CHAPTER 7: SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

7.1. Introduction

The purpose of this chapter is firstly to summarize the content of the preceding thesis and secondly to provide conclusions and recommendations derived from these chapters. The overall goal of the study formulated will be evaluated as well as each objective, and the research question will be addressed.

As mentioned earlier, AIDS has shattered the false sense of security that arrived with the conquest of infectious diseases, like polio. HIV/AIDS, with its far-reaching effect on various aspects of human functioning, is the worst infectious disease in recorded history.

The findings of this research demonstrate that since the advent of HAART, HIV/AIDS has now been transformed into a manageable and chronic condition. Patients receiving ART develop less opportunistic infection, requiring less hospitalization, and show a decrease in viral load and rise in CD4, with at least partial restoration of immune function. The lower viral load slows the progression of HIV-1 disease and subsequently the risk of heterosexual and perinatal transmission is lowered.

The worldwide increase in the prevalence of antiretroviral resistance is of particular concern to all involved in HIV/AIDS matters: as mentioned, one of the greatest challenges is the high adherence rate required. This indicates the need for highly effective social work intervention to address the psychosocial needs of patients referred for HAART.

Not only must the medical perspective be considered in ART matters, but also the psychosocial and social perspectives. ARV treatment is a complex procedure, which is accompanied by severe and wide-ranging biopsychosocial implications. As a result of this there is a need for a comprehensive service which would ensure that the patients are able to adhere to ART for life. Literature has shown that specifically in the field of HIV/AIDS, without accompanying social support and counselling services, any treatment will not be complete and may fail.

The researcher proposed the biopsychosocial model for use in assessing HIV/AIDS patients for ART. This orientation enables the service providers to consider the biological, psychological and environmental information about a patient, to make an appropriate diagnosis and develop a treatment programme that encompasses all these three areas.

The impact of the various psychosocial needs of millions of HIV/AIDS people, living on ART, on current social structures and services, will place stress on the available professional social services. The importance of having the social worker involved in HIV/AIDS and ARV matters, where all the team members will provide the patients with a comprehensive service, cannot be underestimated. No other team member will be able to meet the patient's comprehensive, psychosocial needs. As Saloner (2002:155), in discussing the critical role of the social work profession in HIV/AIDS matters, has asserted: "even though some social workers may not choose to work directly in the field of HIV/AIDS, there is now no way of avoiding the epidemic". The researcher identifies with the above in that the social work profession should facilitate the optimal functioning of people, which includes education regarding morals, values and ethical issues.

7.2 Summary of Research Methodology

The research process utilized in this study was derived from the 5 phases of the qualitative research framework as outlined by Fouche and Delport (in De Vos, 2002:84-85). The researcher will discuss the research process according to the phases proposed above, in the table to follow.

7.2.1 Illustrated Research

Table 50: Illustrated Research

Type of research: Applied		
	Qualitative	**Quantitative**
Approach	Creswell's: dominant-less-dominant design/triangulation Qualitative – (Less-dominant)	Quantitative (Dominant)
Design/strategy	Case study Collective case study	Quantitative descriptive (survey) design Randomized cross-sectional survey
Respondents	Multidisciplinary team (20)	Patients on ART (201)
Data collection	Interview Documents	Personal questionnaires
Sampling	Non-probability sampling	Probability sampling
Sampling technique	Purposive sampling	Simple random sampling
Data analysis technique	Transcribed interviews, themes, sub-themes, narrative meanings	Figures, tables, percentages, frequencies

7.2.2 Phase 1: The selection of a researchable topic

The research problem was identified from the literature, personal experience and interest, previous research undertaken by the researcher on HIV/AIDS and her observations within the Department of Health's ARV clinic, Tshwane District Hospital. The researcher is of the opinion that the specific research topic was not only researchable but also necessary, in the light of the current situation.

7.2.3 Phase 2: Formulation of Formal Model

The researcher decided on a combination of qualitative and quantitative approaches, as this could lead to more confidence in the results. Creswell's dominant-less-dominant model was utilized. According to Fouche, in De Vos (2002:365), the two approaches may be used in one study, with one approach being employed more than the other according to the demands of the study.

The researcher believed that comprehensive and rich data could be gathered by the combination of the two approaches to provide further insight into the research topic.

7.2.3.1 Goal of the research

The researcher defined the goal of this study as follows: "To explore the biopsychosocial factors influencing patient adherence to ART, in order to make recommendations and describe relevant factors which could be considered in assessing patients for ART."

In her opinion this goal was achieved by means of the qualitative and quantitative research undertaken, on the basis of which the researcher did make recommendations and proposed a screening schedule for the assessment of patients.

7.2.3.2 Objectives of the Research

The researcher formulated the following objectives for this study:

Objective 1: "To explore the importance of adherence and the implications of non-adherence, and subsequently, the development of resistance to antiretroviral therapy."

This objective was addressed by means of an in-depth literature study. Rich knowledge was gained from the literature study regarding adherence, resistance and antiretroviral therapy and presented in Chapters 2, 3, 4 and 5, and will be summarized later in this chapter.

Objective 2: "To conduct qualitative empirical research to explore and describe the biopsychosocial factors that influence adherence to antiretroviral therapy in patients, as perceived by the multidisciplinary team members actually involved in service delivery to HIV/AIDS patients on antiretroviral therapy."

This objective was achieved in the qualitative aspect of the study where 20 respondents were interviewed. Rich data was gathered from these semi-structured interviews. A detailed picture was gained of the experiences, beliefs and perceptions of the multidisciplinary teams regarding the biopsychosocial factors influencing patients' adherence to ART.

The empirical findings of the qualitative element of the research were presented as direct quotes from the transcribed interviews, and interpreted in the form of themes and sub-themes.

Objective 3: "To conduct a quantitative study to explore the biopsychosocial factors that influence adherence (negative and positive) to antiretroviral therapy as experienced by HIV/AIDS patients on anti retroviral therapy."

