depth interviews - Routine data	-ART patients - Facility managers
2. Determine adherence levels among ART patients.	*Questions related to missed taking tablets (Q 91-104) *Questions related to follow-up visits (Q 123 –143) * Viral load count	- Exit interview - Data capture sheets	-ART patients -Clinic record
3. What are the factors affecting adherence?	*Questions relating to cost of attending clinic and income lost (Q 19-30) * Questions relating to knowledge about drugs (Q74-87) *Questions relating to participation in support groups (Q 105, 106) *Questions relating to services offered in support groups (Q 107-114) *Questions relating to support from family friends, etc (Q. 115-120) * Questions relating to knowledge about CD4 count. (Q135-137) *Questions relating to quality of care) Q138-152)	- Exit interview - In-depth interviews - Routine data	-ART patients - Facility managers
4. Examine the association between social support and adherence	* Cross tab social support and adherence	- Exit interview	-ART patients
5. Socio-demographic background of patients	*Questions relating to background (Q 11-18)	- Exit interview	-ART patients

Appendix 6: Respondents' File Data Capture Sheet

Name of Hospital/Clinic: **Carletonville Hospital --------**

Zola Clinic ---------

Client File Number

Date

(Day/Month/Year)

File Record:

Type of Data	**Information Required**		
Start date for ART treatment			
Date stopped treatment (if applicable)			
Total visits scheduled (April 2005 and March 2006)			
Actual Number of visits made during this period			
Last viral load count	Date of current test	CD4 count	Next scheduled test
Last CD4 cell count	Date of current test	CD4 count	Next scheduled test
Screening for TB	Date of screening	Result: Neg/Pos	Treated for TB (Yes/No)

Appendix 7: Social Support and Adherence: Research Report Framework**Social Support and Adherence**

Study Objectives	Section Highlights	Results Tables
Determine what types of support services are available at facility and community levels for ART adherence in the sites of the study (*Here I am interested in describing the types of services and support ART clients can get when they come to the clinic and have access to at the community level from family members, friends, or colleagues. This will not include their use of these services, but a focus on how comprehensive these are.*	I can think of social support broadly as anything, which empowers patients to understand, cope and facilitate adherence. This could relate to support gained through relationships, networks/organizations/institutions; skills and information; resources etc. Therefore we can think of the following areas where respondents could derive social support: Education Access to grants Food supplement Medical aid Employment Support group membership Types of support provided by health providers HIV and ART knowledge Assets	a) Socio-demographic results: Age group Gender Educ. level Assets quintiles b) Financial and material support: Disability grant Food supplement Income/employment c) Health Facility support Areas of interactions with health providers Content of interactions d) Community Support Support groups Support from friends, family colleagues e) Adherence incentives/disincentives: Disclosure Stigma issues Reasons why people do not take tablets Clinic attendance and reasons why people do not attend clinic
Investigate what social support services patients are using and how these services are meeting their needs *Here I am interested in assessing how the available social support services are being used, proportions of respondents using services, commonly used services vs. those that are less used, and how relevant these might be to their needs.*	I could quantify the proportions of the use of services by respondents and compare use by gender. Also, would explore service used by age group. Main analyses areas are: Examine the different types of services reported by support group members and the frequency of their use, including by gender. Examine what support service health providers offer and perceptions about these services. Examine the types of support services provided by family members and friends, and assess their comparative frequencies. Examine services that are missing/poorly delivered/utilized	Results to be discussed will include: Support group membership and attendance Services provided by support groups, and proportion of users Support services provided by family and friends Disclosure and concerns about disclosure Provider/client interactions
Determine adherence levels among ART patients and examine the association between social support and adherence	Focusing on VL count below and above 400 copies/ml, adherence levels will be determined for all respondents with VL information. I will also provide VL levels by site,	Results to be highlighted will include: Self-reported adherence, CD4 count and VL counts Cross tabs between VL and key

Will focus on VL and CD4 counts as main measure of adherence. Will compare a range of social support variables to measure correlation between adherence and social support.	and by gender. Will provide levels for respondents based on their duration on treatment. Areas o focus will include: Concerns around SRA and CD4 count as measure of adherence VL as measure of adherence Social support variables linked to adherence	social support indicators