Two hundred and one respondents participated in completing a questionnaire as a data collection tool, for the quantitative section of the study. The questions were based on the principles of the biopsychosocial model. This objective was achieved when the empirical findings from the quantitative part of the study were presented, discussed and compared to the relevant literature in chapter 6.

Objective 4: "To explore and analyze patients' circumstances to determine whether the predictive generalization of the theory holds truth, and to make recommendations regarding the biopsychosocial factors that should be considered in screening HIV/AIDS patients for ART that are practical, relevant and appropriate in the African context."

The researcher has explored the circumstances that may impose on adherence to ART and compared these to the literature. The researcher has also proposed an adherence screening schedule, which is attached.

A thorough literature search was carried out regarding the research topic, which was described in Chapters 2 to 5. In both the qualitative and quantitative aspects of the empirical study, the researcher explored the circumstances of HIV/AIDS patients and compared these with the literature. These findings were presented and discussed in Chapter 6. Conclusions, which have been drawn from these findings, and recommendations, have been made in this chapter, which, it is hoped, could lead to the improvement of services to HIV/AIDS patients, specifically those on ART.

7.2.3.3 Research Questions

In this study the researcher sought to answer the following questions:

Question 1: “What are the biopsychosocial factors that influence adherence to antiretroviral therapy as perceived by multidisciplinary team members involved in the service delivery to HIV/AIDS patients on antiretroviral therapy?”

The researcher desired answers to this question because the multidisciplinary team members involved in ART undergo daily practical experiences with patients on ART. The researcher consequently felt that it would be appropriate to gather their views on the subject. The biopsychosocial factors influencing adherence, as experienced by the multidisciplinary team involved in rendering service to the HIV/AIDS patients, were established by the qualitative research and in Chapter 6 were compared to the relevant literature studies.

This proved to be appropriate since the multidisciplinary team’s experiences were presented as direct quotes and themes. They could describe circumstances in their own words. This created a deeper understanding of the problem. The research findings indicated a specific relationship between poor socio-economic circumstances and the ability to adhere to antiretroviral treatment.

Question 2: “What are the existing biopsychosocial circumstances influencing adherence of HIV/AIDS patients already on antiretroviral therapy?”

The researcher hoped that the answers to this question would specifically establish the reality and the practical factors influencing a patient’s adherence to ART.

In Chapter 6 the empirical findings from the quantitative section of the study were also presented, discussed and compared to relevant literature studies. These findings were found to be very significant for future service delivery since they indicated a specific relationship between poor socio-economic circumstances and the ability to adhere to antiretroviral treatment. The research identified unemployment, families headed by women, little support and total dependency on social security. In addition, family support for adherence to ART, as also HIV/AIDS support services, specifically counselling, were mainly found to be inadequate.

Question 3: "How can these identified biopsychosocial factors be utilized in service rendering to enhance HIV/AIDS patients' adherence to antiretroviral therapy in order to minimize the development of resistance?"

By posing this question the researcher wished to explore ways to use the acquired knowledge to enhance the rendering of service to such patients. She identified criteria that should be used in assessing patients for ART and proposed them in the form of an assessment schedule (Annexure 7). Recommendations to improve service are presented in this chapter.

The combination of the approaches was appropriate because the data collected could answer all research questions.

The hypotheses: The biopsychosocial circumstances of HIV/AIDS will influence adherence to ART. This research has proved/establish a definite relation between the two variables (1) biopsychososical circumstances of HIV/AIDS patients and (2) adherence to ART.

7.2.4 Phase 3: Planning

The research methodology was finalized and the research proposal was submitted and approved by the Research Proposal and Ethics Committee of the Faculty of Humanities, as well as the Research Ethics Committee of the Faculty of Health Sciences, University of Pretoria.

The researcher conducted a literature study as part of her objectives, in order to assess the research findings against the background of existing literature. She utilized a wide variety of sources, including scientific books, articles, the internet, government guidelines and local and international reports. This study was very meaningful, and provided thorough background knowledge on the research subject. It also confirmed the need for more knowledge and research on this topic.

The research design that was selected to meet the goal of the qualitative aspect of this study was the quantitative-descriptive (survey) design, specifically the randomized, cross-sectional survey. Utilizing this design worked very well since a large percentage of respondents could be involved and many facts could be explored using the questionnaire.

The research strategy that was selected to meet the goal of the qualitative part of the research was the collective case study. This strategy facilitated the gaining of knowledge about the research topic and rich, in-depth data could be collected (Fouche, in De Vos, 2005:276).

The data collection method used for the quantitative section of the research was the questionnaire, for which the biopsychosocial model was used as a basis. The researcher is of the opinion that the personal questionnaire, as a data collection method, was appropriate for the quantitative element of the study.

The researcher was involved in obtaining the necessary informed consent from participants and could also explain any uncertainty. This was very time-consuming but proved to be most worthwhile because it limited misunderstandings and very few questionnaires were faulty.

The method of information collection employed for the qualitative element of the study was that of the interview, to gain a better understanding of this social issue. Semi-structured interviews were conducted (using an interview schedule to guide these) with the multidisciplinary team members for these case studies. The schedule was based on biopsychosocial principles.

The sampling technique proved to be appropriate since suitable team members could be identified by means of the researcher's involvement and experience in the field of research. She decided to focus on multidisciplinary team members involved in HIV/AIDS. The team members were eager to participate in the research and no problems were experienced.

For the quantitative part of the research the sampling consisted of 201 patients, selected in terms of the probability sampling procedures and specifically the random sampling method, which ensured the representativity of the population. Pre-testing of data collection was successfully conducted, which reinforced the proposed method of research. The questionnaire could be tested and mistakes rectified. The interview schedule utilized for the interviews could also be evaluated.

7.2.5 Phase 4: Implementation

The quantitative part of the study was conducted during October and November 2005 at the ARV Clinic, Tshwane District Hospital. The researcher is part of the multidisciplinary team at the above clinic and her employer, the Department of Health, as well as the Superintendent of the hospital, endorsed the research, which made the study easier to conduct. The researcher purposively selected 20 respondents in terms of the non-probability sampling method. The researcher identified 20 multidisciplinary team members who could provide rich information and were seen as experts in the field of HIV/AIDS.

The qualitative element of the research was also successfully conducted from October to November 2005. In chapter 6 the findings of this part of the empirical research were presented as direct quotes.

7.2.6 Phase 5: Interpretation and presentation

All data captured from the questionnaires was statistically processed using the SAS, version 8.2 statistical software program with the assistance of the Dept. of Statistics, University of Pretoria. It was analyzed and these interpreted findings of the quantitative part of the empirical research were presented in text, percentages, frequency graphs and tables.

The qualitative element consisted of tape recordings of the interviews conducted with the multidisciplinary team involved in ART. The researcher transcribed the interviews and sorted them into themes and sub-themes. The data was then validated by means of generalization from the different categories. Themes and recurrent ideas, stemming from the different categories used in the interview schedule regarding the bio-, psycho- and social circumstances influencing adherence to ART, were identified. The researcher made use of the linear model for data analysis as presented by De Vos (2002:340).

Triangulation, by mixing the complementary styles of qualitative and quantitative research, contributed to the comprehensiveness of the study and led to more confidence in the results.

The researcher presented the findings of both the qualitative and quantitative processes in text, tabular, quote and graphic form in the ensuing research report. These findings and conclusions were also presented at a doctoral seminar held at Tshwane District Hospital at the end of 2006, where the feedback was very positive.

She is of the view that the findings of this research would be useful in other settings and that they are transferable to settings with a similar population.

7.3 Summary of Literature Study

The researcher reviewed current literature in depth, focusing on the research goal. By this means, she obtained a clearer understanding of the nature and meaning of the problem that had been identified. She also established, through the literature, the path of prior research and determined how this exploratory study could be linked to current knowledge.

The researcher has further established that this project will definitely contribute to knowledge about an extremely relevant social work concern. The following matters were reviewed by means of textbooks, government guidelines, journals, research reports and the internet.

7.3.1 Chapter 2: Clinical Aspects of HIV/AIDS

In chapter two the clinical aspects of HIV/AIDS and antiretroviral therapy were discussed. The researcher holds that unless we understand the virus and anti-retroviral therapy we cannot try to conquer this epidemic.

Matters discussed in this chapter were the aetiology of AIDS; morphology of HIV; infection routes; VCT; human immune system; CD4 cell count; viral load and WHO stages.

7.3.2 Chapter 3: Antiretroviral therapy

Since antiretroviral treatment was introduced in 1986, it has been demonstrated to reduce deaths and accompanying opportunistic infections in patients with advanced HIV infections. According to the World Health Organization (2002:2) guidelines regarding the use of antiretroviral therapy, mortality has dropped significantly in Europe and North America, owing to access to HAART.

In this chapter the following matters related to ARV were discussed: the goals of antiretroviral therapy, different antiretroviral drugs, response to and prognosis of antiretroviral treatment and treatment failure. The researcher believes that it is only when one understands the pathophysiology of HIV/AIDS and the pharmacology of ARVs and the body’s response to these, coupled with the importance of adherence, that strategies for the long term can be developed.

7.3.3. Chapter 4: Adherence and resistance and the role of adherence to anti-retroviral therapy

The introduction of HAART has extended and improved the quality of life for people living with HIV by reducing their viral load, often to undetectable levels.

However strict adherence to the antiretroviral treatment regimen is essential, as pointed out above.

In this chapter adherence to antiretroviral (ART) and drug resistance were consequently explored, the following matters being discussed: resistance; adherence; predicting of adherence; special adherence groups; patient, providers and regime matters influencing ART; with a specific focus on the adherence team. Support in the different adherence phases and strategies to support adherence, such as medication alerts and measuring adherence, were also considered.

7.3.4 Chapter 5: The social worker's role in assessing the HIV/AIDS patient for anti-retroviral therapy utilizing the biopsychosocial model

Medical advances alone, no matter how effective in reducing the number of AIDS-related deaths, cannot support the needs of the many HIV-positive people, now living normal lives as a result of ART. (Strug, Grube, and Beckerman, 2002:7) postulate that social workers will increasingly become involved in primary prevention efforts since medical interventions alone are insufficient to prevent new infections, especially in the light of the increasing number of HIV/AIDS people now living normal lives as a result of ART. Infected persons will need a wide variety of medical and psychosocial support services for long periods because HIV/AIDS becomes a chronic condition for persons living with the disease.

People on antiretroviral therapy are doing so with guarded optimism about how long these medications will be effective and feel limited in their ability to live life fully. Prevention of the spread of this virus will again have to be focussed on.

In this chapter the focus was placed on the social worker's role in utilizing the biopsychosocial model for assessing HIV/AIDS patients for receiving ARV. The specific factors to be focused on in assessing the patient and utilizing the biopsychosocial model were discussed in this chapter. Factors discussed included physiological, psychological and social needs.

A guideline for utilizing the biopsychosocial model in assessing HIV patients for their adherence to ART was proposed. Insight was obtained into the factors influencing such adherence.

An in-depth understanding of all the concepts and related dynamics of HIV/AIDS and ART was gained by means of the above literature reviews.

As a result, the researcher asserts that a thorough and detailed assessment of each individual regarding adherence to ARV treatment is essential. It is not possible for health care providers to predict reliably which individuals will ultimately be adherent to their treatment plan, as adherence does not correlate with gender, cultural background, social-economic, educational level or language barriers between provider and patient. Adherence has been rightly called the Achilles heel of antiretroviral therapy (Wilson and Fairall, in Abdool Karim, 2005:489).

7.4 Summary of Empirical Study (Findings)

The findings of the empirical study were analyzed and interpreted in conjunction with the format of the interview schedule and questionnaires. These findings were also integrated with the literature findings.

The researcher decided beforehand on 4 main themes for the research, which were used in compiling the questionnaire as well as the interview schedule. Recurrent ideas and patterns of beliefs emerged and were discussed and formulated into categories during data analysis, during which the researcher identified, described and compared the data. She further interpreted the quantitative data and linked it to the available literature.

The biographical section of the study has revealed that the majority of respondents taking part in this research were women, in the age category < 40 years. This correlates with literature and other research findings in that women are the more vulnerable group and men are underrepresented in ARV clinics.

The research has also confirmed that many people are not married or in stable relationships, which could complicate disclosure since the majority of respondents reported being single and unemployed. Hence this finding shows why patients are reluctant to disclose their status to their sexual partners. The assumption can be made that people are practising unprotected sex whilst not in stable relationships.

The research further indicated higher educational levels amongst patients, in contrast with the general assumption that it is mainly less-educated people who suffer from HIV/AIDS. The researcher considers that this finding might indicate that the better-educated person seeks treatment sooner; thus literacy plays a role in seeking medical treatment and adhering to it, but not in being infected.

The majority of respondents were, as could be expected, speakers of North Sotho since the research was conducted in the ART clinic at Tshwane District Hospital, and this is the local language of prevalence.

Regarding accommodation, the findings indicated that most patients were residing in an urban area, living in properly constructed dwellings.

As far as medical and adherence issues are concerned, respondents mainly reported factors which enhance adherence to ART as consisting of family support. More than half of the respondents reported receiving no support at all, which is alarming. A lack of interest in support groups was reported.

In contrast, respondents reported the assistance received as regards ART, from the Government’s comprehensive ART clinics, as very important and often their primary form of support.

CD 4 counts of respondents were mostly reported to be <200 but >100, which could indicate that patients are still suffering from minor AIDS-related symptoms but also that they are adhering to ART, since the initial indication for initiating ART is a CD 4 count <200. Most respondents had been on ART for a short period of only 6-12 months; this short time-span could be explained in that the Government's ART Rollout plan was only initiated during July 2004. Respondents could thus be seen as adherent.

Respondents reported that their current performance status (according to the Karnofsky scale) and physical appearance have improved, and also that they were experiencing mostly normal health.

Regarding their social circumstances, the research revealed financial needs to be the most urgent. Most of the respondents were unemployed and thus economically dependent on either a disability grant or family support. Hence the high rate of unemployment and poverty generally hinders access to a number of services, including adherence to ART. Patients living under poor socio-economic conditions are more susceptible to HIV infection. Specifically, women are disproportionately more severely affected by poverty and HIV/AIDS because of the inequalities in society and a general lack of resources. They are traditionally responsible for caring for the sick and also more vulnerable to HIV-infection due to their inferior position and often cannot negotiate safe sex or are obliged to sell sex for money or material goods in order to improve their living conditions.

Furthermore the majority of patients require assistance in applying or reapplying for disability- or foster-care grants. Deficits in external systems, such as the bureaucratic delays in approval of grants, were noted as major barriers.

Alcohol, drugs, accommodation or criminal records were not significantly reported, while regarding sexual activity more than half of the respondents indicated that they are sexually active, but practising safe sex. Respondents reported the use of condoms as the major means of practising safe sex.

Owing to the sensitive matters surrounding HIV/AIDS/ART, respondents reported disclosure mainly to family members. Disclosure was considered still to

be an issue, which could also be attributed to the fact that respondents are single and not in any stable relationship. Among HIV/AIDS patients' needs, socio-environmental problems were the most prevalent.
Side-effects of ART are reported by more than half of the respondents as a problem. The lack of available or intact social support systems was also reported.

Alternative healing methods and the influence of traditional culture and beliefs should not be underestimated because more than half of the patients reported that they were making use of alternative healing methods.

The patient's motivation for receiving ART was seen as an important determinant for adherence. Respondents reported their major motivations in this respect as being the following: to care for their families; to stay alive; be physically stronger; symptom–free; and the fear of losing control. These motivations can be seen as the patients' reasons to live and should be focussed on in matters of adherence.

The majority of respondents did not indicate a particular need for counselling, leading the researcher to posit that the reason is that their basic human needs, regarding socio-environmental issues, are not being met.

It is evident from the study that the emphasis placed on counselling should focus on furnishing trained, skilled and experienced counsellors who can deliver a comprehensive service. The specific counselling needs reported were those for adherence counselling.

A large number of respondents expressed satisfaction with their current quality of life since they generally reported positive feelings coupled with improved physical appearance and enhanced quality of life, as noted earlier.

In conclusion, these research findings have again confirmed that while ART has brought hope to and enhanced their quality of life for millions of HIV/AIDS sufferers; it has also created special challenges with regard to treatment adherence and support.

7.5 Conclusions

The following conclusions regarding challenges to adherence to ART are drawn from the literature study and the quantitative and qualitative empirical findings.

7.5.1 Biographical

Gender has always been a prominent issue in HIV/AIDS discussions. The gender distribution of the participants in this study appears to be more that of heterosexual, African, women, the majority of respondents, a result which correlates with literature and other research findings, in that women are the more vulnerable group. The qualitative element of the study also indicated women to be more adherent than men in general. The researcher therefore speculates that women are testing for HIV and seeking ART sooner than men. She reports that women are actively targeted through various programmes focussing on woman and child related issues, such as PMTCT, and is of the opinion that men are underrepresented because they are not actively targeted.

The higher educational levels established by the study lead the researcher to the opinion that the better educated might seek treatment sooner. This could be an indication that literacy does play a role in seeking medical treatment but it also shows that education and knowledge do not offer a deterrent to becoming infected with HIV / AIDS.

Furthermore the effect of alternative healing methods and the influence of culture and beliefs should not be underestimated.

The research also indicates that church and spiritual leaders should become more fully involved in HIV education programmes, because the majority of respondents reported membership of a church such as the ZCC, Apostolic, or Roman Catholic. This is significant because it indicates the important part religion and spiritual beliefs play and the influence that church groups could exert in educating, motivating and supporting patients on ART.

The research findings indicated that the majority of respondents are not married or in stable relationships. Hence the researcher has arrived at the view that, in spite of sex education and HIV awareness programmes; people are still practising unprotected sex, whilst not in stable relationships. The qualitative aspect of the study has also drawn attention to the lack of relationships with life partners which also negatively impacts on the call for disclosure. The researcher tentatively concludes that it is difficult to disclose if one is not in a stable, trustworthy relationship.

The higher educational level also proves to influence adherence since patients have developed more insight into HIV/AIDS in general.

7.5.2 Biomedical

Regarding their performance status, according to the Karnofsky scale, respondents reported normal health or that they were merely suffering from minor illness. This is positive and could indicate that patients are adhering to ART.

Both the qualitative and quantitative elements of the research established the side-effects of ART as a significant difficulty. Routine clinic visits are perceived as offering good support, but owing to impoverished socio-economical circumstances are also reported as a financial difficulty. This is an indication that better access to ARV clinics is needed. The daily responsibility of taking medication, which leads to pill fatigue, was also indicated. Education regarding this responsibility of chronic medication regimes is consequently necessary.

The respondents’ CD4 counts were mostly above 200 but still under 300, which could indicate that patients are still suffering from minor AIDS-related symptoms but are adhering to ART. An increase in the CD4 count serves as a strong motivation for good adherence, as do patients' desires to be symptom-free, physically stronger and to stay alive in order to care for their families.

It has been confirmed by the findings of this research that since the advent of HAART, HIV/AIDS has been transformed into a manageable and chronic condition. However the study also confirms that ART is a complex intervention, which is accompanied by severe biopsychosocial implications, requiring near-perfect adherence to prevent the development of resistance.

7.5.3 Social

The respondents reported socio-economic problems to be the most prevalent factors. In the majority of respondents their lack of money featured strongly as a factor affecting adherence. Most of the respondents reported unemployment and their being economically dependent on either a disability grant or family support. This indicates the need for a national programme to support the unemployed. The researcher is of the opinion that food parcel programmes are not enough: people need financial support.

The researcher further confirms that poverty seriously affects the life of a person infected by HIV and impedes adherence. Poverty directly influences attendance at clinics and many other matters, indicating the need for employment-creating programmes where patients can earn while recuperating.

The findings demonstrated that patients rely strongly on ART clinics as their primary means of support and often the only form of support. Yet transport costs are still a hindrance.

As is evident from this study, respondents face serious financial problems and matters regarding social security must be addressed. The fear that the disability grant could be stopped if the CD4 counts rise above 200 seriously affects adherence. A disability grant should not be linked to a high CD4 count.

The social interlinking of HIV/AIDS and poverty is endorsed by this research empowering impoverished HIV/AIDS sufferers to adhere to antiretroviral therapy is therefore essential.

The qualitative part of the study also reported that patients require assistance in applying or reapplying for various grants such as disability-, foster-, or care dependency grants. Deficits in external systems like the bureaucratic delays in approval of grants and screening criteria constitute primary barriers according to the qualitative research. The lack of identification/ birth documents is also delaying these processes. Consequently the Departments of Home Affairs, of Health and of Social Development should work more closely together to streamline the procedures.

The findings reveal further that respondents reported clinic staff and daily medication charts, as supplied by the Tshwane clinic's pharmacist, and their family as major forms of support. Patients prefer to visit a specialized ART clinic, rather than a local clinic, for support, as they fear a lack of confidentiality and discrimination in their own areas. They also assume that medical treatment in urban areas is better than that available in rural treatment centres. This is a contraindication as a need for greater accessibility to ART clinics and lower transport costs are indicated, yet patients prefer to travel further to urban clinics.

Other social factors include a lack of family support, and of interest in support groups: the researcher attributes the latter to the conspiracy of silence surrounding sexual matters in most cultures and the lack of a governing body to control support structures. The researcher is also of the opinion that owing to the sensitive issues related to HIV/AIDS/ART, the respondents are not motivated to be part of a support group. In the present study, such groups were not indicated as being of any significant influence as far as adherence is concerned. Thus the focus in counselling should fall on family support.

As already mentioned, the majority of respondents who participated in this study were single women, unemployed and financially dependent on a grant or family support. Hence disclosure is not always possible for the following reasons:

respondents are not in stable relationships; they have no contact with the person who has infected them; they are in new relationships and they do not want to disclose their status as they fear discrimination, abandonment, loss of financial support and / or income. The researcher is therefore of the opinion that non-disclosure should not exclude patients from ART. The buddy system should be re-evaluated. Respondents reported that they disclosed mainly to family members, which could also be attributed to the fact that respondents are single, and only have relatives to disclose to. Most respondents were forced by factors beyond their control such as the appearance of symptoms or deterioration in health, or a lack of productivity, to disclose their status and achieve critical support from family members. Supportive stable relationship is, however, indicated for good adherence.

The request for a buddy to accompany a patient as in the guidelines, is also undermined by the fact that patients are single and just do not have anybody to bring to the clinic as a treatment buddy – for example patients who work in an urban area but whose family lives in a rural area. Such patients are not willing to disclose their status to employers. To require the company of a buddy/or family member who is not living with them and supporting them does not serve any purpose. Furthermore, there are patients who can take medicine responsibly and simply do not need a buddy. The researcher is of the opinion that to demand a buddy, against the patient’s will, is discriminatory. The equality clause of the Constitution of South Africa (Act 108 of 1996) as well as the National Health (Act 61 of 2003) makes it illegal to discriminate unfairly against any person. “The right to equality is violated whenever a person is treated differently in a way that is unfair discrimination.” (HIV/AIDS and the Law, 2001:70). No other diagnosis requests a buddy before treatment is given.

Devices such as pillboxes do not seem to be popular, although respondents report that cell phones can be used as a reminder to enhance adherence.

More than half of the respondents indicated that they are sexually active, further mainly reporting using condoms for contraception and / or safe-sex practices. Confusion regarding safe sex still prevails: some patients still perceive methods such as hormonal contraception as a safe-sex method. The researcher is of the opinion that abstinence is not an appropriate alternative to promote as a method of safe sex, since sexual behaviour is part of basic human needs and is not always a planned deed but is based on emotions and linked to specific circumstances. Respondents further reported an increase in sexual drive, which could be contributed to the above-discussed improvement in quality of life. Thus safe-sex practices should be addressed in all adherence counselling.

From the above it is evident that social work interventions need to be altered, supporting millions of HIV/AIDS/survivors now living with a chronic disease.

7.5.4 Psychological

Respondents reported that the major motivations for receiving ART were to stay alive and be symptom-free (related to quality of life), as well as wanting to take care of their children and see them grow up. The researcher is of the opinion that whatever the person’s motivation for ART, it will be one of the strongest determinants for adherence.

The research has further indicated that the majority of respondents do not report a particular need for counselling, and in the researcher’s opinion will not do so until they have their basic human needs met.

It is evident from the qualitative research in particular that there is a general problem regarding counselling services. Trained, skilled and experienced counsellors, who can deliver a comprehensive service, are called for, and the Department of Health places a high priority on counselling, but there is little monitoring, training and support of such people. The public service should start turning this situation around by being both a guardian of standards and an advocate of the committed support structure. Lay counsellors in the public sector specifically are not employed, receiving a stipend, are often living with HIV themselves and receive minimum training.

The researcher argues that in the recruitment of counsellors, universal standards regarding education and the motivations for their involvement, specifically in HIV/AIDS matters, should be laid down since people in such a position of responsibility, regarding patients' most intimate circumstances, should be governed by high standards. These, if implemented by a regulator, might increase confidence in counselling services.

Counsellors further indicated that they are not valued, and that this affects their morale.

It was felt that knowledge, training and experience is essential for effective service provision to traumatized individuals, groups and communities and to deal with ethical issues surrounding HIV/AIDS issues. The need for the social work profession to render a comprehensive service was strongly indicated.

Regarding their quality of life the majority of respondents expressed satisfaction with their current circumstances. A remarkable number reported positive feelings or results such as that their health had improved drastically on ART and that they have regained lost roles. The researcher concludes that physical improvement leads to psychosocial improvement and thus in general to improvement of quality of life.

7.6 Recommendations

Based on the above conclusions, the following recommendations are proposed, directed at the 3 main categories in adherence issues namely: provider, patient and regimen.

7.6.1 Recommendations focused on the provider

7.6.1.1 Recommendations regarding Government guidelines

The researcher considers that the *Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November 2003* (2003:4), which guides the treatment of

HIV/AIDS patients in South Africa, is very comprehensive and makes provision for various aspects, but the following further recommendations are proposed:

Guidelines should be evaluated and updated regularly at least annually to remain appropriate, effective and relevant as well as to keep up with the latest research.

Provision must be made for individual circumstances. The researcher is of the opinion that it is discriminating to demand certain behaviour before treatment can be initiated. These demands include: patients disclosing their status; patients to bring a buddy or support person; the need for multiple visits before initiating, ART; the requirement that identification documents be produced. This is contraindicated by the Equality and Prevention of Unfair Discrimination Act (2000) and contravenes The Bill of Rights in the Constitution of the Republic of South Africa (Act, No 108 of 1996).

7.6.1.2 Recommendation regarding closer co-operation between service providers

Closer co-operation between the Departments of Home Affairs, Health, and Social Development is called for. People in need of ART do not have the time (3-6 months) to wait for legal documents. The rapid issuing of emergency identification documents for medical reasons, or in order to obtain a grant, is crucial. Financial support is an essential requirement and may enhance adherence to ART.

7.6.1.3 Recommendation regarding equal standards of care for HIV/AIDS patients on antiretroviral therapy

Patients do not receive equal standards of care at treatment facilities. There are no standard assessment criteria prior to initiating patients for ART. Hence these are necessary and should be applied uniformly within the private as well as the public sector in order to facilitate ease of migration of patients between hospitals and clinics, in rural as well as urban areas. Training programmes should also conform to common standards.

7.6.1.4 Recommendations regarding education

Recommendations focusing on men

These findings further call for education and information programmes regarding ART, specifically targeting men: workplace programmes, or male wellness clinics are required. There are no active case findings for men which would provide similar results to findings regarding PMTCT programmes for woman. Such a clinic could perhaps be attached to an antenatal clinic. The researcher is of the opinion that for every pregnant woman there is at least one sexually active man who could be actively involved or enrolled at such a “male wellness clinic”.

Recommendations regarding education focusing on woman

The importance of preventing the spread of HIV infection is crucial. The research has indicated that women are still the more vulnerable group. Prevention strategies should aim at improving life skills and awareness, specifically in terms of empowering people regarding health and safe sex issues. Teenagers and young females should also be targeted. Patients still harbour the idea that using a contraceptive pill constitutes safe sex – education should counteract this fallacy.

7.6.1.5 Recommendation regarding social grants

The state shoulders the responsibility, underpinned by section 27(1) (c) of the Constitution, to provide social assistance in the form of grants for varying levels of need. Studies have demonstrated that households affected by HIV/AIDS are significantly poorer than non-affected households. This study has reflected the complexity of socio-economic issues and their influence on adherence to ART.

While high levels of poverty and unemployment are manifest, access to social grants is hindered by issues such as eligibility, violations of dignity, and bureaucratic red tape, in particular the lengthy period between applying for and receiving the grants. This issue has been formulated in various documents and policies, on the national and provincial levels, but still needs to be addressed in the broader context of HIV/AIDS and access to ART.

Recommendations regarding disability grants

The researcher recommends a definite guideline regarding disability grants for persons suffering from HIV/AIDS. There should be uniformity regarding who is eligible for the grant, with clearly defined criteria, as well as concerning when it should be reviewed. The medical report which must be completed for the disability grant exhibits shortcomings as regards HIV/AIDS patients, especially HIV/AIDS patients on ART.

The use of the CD4 count, as a benchmark for the purpose of determining physical impairment in order for patients to access grants, is problematic and counter-indicated for adherence to ART. The fear that the grant, usually the only means of income, will be stopped when the CD 4 count is above 200 was evident in this study. The researcher recommends that the definition of disability be changed in the light of HIV.

Recommendations regarding social relief

The Department of Social Development’s role in offering sustainable programmes and / or developmental projects and activities to address poverty and unemployment issues should receive priority. All patients receiving grants could be enrolled in skills development / or entrepreneurship training programmes or community projects prior to the termination of the grant. Various other forms of social relief, such as food parcels or coupons, are not successfully implemented at the grassroots.

The grant-in-aid (an extra amount) for which patients could apply for, if they already receive a grant, but need full-time care from someone, needs to be extended to include HIV/AIDS positive individuals, who is dependent on support, regarding adherence.

Recommendation regarding care dependency grant

The care dependency grant (focusing on children with special needs and disabilities) could be extended to include HIV/AIDS children on ART. The researcher contends that the cost (symptom control, transport, nutrition and medication) incurred to maintain a child successfully on ART warrants the inclusion of such children in this grant. This will promote treatment and adherence to ART.

7.6.1.6 Recommendation regarding social structures

Greater availability of, and easier access to foster-care or a place of safety will also encourage better adherence to ART. Caregivers of HIV/AIDS children/orphans are not always aware of these resources.

The researcher holds the view that child-headed households should not exist. The reality of AIDS is that children are caring for the sick and assuming adult responsibilities. All children without care, according to the Child Care Act (74 of 1983), should be placed in substitute care. This includes children orphaned as a result of HIV/AIDS.

The Constitution and the said Act (1983) and the new Children's (Act 38 of 2005) (not yet in force), makes provision for children to be cared for. According to section 28 of the Bill of Rights of the Constitution (1996), “every child has the right to family care or parental care, or to appropriate alternative care when removed from the family environment, to basic nutrition, shelter, basic health care service and social services to be protected from maltreatment, neglect, abuse or degradation.” This is often overlooked in children's matters, especially regarding HIV/AIDS.

7.6.1.7 Recommendations regarding the multidisciplinary team members involved in antiretroviral adherence issues

HIV/AIDS and antiretroviral issues, specifically adherence to antiretroviral therapy, are dynamic in nature. There is a need for on-going assessments and the training and support of the multidisciplinary team. The Government ARV training programmes regarding antiretrovirals should be extended to include all parties involved in ARV and to make provision for newly appointed staff. Ongoing training programmes are essential.

Recommendations focused on the social work profession

The social work profession needs to take responsibility for psychosocial services, education and training regarding HIV/AIDS. Social workers' specialized knowledge, skills and training cause them to be the most suitable profession to deal with all psychosocial issues regarding HIV/AIDS.

Social workers need to define their role clearly and claim their rightful place in the rendering of service to HIV/AIDS patients. Patients do present with various psychosocial problems, some of which involve work regulated by statute. This can only be performed by registered social workers and not lay counsellors.

The social work profession should also be actively involved in making available prevention strategies, education, training and policy development to different stakeholders on all levels. The profession could also develop more training programmes and actively participate in the training of other professions and lay counsellors as well as in policy development. The social work profession, with its specialized skills regarding human interaction, should become actively involved in the supervision of counsellors.

The dissemination of basic social work skills, knowledge and attitudes to other lay and professional team members is recommended. It is each social worker's obligation to ensure that a portion of his/her role involves an education and training component, but as yet there are many graduate and postgraduate social workers with various inadequacies in their skills, knowledge and attitudes regarding HIV/AIDS and ART matters.

Recommendations regarding counsellors

Lay counsellors are rendering very valuable services to HIV/AIDS patients. There is a dire need to improve these counsellors' working conditions as well as skills. Formal or in-service training is proposed for them.

The researcher is strongly of the opinion that a workforce regulator of counsellors is necessary to protect the public, promote high standards of practice and build professional credibility. This will accord increased status to the workforce, which should lead to improved recruitment, retention and morale and to the overall raising of standards. Universal standards will culminate in better services for the people in need of counselling.

It is recommended that lay counsellors, being in a position of responsibility, be placed on a nationwide register; adhering to universal standards could increase confidence in the services that they provide. This will demonstrate to others their commitments to high standards, abilities and skills and could guard against malpractice or abuse.

Such standards could include: Physical and mental fitness; good character; qualifications; training and agreeing to a code of conduct. Patients and families along the HIV continuum require constant and in-depth counselling, the goal of which is to impart accurate information that empowers patients and families to make informed decisions and also mobilizes adequate mechanisms of support and adaptation for these people to cope with multiple biopsychosocial problems and stressors.

Recommendations regarding community support and NGO's

The research findings indicated that formal clinics and support structures are important but the lack of social support was highlighted in this research.

There is no confidence in most support groups. Support groups are not perceived as consistent and their credibility is questioned. As with the counselling services a workforce regulator is proposed to protect the public, promote high standards of practice and reinforce credibility. There are many organizations dotted around the country with similar aims in supporting people affected by HIV/AIDS, and all of them need to be coordinated. Until they are, there will invariably be conflicting and contradictory messages.

As a result the researcher recommends a National AIDS Support Front, where all NGOs and support groups are part of a nationwide register and adhere to set standards; before being affiliated their credentials should be assessed. This could increase confidence in the services that are provided. Furthermore the country can no longer afford the mismanagement of funds directed at alleviating HIV/AIDS suffering and poverty.

Closer networking with NGO's and better utilization of their services may be beneficial and they could contribute to the reinforcement of adherence by means of home visits, thus supporting patients. By utilizing NGO's the workload of social workers could be shared and relieved.

Recommendation regarding support from religious and spiritual denominations

As most respondents are part of some religious or spiritual community, churches are urged not only to respond to the burden of HIV/AIDS individuals, but also to the challenges of motivating and supporting people regarding treatment. These institutions could become more involved in promoting stable relationships, be more visible and take part in policy development and programmes, for instance through public and public statements.

7.6.1.8 Recommendations re adjustment of salaries in the public sector

The public service and, more specifically, the Department of Health is steering the ART programmes. Within the HIV/AIDS directorate, public servants in managerial positions are earning salaries in excess of R300 000.00 per year.

Social workers, and pharmacists who are primarily responsible for adherence counselling and support, earn salaries less than R90 000 a year. Lay counsellors are not officially employed and only receive a stipend of R12 000 a year (R1 000.00 per month). If the government wishes to see these programmes succeed, it should adjust salary structures more fairly. Employees at the grassroots, who are responsible for doing the actual work, should be sufficiently remunerated.

Millions of rands worth of foreign currency are being donated for HIV/AIDS causes in South Africa. A portion of this money could be used to attract and retain experienced, dedicated people to work in the field of HIV/AIDS. For example, employees could receive an incentive to be willing to do so.

7.6.1.9 Recommendations regarding the faces of AIDS in South Africa

The researcher is of the opinion that the face of AIDS, specifically in the public sector (public servants), should be multiracial and not primarily be represented by one race as is prevalent. This fuels the perception that AIDS is an illness suffered by certain population groups.

7.6.2 Recommendations regarding patient factors

Assessment of HIV/AIDS patients’ biopsychosocial circumstances

The researcher recommends the use of a standard biopsychosocial assessment schedule to include all criteria to be evaluated. Such a schedule was developed as part of this research and is attached as Appendix 7.

The social worker could lead, but at least should be actively involved in assessing patients for adherence to ART and not leave this to lay counsellors and other members of the multidisciplinary team.

Patients must be educated to take responsibility for their own wellness. The perception that “the Government must do something” about individuals’ choices and behaviour must be challenged. Education should incorporate emotions and sexual needs, life skills and informed decision-making. Educational programmes focusing on intellectual decisions should be complemented by education focusing on peoples' emotions and basic needs, since sexual behaviour is not primarily a cognitive decision.

7.6.3 Recommendations regarding regime factors

Recommendations regarding adherence education

Mass campaigns should be launched. The community must be educated about antiretroviral treatment and the importance of adherence to ART. Coupled to the above is the necessity of educating the public in general about pill-taking, about adherence in general to medication and specifically to chronic medication. A culture of general adherence to dose regimens should be campaigned for.

Recommendations regarding the responsibility of the pharmaceutical profession

The pharmacist should take responsibility in counselling and supporting patients regarding adherence to ART treatment, for instance by supplying information leaflets to accompany instructions to patients regarding taking their medication, and the side-effects and contra-indications of ART.

Treatment awareness should be included in all educational activities. The Department of Education could consider running clinics at schools. With such clinics, a culture of health education and awareness could be developed from a young age. Pharmacists should take responsibility for educating children regarding their medication.

7.6.4. Recommendations regarding future research

The social work profession should carry out more research into improving their profession's involvement in rendering services to HIV/AIDS patients, specifically regarding prevention, educating and training. The researcher strongly believes that the social work profession should have been in the forefront in this field. Yet this profession has up to now taken a back seat to lay counsellors, PWA's and AIDS activists - who lead the field in rendering service to the HIV community. The researcher is of the opinion that this situation should be challenged by the social work profession. Undergraduate training is an appropriate place to introduce prospective social workers to deal with the greater involvement of multidisciplinary teams in HIV/AIDS matters.

Continued research is needed within South African social work to measure attitudes towards and knowledge of various aspects of sexuality, by virtue of its central role in the transmission of HIV, adherence to medication and HIV/AIDS matters. Results would provide insight into the way the profession is confronting the challenges of HIV/AIDS and suggest what still needs to be done so as to meet the new challenges of millions of people living on ART. Social workers are in danger of themselves becoming victims of the abolition of the social work profession or at least seeing their jobs being passed on to others in the field who will provide what the market demands (Phillips & Waterson, 2002:183).

Also recommended are the development of relationships between the social worker and the other professional and lay workers in the field of HIV/AIDS. Social workers are urged to become mentors and to strengthen networks.

Further research regarding motivations, needs and quality of life as indicators of adherence to medication, specifically focused on the South African situation, is recommended.

Future research regarding behaviour change and educating people regarding sexual behaviour, a basic human need, is also called for.

Further research by pharmaceutical companies to improve antiretroviral medication, focusing on pill burden, toxicity and side effects, is also necessary.

7.7 Closing Remarks

Recommendations were made in this chapter to address some of the issues identified, which include legislative and policy changes in order to improve socio-economic difficulties.

An intensified effort is required from social welfare services, and in particular the Department of Social Services and Development in conjunction with the Department of Health and Department of Home Affairs, regarding legal documents and material support, and the improvement of all social support and social relief programmes to meet the specific needs of HIV/AIDS adults and children on ART. Specifically, the medical criteria for obtaining disability grants should be reviewed.

Increased awareness campaigns and access to ART medication have been recommended, as well as improvements in counsellors' working environments, training and possibly registration. The social work profession is urged to take up the psychosocial challenges of HIV/AIDS patients and become leaders in the field of service rendering.

The high rate of HIV/AIDS infection calls for an integrated and coordinated response to the epidemic. The South African government is leading by example through its commitment to a multi-sectoral approach, working closely with a range of government departments, business community and NGOs. The government has at many levels attempted to address this epidemic through the South African National AIDS Council (SANAC), comprising the Minister of Health, provincial ministers of health and provincial and local government AIDS councils. The broad framework for HIV/AIDS and the STI strategic plan for South Africa 2007-2011, which represents the country's multi-sectoral response to the challenge of HIV infection and the wide-ranging impact of AIDS (South Africa, 2006) have again demonstrated the government's commitment to tackling the HIV/AIDS pandemic.

From the researcher, the following final remark: *The Government's Comprehensive Care and Treatment of HIV/AIDS and TB: Rollout plan for Antiretroviral Treatment accepted during November 2003* (2003:4) is one of the most comprehensive treatment programmes in the world. It has shown commitment by the government but the final responsibility to adhere to treatment still lies with the individual. People should be empowered to make informed decisions about their lives and social workers should play a more active role in HIV/AIDS matters.